Supporting People with Dementia in Acute Care
Learning Resource
<table>
<thead>
<tr>
<th>Contents</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>4</td>
</tr>
<tr>
<td>Module 1 Understanding dementia</td>
<td>9</td>
</tr>
<tr>
<td>Module 2 Person-centred assessment and screening</td>
<td>25</td>
</tr>
<tr>
<td>Module 3 Holistic approaches to supporting the healthcare needs of people with dementia</td>
<td>45</td>
</tr>
<tr>
<td>Module 4 The care experience</td>
<td>71</td>
</tr>
</tbody>
</table>
Introduction

Welcome!
Welcome to the Supporting People with Dementia in Acute Care Learning Resource. The resource has been designed for acute general hospital staff to help them develop their abilities in supporting people with dementia, their families and carers.

The learning in the resource will help you develop the knowledge and skills set out at the ‘Dementia Skilled Practice Level’ of Promoting Excellence: a framework for all health and social services staff working with people with dementia, their families and carers.

Please note this resource is also available as e-learning via LearnPro. Accessing the LearnPro version will enable you to make links to wider learning resources and assessment activities and record completion of your learning.

Why is dementia so important in acute general hospitals?
As life expectancy rises, more and more people in Scotland will develop dementia. Dementia is not a condition that only affects older people, however. People in their 40s or 50s, or even younger, can develop dementia. Dementia also has a profound impact on families, friends and wider networks of people and they too need our support to help them achieve the best quality of life.

Consider some of these issues.
- Approximately 90,000 people in Scotland were living with dementia in 2015.
- The number of people over 65 is predicted to increase significantly over the next 20 years. It is likely that the numbers of people with a diagnosis of dementia in Scotland will also increase considerably.
- It is estimated that up to 70% of acute general hospital beds in 2016 will be occupied by older people. Approximately two-thirds are currently occupied by people over 65, in whom the prevalence of dementia is around 30%.
- Approximately 40% of people over 75 who are admitted to hospital have dementia.

These numbers may change over the years, as will many of the statistics given in this resource. It is important that you keep up to date by checking the websites of the Scottish Government or Alzheimer Scotland.

Given these statistics, it is essential that all staff working in acute general hospitals and emergency departments are able to recognise when a person may have dementia and are confident of their ability to provide appropriate support, care and treatment.

Particular issues for people with dementia in acute general hospitals
People with dementia enter acute care environments for the same reasons as other people. Most of the reasons are not related to dementia, but the experience is likely to present a greater challenge to people with dementia than for some others. Along with the distress caused by illness or injury, the trauma of facing such a change in their daily life and routine can also have an impact and contribute to poorer outcomes.

An older person with dementia may be affected by any number of other long-term conditions, such as diabetes, Parkinson’s disease, chronic obstructive airways disease, heart disease and arthritis. These multiple health problems, alongside dementia, are often exacerbated by dehydration, malnutrition, constipation and infection, placing the person...
Introduction

at greater risk of unplanned admission to hospital.

An acute general hospital can be a disorientating and often frightening place for anyone, but this may be considerably worse for someone who has dementia. The stress of an unfamiliar environment and the constant challenge the person faces in understanding what is happening can be overwhelming. The risks of distress and deterioration in health and wellbeing consequently increase.

Evidence suggests that care, treatment and outcomes of hospital admission are markedly poorer for people with dementia than for those without. Several potential factors may contribute to this, including:

- pressures of acute care;
- the unique and complex needs of the person with dementia not being recognised;
- organisational systems and processes – acute general hospitals are fast-paced and intense, with a focus on rapid responses, meeting acute needs and achieving discharge as soon as possible.

These can lead to a number of risks for people with dementia, including:

- prolonged stay in hospital;
- increased complications, such as pressure ulcers, falls and delirium;
- increased adverse drug reactions;
- loss of previous abilities and increased levels of dependence;
- incidents of incontinence that can become permanent;
- decline in cognitive function;
- an increased likelihood of admission to a care home;
- increased morbidity and mortality.

A further risk is that the person’s level of cognitive impairment may be misjudged with a focus on dementia rather than on the medical co-morbidities and the impact of delirium and frailty. Worsening confusion and disorientation in older people, and those people known to have dementia, often go unnoticed in a busy acute care environment and may be attributed to the person’s acute illness.

What is the background to this resource?

Scotland’s National Dementia Strategies

National dementia strategies have been developed and implemented in Scotland since 2010. Key elements supporting implementation include the Promoting Excellence framework and the Standards of Care for Dementia in Scotland. Together, these documents represent a means of making sure that improving the quality of life for people with dementia is at the heart of what we do.

Promoting Excellence

Promoting Excellence describes various levels of knowledge and skills required by ALL of the health and social service workforce. The levels are:

- Dementia Informed Practice Level
- Dementia Skilled Practice Level
- Enhanced Dementia Practice Level
- Expertise in Dementia Practice Level.
Introduction

This resource is designed to help acute care staff achieve the knowledge and skills set out at the Dementia Skilled Practice Level of Promoting Excellence. Before using the resource individually or facilitating or delivering training based on it, you should ensure you have gained the knowledge and skills set out at Dementia Informed Practice Level.

We have produced the Informed about Dementia: Improving Practice DVD to enable this. If you have already seen the DVD or have used it in a learning session, you may want to refresh your memory – it provides a starting point for this resource.

Acute Care and Scotland’s National Dementia Strategies

Improving experiences and outcomes for people with dementia in acute care has been, and remains, a priority in Scotland’s National Dementia Strategy. It is supported by a range of national and local activities, including:

- the establishment of Alzheimer Scotland Nurse Consultant posts;
- the establishment of Alzheimer Scotland Allied Health Professional (AHP) Consultant posts;
- the National Dementia Champions Programme.

The Scottish Government also published the 10 Dementia Care Actions for Acute General Hospitals, with much activity taking place to support implementation.

How is the resource structured?

The learning resource has four modules. Learning outcomes and activities have been written to reflect Level 7 of the Scottish Credit and Qualifications Framework. The modules include suggestions for further learning that will help you explore issues in greater depth.

The modules are:

Module 1: Understanding dementia
Module 2: Person-centred assessment and screening
Module 3: Holistic approaches to supporting the healthcare needs of people with dementia
Module 4: The care experience

We use different types of learning activity throughout the resource to help you reflect on how you can best support people with dementia, their families and carers, and put your learning into practice. The activities play a key part in helping you develop the knowledge, skills and attitudes that are central to your role. The focus is on practical application of the learning, reflective practice and putting learning into action.
Introduction

The 10 Care Actions

We will refer to the 10 Care Actions throughout this resource.
How should the resource be used?

We want you to use the resource in the way that best suits you, your team and your organisation.

It can be used for individual learning, learning as a group or team, in a facilitated teaching and learning event, or a mixture of all. Whatever approach is favoured, we recommend that learners are provided with opportunities for reflective discussion with their supervisors and group discussions with peers and teams. This will help to put their individual experiences into a broader context and enhance their learning.

Your learning from the resource will also be enhanced by undertaking these additional learning resources:

- ‘Think Capacity: Think Consent’ – Learning Resource (available on the NES website);
- NES Delirium eLearning Modules – available on LearnPro;
- NES Stress and Distress and Dementia in Acute Care eLearning Modules – available on LearnPro.

We make reference to these throughout the resource.

How does the learning in this resource contribute to wider development opportunities?

The resource provides a range of learning activities and reflective exercises. Completing the assessments on the NES LearnPro version will enable you to evidence successful completion of each module: if you are a nurse, this can contribute to your revalidation.

The Nursing and Midwifery Council (NMC) introduced a revalidation process in 2015. It has a number of requirements, including registrants submitting evidence of continuing professional development (CPD) and the submission and verification of reflective practice accounts.

NMC registrants should be able to use the learning from this resource to:

- verify that they have undertaken the CPD required;
- evidence successful completion of the modules by completing the assessment on the NES LearnPro version;
- apply learning to reflect on, and improve, their practice.

What about you?

Caring for people with dementia, their families and carers in an acute ward environment can be stressful at times. The busy environment, the fast turnover of patients and the complex presentation of people with dementia can contribute to care being a challenge for staff. A clearer understanding of how to approach care for people with dementia in this setting may make the experience more satisfying for all.
Module 1
Understanding dementia
Module 1 Understanding dementia

Introduction
This module focuses on how people with dementia, their families and carers can be supported through the process of admission to acute general hospitals. We look at some of the common types of dementia, examine their prevalence and how they affect the brain, and consider common difficulties experienced by people with dementia.

We start by setting out why dementia is such an important issue for staff working in acute general hospitals. People with dementia may be at risk of a number of poor experiences and outcomes of care when being admitted to hospital. Getting the initial admission and assessment process right can have a significant positive influence.

Learning outcomes
By the end of this module, you should be able to:

- identify and describe the different types of dementia;
- understand common symptoms and difficulties and how they affect people’s experience of admission to hospital;
- begin to appreciate the importance of communication, environmental issues and involvement of families and carers during the admission process;
- apply this learning to develop your practice.

Links to the 10 Care Actions
Learning in this module links to the following 10 Care Actions for Acute General Hospitals:

- plan and prepare for admission and discharge;
- develop and embed person-centred assessment and care-planning;
- develop a safe and therapeutic environment;
- work as equal partners with families, friends and carers.

Activity
We highlighted work being undertaken to deliver the 10 Care Actions in the introduction to this resource.

Before starting the module (and if you are not already aware):

- find out who the Alzheimer Scotland Nurse Consultant is for the NHS Board in which you practice;
- find out what local improvement activity is already going on to support the specific care actions outlined above;
- find out if you have a Dementia Champion in your area.
Module 1 Understanding dementia

What is dementia?
Dementia is a term used to describe the symptoms that occur when the brain is affected by specific diseases and conditions. It is not a single disease, but a collective term for a large number of degenerative brain disorders.

There are more than 100 types of dementia, each caused by a different disease. There is currently no cure, and while medicines can improve some symptoms or temporarily slow progression, the condition is terminal. All types of dementia are progressive, though the progression can be halted in some less common types. Some symptoms are common to all types of dementia, while others are more likely to occur in specific types.

It is important to understand that many people are able to live well with dementia. They lead active and fulfilling lives for a number of years after they first experience difficulties and receive a diagnosis.

While a person with dementia may only be in hospital for a short time, the way you communicate with and support him or her will have an influence on the impact of the whole care experience and how quickly the person can return home. We explore throughout the learning resource how you can take positive action to ensure the best possible outcome and quality of life for people with dementia, their families and carers.

Common problems people with dementia may experience

| Difficulty performing familiar activities | The person may have problems with activities such as getting dressed or brushing teeth. The sequencing of steps in completing the activity may be in the wrong order, or the person may skip a step completely. |
| Communication difficulties | People in the early stage of dementia may be aware of some of their communication difficulties. As the dementia journey progresses, their ability to process information becomes slower and more difficult, and their responses to communication from others can be delayed. Communication may become frustrating as the person struggles to find the right word or uses the wrong word with increasing frequency. This may result in difficulty holding conversations and expressing thoughts and feelings. The person will nevertheless be able to communicate on an emotional level and recognise facial expressions and tone of voice. |
| Disorientation and confusion | People with dementia may become disorientated to the time of day, the place in which they are situated and the people around them. Those admitted to hospital, for example, may not know where they are or how they got there. |
| Poor or decreased judgement | This is usually caused by difficulty with concentration, memory and understanding, leading to problems in decision-making. |
| Difficulty with recognition | This may involve recognising familiar objects, people, sights, places or sounds. |
| Difficulty understanding visual images | People with dementia may not be able to judge distances or colours, for example, or may have decreased sensitivity to contrasts. They may also have difficulty recognising their own reflection. |
Module 1 Understanding dementia

Common problems people with dementia may experience (continued)

**Misplacing things** Repeatedly putting things in an unusual place or being unable to retrace their steps are common examples. People may also think others have been interfering with their possessions.

**Changes in mood or behaviour** The person may have rapid mood swings, from being calm to tearful or angry, for no apparent reason.

**Changes in personality** People with dementia may become suspicious or fearful, or just apathetic and uncommunicative. They may also become disinhibited, over-familiar or more outgoing than previously.

**Loss of initiative** The person may become very passive and require cues prompting him or her to become involved, or may withdraw from social activity.

Activity

Reflecting on the common difficulties people with dementia might experience, take five minutes out of your busy shift to consider the area you work in.

- What can you hear, see, smell and feel?
- What did you notice most? Sit somewhere safe in the ward or department, out of the way but near the main areas.
- Close your eyes for two minutes and just become aware of the environment around you.
- Again, what can you hear, see, smell and feel – is it different from when you had your eyes open?
- What did you notice most?
- Was the ward/department quiet or noisy?
- Did you feel safe and secure?
- What sounds did you hear?

What have you learned from this activity in terms of supporting people with dementia during their admission?

**Record your answers here:**
Different types of dementia

People with different types of dementia have many similar experiences, but no two people will experience dementia in exactly the same way. The rate of progression will also vary greatly and will be influenced by the type of dementia and area of the brain affected. Dementia has many forms, can change as the condition progresses and, most importantly, happens to an individual who has strengths and a life story.

### Alzheimer’s disease

<table>
<thead>
<tr>
<th>Prevalence</th>
<th>Alzheimer’s disease is the most common cause of dementia. It is estimated to affect more than 520,000 people in the UK (2015 figure). Around twice as many women over 65 have Alzheimer’s disease.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age groups affected</td>
<td>Most people with Alzheimer’s disease are over 65. The risk of developing it increases with advancing age, but less commonly, Alzheimer’s disease can develop in younger people. You will find out more about younger people with dementia later in this module.</td>
</tr>
<tr>
<td>Typical symptoms</td>
<td>Alzheimer’s disease involves a general decline across a range of cognitive abilities. Typical symptoms include poor memory for recent events and learning new information, impaired concentration, decision-making difficulties, disorientation and difficulty in carrying out everyday tasks.</td>
</tr>
<tr>
<td>Progression</td>
<td>Alzheimer’s disease is progressive, but the rate of progression differs widely between individuals. Memory loss will increasingly impact on daily life as the condition progresses.</td>
</tr>
</tbody>
</table>

### Atypical forms of Alzheimer’s disease

Atypical Alzheimer’s disease is found in around 5% of people diagnosed when over 65. However, it accounts for around one-third of people who are diagnosed under 65.

**Posterior cortical atrophy (PCA)**

The early symptoms of PCA often include difficulties identifying objects or reading, even though the person’s eyes are healthy. People may also have problems judging distances when going down stairs, or appear uncoordinated when carrying out tasks.

**Logopenic aphasia** causes difficulties with language. The person’s speech can become slowed and lack fluency due to word-retrieval difficulties.
## Vascular dementia

<table>
<thead>
<tr>
<th>Prevalence</th>
<th>Vascular dementia is the second most common type of dementia, affecting around 150,000 people in the UK in 2015.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age groups affected</td>
<td>The risk of vascular dementia increases with age, but it is one of the most common types of dementia among younger people with dementia in the UK.</td>
</tr>
<tr>
<td>Typical symptoms</td>
<td>Symptoms vary depending on the underlying causes. They can include problems with concentration and verbal communication, visuospatial difficulties and memory problems (though this may not be the first symptom), periods of acute confusion and epileptic seizures. Planning, making decisions or problem-solving can be difficult. Physical symptoms of stroke, such as physical weakness or paralysis, may be present. People with this type of dementia often have good awareness of their difficulties, which can lead to depression and/or anxiety.</td>
</tr>
<tr>
<td>Progression</td>
<td>Vascular dementia can often involve a ‘stepped’ progression, with symptoms remaining at a constant level and then deteriorating suddenly.</td>
</tr>
</tbody>
</table>

## Mixed dementia

Some people with dementia have a diagnosis which means that the progressive damage to the brain is being caused by both Alzheimer’s disease and vascular dementia.

## Dementia with Lewy bodies

<table>
<thead>
<tr>
<th>Prevalence</th>
<th>Dementia with Lewy bodies (DLB) may account for about 10% of those with a diagnosis of dementia in the UK.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age groups affected</td>
<td>As with all forms of dementia, it is more prevalent in those over 65, but in rare cases may develop in younger people.</td>
</tr>
<tr>
<td>Typical symptoms</td>
<td>In common with most other types of dementia, symptoms include memory loss, shortened attention span, disorientation and verbal communication difficulties. Additionally, people with DLB will often experience symptoms associated with Parkinson’s disease, such as tremor, muscle stiffness and visual hallucinations, with fluctuations in symptoms from day to day or within the same day. People may also be prone to fainting or unexplained falls and sleep disorders can be common.</td>
</tr>
<tr>
<td>Progression</td>
<td>DLB is a progressive disease, meaning the symptoms will worsen over time. In general, DLB progresses at about the same rate as Alzheimer’s disease, typically over several years. Many people have problems with speech and swallowing, with additional risk of choking, as the condition progresses.</td>
</tr>
</tbody>
</table>
Fronto-temporal dementia

<table>
<thead>
<tr>
<th>Prevalence</th>
<th>Fronto-temporal dementia (previously known as Pick’s disease) is a relatively rare type of dementia.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age groups affected</td>
<td>It is more likely than other types of dementia to affect people under 65.</td>
</tr>
<tr>
<td>Typical symptoms</td>
<td>Memory typically remains intact early in the condition, but personality and behaviour change. People may lack insight into what is happening to them, lose the capacity to empathise with others, behave in socially inappropriate, disinhibited or occasionally aggressive ways, or become withdrawn and lacking in motivation. They will often experience verbal communication difficulties, spatial disorientation and shortened attention span, and may develop compulsive behaviour, such as over-eating.</td>
</tr>
<tr>
<td>Progression</td>
<td>The rate of progression varies enormously, ranging from less than two years to more than 10. Damage to the brain becomes more generalised and symptoms become similar to those of Alzheimer’s disease.</td>
</tr>
</tbody>
</table>

Other types of dementia

Approximately 23,000 people in the UK have a rarer form of dementia. Two such conditions are caused by alcohol: Korsakoff’s syndrome and alcohol-related brain damage. These are serious brain disorders but will only be progressive if the person continues to drink alcohol. The progression of other rarer types of dementia, including those caused by deficiencies of thyroid hormone, vitamin B12 and folic acid, can be stopped, but most types are progressive. Some of the more widely known of the rarer dementias include Creutzfeldt-Jakob Disease (CJD) and Huntington’s disease. Between 15–30% of people with Parkinson’s disease will develop a type of dementia closely resembling dementia with Lewy bodies.

The effects of dementia on the brain

Every type of dementia involves progressive physical damage to the brain. The most common areas affected in most types are the temporal, parietal and frontal lobes. Damage will lead directly to problems related to the function of the particular lobe.
Some examples of the potential impact of damage to specific lobes of the brain are outlined below.

**Parietal lobe**
As the parietal lobe helps people to organise their body in space, damage in this area can:
- often lead to people having problems in processing visual information, for example, difficulty in recognising faces and objects;
- lead to people having problems in carrying out a sequence of actions, such as getting dressed;
- affect people’s body sense – that is, knowing which part of your body is where;
- affect people’s spatial awareness – this means knowing where objects are relative to their own body.

**Frontal lobe**
The frontal lobe helps people organise and control their behaviour, so damage in this area means people may experience:
- lack of inhibition;
- difficulty initiating or stopping actions or sounds, which can become repetitive;
- problems with planning, decision-making and abstract thinking, making it very difficult to make a choice in certain situations;
- problems with reasoning.

**Temporal lobe**
The temporal lobe helps people to store new information, so damage in this area can cause problems with:
- understanding and producing speech;
Module 1 Understanding dementia

- remembering recent events;
- more recent memories, although memories from the past can be more accessible;
- attention span.

**Occipital lobe**

The occipital lobe receives visual information from the eyes. It transfers this information to the parietal lobe to support the construction of 3-D visual images. Damage in this area can:

- lead to difficulties in the perception of shape, movement and colour;
- contribute to the inability to recognise or identify objects.

Brain damage in dementia is progressive and some people’s abilities may deteriorate over time. Many additional factors related to other aspects of people’s lives can influence their dementia journey both positively and negatively.

**Activity**

Reflect now on what you have learned about the types of dementia and how dementia affects different areas of the brain.

How will this influence your practice in the future? Outline three key learning points and changes you might make.

**Record your answers here:**

-Dementia causes damage to the brain, and an affected person will most likely experience problems with carrying out day-to-day activities. If we understand a little about how the brain works, this can help to explain some of the problems the person faces and the particular challenges when admitted to an acute general hospital.
The experience of admission for people with dementia – the importance of communication

The sights, sounds, noise and smells of an emergency department and acute ward can be overwhelming and frightening for people with dementia. The essence of caring for a person with dementia is knowledge of the impact of change and careful communication.

Practice guide – initial assessment of the person with dementia

- Carry out the assessment in a quiet, calm area.
- Ensure the person’s family and/or carer is there at all times.
- Try to arrange for one member of staff to work with the person during his or her time in the department.
- Make every effort to avoid moving the person to different areas in the department or ward.
- Ask what the person needs, listen to those needs and then explain what is happening (and going to happen) at each step of the procedure.
- When recording details, provide a full description of what you see and hear. Avoid interpreting behaviour and putting a label on it. Full descriptions aid assessment, communication and care delivery. Describing someone as ‘agitated’, for example, provides very little information from which to care for that person.

Communicate carefully – essentials

- Consider if older people need dentures, glasses and hearing aids to enable them to communicate effectively, as they may not remember or be able to explain that they need them.
- Communication skills are progressively affected as dementia develops. Finding words can be difficult in the early stages and the person may try to talk around the word they are looking for. They may be less fluent: language requires more thought and effort. It is important to give the person time to think and respond.
- The loss of language skills starts with words we use least and those we learned last. This provides a useful guide to our use of language when we communicate with people with dementia.
- Communication that uses health-related jargon and words that have become popular only recently are least likely to be understood. The shorter the sentence and the more everyday words we use, the more chance the person will have of understanding what we are saying. In short, we should try to match our level of communication to theirs.

People in the early stage of dementia will be aware of some of their communication difficulties. Putting pressure on them by rushing will only make the situation more difficult. Reinforcing verbal information with written and other visual materials may help them understand what is going on. As dementia progresses, people may develop a range of more specific language problems. Some experience expressive dysphasia, where they may understand what is said to them but are unable to express their understanding. They may also develop receptive dysphasia, where they are unable to understand what is being said to them.
You need to attend more carefully to communication as people move into the later stages of their dementia journey. Attempting to reason or disagree with the person only has the effect of making them more distressed and confused. Instead, you should try to follow their line of thought – this can make your communication more effective. Use gestures and facial expression as well as words to reinforce your message. A person in the progressed stages may not understand words at all, but will still recognise facial expression and tone of voice. A gentle tone means more than words here.

We will revisit communication and provide more in-depth guidance later in the resource.

**Communication that can disadvantage the person with dementia on admission**

Here are some of the ways we can disadvantage people with dementia through our communications, although some of these would challenge any person.

We should avoid:

- interrupting the person while trying to speak;
- contradicting or arguing;
- speaking for the person, perhaps to another professional;
- reinterpreting what you think the person has said in your own words;
- using technical, complicated language;
- talking out of earshot or lowering your voice – this can cause the person to become very suspicious of you and what you are doing, which may lead to distressed reactions such as agitation and aggression;
- displaying negative non-verbal communication, such as sighing, turning away and frowning, can easily be recognised by the person, who still understands non-verbal communication.

**Working with families and carers during admission**

People with dementia are often cared for at home or in a care setting by familiar people. Coming into hospital will bring them into contact with a bewildering number and range of people.

If the person has someone with them, try and make sure they stay with them. Having someone familiar there can calm and reassure people, making the initial contact and gaining information much easier. Concerns about confidentiality are understandable, but most people with dementia can give permission for their supporter to be involved in their care.
Practice point – key things you need to know from families and carers on admission

- What is the name the person prefers?
- What is their normal routine for sleeping, eating, personal care, going to the toilet and taking their medicines?
- What is their usual health status – in particular, do they have any pain-causing conditions?
- What upsets them and how do they show it?
- What calms them when they get upset?
- What are their religious or spiritual needs?

We will revisit the importance of working in partnership with families and carers and provide more in-depth guidance later in the resource.

Capacity and consent

The ability of people with dementia to make decisions varies enormously. Most people can make decisions about some aspects of their lives, but need support in other areas. For some, the ability to make decisions depends on their capacity at any given point, which can be affected by physical illness, pain or delirium. It is important to establish the person’s capacity on admission, noting that this may fluctuate.

A person is considered to have capacity if he or she:

- has been given appropriate information that they can understand and can make a decision based on it;
- has experienced no undue pressure from other people;
- can communicate decisions to others;
- holds this decision consistently.

The Adults with Incapacity (Scotland) Act 2000 offers options to help people with dementia, a learning disability or mental illness who lack capacity to make decisions. The Act sets out guidance and arrangements for providing medical treatment and granting intervention orders to allow decisions on specific issues to be made for the person. It also provides for the appointment of welfare and financial guardians who have authority to make decisions for a person who is unable to do so. Consent to care and treatment is therefore dependent on the person’s capacity.

Valid consent must be:

- given freely and without coercion;
- given by a person who is considered competent;
- specific to the intervention or procedure;
- informed, so the person understands what is involved;
- continuous for the duration of the treatment or procedure.

Remember

It is vital that you understand the Adults with Incapacity Act.

To learn more, please access the ‘Think Capacity: Think Consent’ learning resource on the NES website.
We will also explore capacity and consent in more depth in later modules.

**The importance of the environment**

The acute care environment – physical, social and cultural – can have a profound effect on the quality of life and experiences of people with dementia.

Something that might seem simple to a person without cognitive impairment can feel difficult, frustrating, confusing and even frightening to someone with dementia. Multiple sources of stress from noise, light, people and activity can become incomprehensible to the person, who will struggle to make sense of what is happening. All this can be compounded by the attitudes of staff and how they approach the person.

Changes people experience as their dementia progresses may alter how they interpret what they see, hear, taste and smell. The changes will be unique to each individual, but generally, people with dementia find it difficult to orientate to an unfamiliar environment and have a reduced stress threshold to many environmental stimuli.

The environment needs to be enabling for, and not a barrier to, people with dementia. It shouldn’t isolate them – the physical environment can play an important part in improving the lives of people with dementia by complementing treatments, supporting people to maintain their abilities and strengths, and helping them to cope with difficulties such as impaired memory and loss of reasoning and learning skills. A few simple changes can have a significant, positive impact.

This is why the environment should be assessed and modified, sometimes in very simple ways, to promote independence and quality of life for people with dementia. Some aspects are particularly amenable to change – things like sound, light and design can be altered to promote independence and social interaction.

**Activity**

Look at the hospital corridor below. Imagine you are 80 years old and have fallen today. You have a painful arm and knee. You really do not know where you are. Now you suddenly realise you need to urinate. How do you find the toilet?
Alternative to hospital admission

We have highlighted that admission to hospital can be a very traumatic experience for people with dementia. It can result in extended stay in hospital, leading to repeated illness, loss of independence and inappropriate admission to residential care. It is well recognised that people with dementia receiving care and treatment in their own home have better outcomes. Many NHS Boards have established hospital-at-home services that provide rapid responses from a team of specialists to avoid the need for hospital admission. Please take time to find out what services are offered to people with dementia in your area.
Module summary

This module has focused on how people with dementia, their families and carers can be supported through the process of admission to acute general hospitals. We have explored: different types of dementia; common symptoms and difficulties people experience and how this affects their experience of admission to hospital; and the importance of communication, environmental issues and involvement of families/carers during the admission process.

We will further develop the learning from this module in later modules.

Module assessment

Reflective activity

What did you learn from completing this module?

How did you change or improve your practice as a result?

How is this relevant to your Code of Professional Practice?
Module 2
Person-centred assessment and screening
Introduction

Early identification of key risks, such as delirium, undiagnosed dementia and depression, is vital to ensure the person receives timely and appropriate care. A person-centred approach to screening and assessment is essential and may improve outcomes for the person. In this module, we will explore approaches to communication that support the person and enable them to be fully involved in decisions about their care and treatment. We stress the importance of finding out what is usual for the person so they can be supported to maintain their skills and to allow timely recognition of indicators of possible dementia, delirium and depression. We will also consider the potential impact of co-morbidities and frailty on people with dementia and the application of screening and assessment tools to support person-centred care planning.

Learning outcomes

By the end of this module, you should be able to:

- describe the indicators that may suggest a person has cognitive impairment;
- appreciate the importance of communication when carrying out person-centred assessment of people with cognitive impairment or dementia;
- understand how to distinguish between dementia, depression and delirium;
- understand how to appropriately apply evidence-based screening tools for dementia, delirium and frailty;
- understand the implications for person-centred care planning when screening indicates the person has cognitive impairment;
- develop your knowledge and skills in involving families and carers in the assessment process.

Recognising dementia and cognitive impairment

If a person has a diagnosis of dementia and staff know about this, his or her care needs can be addressed through following the information in this learning resource. The situation becomes more complicated when the person:

- does not have a known diagnosis of dementia but seems confused;
- is known to have dementia but is more confused than expected;
- shows signs of dementia but has no known diagnosis.

Despite the complexity and variety of presentations described, most of the information in this resource can be used effectively in any of the situations identified. The principles of good communication and reducing distress apply universally.

We provided an overview in Module 1 of different types of dementia and the common and specific problems people might face. Front-line identification of possible dementia or cognitive impairment is vital to ensure that older people...
receive appropriate care in the short and long term from health and social services provision.

A diagnosis of dementia should only occur following a specialised assessment either in a memory clinic, by a liaison mental health service or by a consultant psychiatrist or geriatrician. Staff in acute care, however, have a vital role in identifying someone they suspect of having dementia or cognitive impairment and ensuring this informs future care and treatment. Please find out more about local pathways for assessment and diagnosis within your own NHS Board area.

The importance of communication in person-centred assessment for people who appear confused

The way you communicate with the person and carry out your assessment will influence the impact of the whole care experience for him or her. Your assessment is an opportunity to form relationships and partnerships with the person, the family and carers.

Communication difficulties people might experience

People with dementia and those with confusion caused by other conditions often have extreme communication difficulties in expressing and receiving information. These are extremely complex, involving neurological, psychological and interpersonal elements.

Not everyone with dementia can communicate using speech; the person may have impairments in expression, but is still able to understand what is being said. As dementia progresses, different areas of the brain are damaged and a range of communication difficulties can arise as a result. Here are some examples, with suggestions for helpful responses.
Communication issues

The person keeps repeating the same word or phrase

This may be the result of stress and anxiety – the person could be overwhelmed and trying to express their worries. You could try repeating the word or phrase back to the person: this can make them feel you are trying to understand and may help them move their communication on again. Distracting the person may also help. Families and carers may be able to help with advice on what might work.

What the person is saying does not seem to make sense to you

Listen for any specific words or phrases they keep repeating and try to build on these, perhaps reflecting these back to them. This can help them feel listened to and that you are trying to understand. Sometimes you can intuitively guess what someone is saying by listening to the tone of their voice and watching their non-verbal gestures and behaviour.

The person calls you by someone else’s name

This can happen when you remind the person with dementia of someone they know. You may be making them feel the way they do with the person whose name they are using. This can be positive or negative, depending on who they think you are. It is usually best to gently remind them who you are, perhaps pointing to your uniform if they can understand these cues. The use of validation or listening to feelings rather than words can be very helpful if someone is distressed and becoming agitated. If the person wants to go and find her mother, for example, it should be remembered that most people would consider their mother a safe person, someone who could protect them and make things better. An understanding of the feelings behind the words the person is using can guide staff to respond differently.

The person keeps repeating what you have said

They may not be clear about what you are saying or you may be communicating too quickly for them to process what you are saying. You could use the Key communication tips below and try again. Repetition may not be within the person’s control and it may sometimes be more helpful to use distraction instead.

The person has difficulty finding words

You should try and pick up the sense of what they say or ask them to show you what they mean. If you can guess the word, then suggest this to them: it is much more stressful for the person to desperately try and find a word than have you supply it. You could point to objects or people in the environment if you cannot guess the word.
A person with dementia, and other people who appear confused, benefit from a more focused approach to communication. All of these key skills will make communicating much easier for you and the person. People can often give good information during assessment but simply need more help to provide it. Remember to seek advice from a person who knows them well, if possible. The following communication tips will help to reduce distress.

### Key communication tips

<table>
<thead>
<tr>
<th>Tip</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gain the person’s attention</td>
<td>It is important to gain the person’s attention first, before you begin to speak. Approach them from their visual field so they can see you coming towards them. Try and make eye contact, and make sure you are close enough and in the correct position for them to see your face and body movements. You may find it helpful to touch their arm gently but be mindful of their feelings about being touched and ensure it does not frighten them.</td>
</tr>
<tr>
<td>Use the person’s name</td>
<td>Importantly, use the person’s preferred name when you address them. Using the person’s name may help them to understand that you know them and are not a stranger – this can be very reassuring.</td>
</tr>
<tr>
<td>Remind the person who you are</td>
<td>It is very helpful to remind the person who you are each time you return and at frequent intervals while you are supporting and caring for them. This ensures they do not become alarmed at this ‘strange person’ trying to engage with them. Repeating who you are frequently may feel rather artificial, but it will remind the person they are with someone who is caring for them. This is particularly important if you move out of their space and then return.</td>
</tr>
<tr>
<td>Keep the noise down</td>
<td>Reduce distractions such as activity and noise wherever you can. Try and find a quiet area where the person can concentrate on what you are trying to communicate.</td>
</tr>
<tr>
<td>Do not rush</td>
<td>Take your time with the person. It is tempting to hurry when you are busy but this will inevitably mean it will just take longer, as the person may not engage with you. Simply slowing down your rate of speech can help. Try to increase your communication time both in speaking and listening. It may help if you silently count to seven between short sentences and then give the person the same time to answer.</td>
</tr>
<tr>
<td>Listen to the person</td>
<td>Taking time to really listen is important as the person may be struggling with their words and any pressure from you may increase their anxiety, making it much more difficult to communicate their needs.</td>
</tr>
</tbody>
</table>
### Key communication tips (continued)

- **Keep calm** Use a calm tone and manner to reduce distress and make the person feel more comfortable with you. It is important to remember that no matter what stage of the journey they are at, the person with dementia will respond to your non-verbal signals, even very subtle movements of your face and body. If you need to repeat information, try not to look or sound impatient, even if you are in a hurry.

- **Make things simple and straightforward** Try and use words the person will understand, free from jargon. Sentences should be short and contain only one idea at a time. In the same way, when giving guidance to the person, break down complex instructions into simple stages, delivering them one at a time. Open questions can be very challenging for a person with dementia partly because of their memory difficulties. It can be helpful to present them with simple choices rather than complex questions. It is vital that you are specific in your language, using full names rather than pronouns. Give clear instructions: for instance, rather than saying ‘please sit there’ you could try saying ‘please sit in this blue chair’.

- **Use prompts and cues where possible** Written or photographic prompts can help a good deal as they provide cues for the person who may not understand what is being asked of them.

- **Use humour when appropriate** Humour can be a very useful way of communicating and of diffusing tense situations, but it must be used very carefully as it can misfire if the person has been unable to process any subtle or complex message involved in what you say. A smile and pleasant manner is almost always as effective in smoothing the communication pathway.

- **Use the person's preferred methods of communication** It is important to establish a person’s preferred methods of communication using information from them and from others, such as families and carers, friends, support workers or health/social services professionals involved with their care – in fact, anyone who knows the person well. Examples of preferred methods include using the person’s first spoken language, Makaton or communication aids such as pictures or speech mats.
Knowing the person who appears confused and may have dementia

Understand what is usual for the person

The term cognitive impairment is an overarching one for someone who may be experiencing problems with the mental processes of memory, perception, judgement and reasoning. Identification of cognitive impairment can help you to deliver appropriate care at the time and provides a prompt to refer on for further assessment for dementia.

We need to establish what is usual for the person to identify the presence and causes of confusion. The main sources of this information are the person him- or herself, the family, carers and staff who know the person. Asking the right questions and listening for informal or formal reports of symptoms provides the key assessment information to inform person-centred care-planning.

Mary’s story

Mary is 82 years old and has lived in a care home for three years. She has a daughter, Grace, who lives in London and visits every couple of months. Mary has chronic obstructive pulmonary disease (COPD) and peripheral vascular disease. She also needs assistance with dressing, walking, eating and drinking. She has been admitted to hospital with a suspected fractured femur following an unwitnessed fall. Mary does not appear to notice you when you speak to her and she is quite drowsy and lethargic.

You need to rapidly establish what is usual for Mary and, if possible, get a collateral history of the changes she has been experiencing. While it is suspected that she has a fractured femur, there are other important considerations, especially as she does not appear to notice when you speak to her.

Generally, the main sources of this information will include the person him- or herself, the family and carer, ambulance clinicians or health and social care workers who know the person. Asking the right questions and listening for informal or formal reports of symptoms provides the keys to identification of dementia or delirium and appropriate care delivery.

We will look at delirium in more detail later in this module.

If the person has someone with them, try and make sure they stay with them. Having someone familiar there can calm and reassure them, making their experience, and your opportunity to gain information, much easier. Concerns about confidentiality are understandable, but most people with dementia can give permission for their supporter to be involved in their care.

Sometimes a person arrives alone, especially if the admission is unplanned, and it is important to contact a supporter as soon as possible. In the meantime, one person should be assigned to the person to make them feel safe.

Activity

What will be the key consideration in your assessment?

Record your answer here:
**Practice point – key things to consider**

- Does this person already have a diagnosis or a history of dementia or delirium?
- Is the person able to give a good history, or do you need a carer present?
- What are the usual behaviour, speech, mobility and mental abilities of this person?
- How does the current problem differ from what is usual for this person?
- How long has this been a problem for the person?
- Is there anything else different or unusual for the person that the carer or others have noticed?

The recommended documentation to support person-centred approaches to assessment and care in acute general hospital in Scotland is ‘Getting to Know Me’. This can be completed before the person goes into hospital or while they are in hospital. It is important that you are familiar with this document and ensure that it is completed with the person and their family and carers.

**The main benefits of using ‘Getting to Know Me’**

- It enables us to support the person with what they actually want and need, rather than guessing.
- It helps us to have a better understanding of the causes of someone’s behaviour or distress.
- It allows us to support the person to engage in activities that are of interest and are meaningful to them. A person may have advanced dementia but is still able to engage to some extent in something that has held great interest for them. Dementia changes a person’s ability to interact with their environment, but the person is still there.
- It enables us to form relationships based upon understanding and empathy.
- It can provide the basis of assessment of risk and risk enablement across a range of situations and knowing what is important to the person.
Activity

Below are some examples that illustrate the importance of knowing the person.

Cover up the right-hand side of the table and read the behaviours first. Imagine how you would react caring for this person, then read the snapshot life story.

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Snapshot life story</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fred went around the unit at night switching all the lights off and would scold the night staff for being up.</td>
<td>Fred was a night security worker at a coal mine all his life and was just doing his job.</td>
</tr>
<tr>
<td>Mary would search the unit for her children constantly and would gain great joy when a visitor brought a newborn baby to the unit.</td>
<td>Mary had a large family, totalling 12 children, some of whom died as babies.</td>
</tr>
<tr>
<td>Joanne would get up at 4am and try to leave the unit, stating she needed to go to work.</td>
<td>Joanne was going to start milking the cows, something she had done all her married life.</td>
</tr>
<tr>
<td>Lewis hit out at staff whenever he required assistance to go to the toilet. He became upset, angry, swore and tried to use his fists against staff.</td>
<td>Lewis was an adult survivor of repeated and prolonged childhood sexual abuse.</td>
</tr>
</tbody>
</table>

These examples emphasise the need to ensure we have sufficient information to support the person and develop care plans to meet their needs. The ‘Getting to Know Me’ document should be used all the time to help to develop positive partnership relationships with the person, their family and carers to ensure that the person is engaged in activities that are meaningful to them.

How do you feel about your initial thoughts about the people described above now?

Would you approach their care differently with this snapshot?

Record your answers here:
Screening for cognitive impairment

Cognitive impairment is not a distinct illness but happens when a person has difficulty remembering, learning new things, concentrating or making decisions. This can be caused by a range of physical and psychological conditions. Screening is concerned with minimising risks, reducing the number of moves within the hospital, avoiding unnecessary admission and delivering appropriate care.

The person may present with a known diagnosis of dementia. There may be difficulties when someone has no diagnosis but the clinical picture suggests dementia. Screening cannot be carried out for dementia, as the diagnosis is too complex. Most screening tools are therefore used to identify the presence of cognitive impairment.

It is recommended that you initially use the four-item Abbreviated Mental Test 4 (AMT4) to identify the presence of cognitive impairment. Different screening tools may be used and you should refer to local guidance on screening tools in your own NHS Board area.

AMT4

Ask the person:

- How old are you?
- What is your date of birth?
- What is this place?
- What year is it?

A score of 1 should be awarded for each correct answer: a score of 3 or less on this scale would indicate the possible presence of cognitive impairment and must lead to a referral for further assessment. This could be carried out in the hospital or in the community if discharge home is seen to be safe and appropriate.

If you suspect delirium, treat as a medical emergency and assess for delirium using the 4AT detailed later in this module, which incorporates the AMT4.

Activity

- Who would you refer to if you suspected dementia or depression and at what point?
- Does everyone in your team know who to refer to for further assessment?

Record your answers here:

Differentiating delirium, depression and dementia in a person who appears confused

It is vital to identify key risks such as delirium, undiagnosed dementia and depression quickly, allowing you to implement effective care. Front-line identification of dementia, delirium and depression is vital to ensure that older people receive appropriate care in both the short and long term. These three conditions may have a confused and blurred presentation in an older person. An older adult in hospital may have one, two or all three, and it is important to understand each one.
The table below shows the key differences between delirium, undiagnosed dementia and depression.

<table>
<thead>
<tr>
<th>Domains</th>
<th>Dementia</th>
<th>Delirium</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>History</td>
<td>Slow onset over months and years.</td>
<td>Recent sudden onset.</td>
<td>Progresses over weeks and months.</td>
</tr>
<tr>
<td>Course</td>
<td>Progresses slowly, symptoms are generally stable on a day-to-day basis.</td>
<td>Develops over a short period of time and fluctuates over the course of the day. May be significantly worse in the evening and at night.</td>
<td>May be limited to one episode, can be recurrent or chronic.</td>
</tr>
<tr>
<td>Awareness, alertness, attention</td>
<td>Usually unaffected.</td>
<td>Reduced awareness, changing alertness, very alert or not alert, short attention span, easily distracted. Sleepiness.</td>
<td>Generally unaffected, concentrating may be difficult at times.</td>
</tr>
<tr>
<td>Sleep/wake cycle</td>
<td>Each person may have their own sleep/wake cycle, which will generally be stable.</td>
<td>Sleep may be significantly disturbed from the person’s normal pattern.</td>
<td>Difficulty getting to sleep, early-morning waking or wakening through the night.</td>
</tr>
<tr>
<td>Psychomotor presentation</td>
<td>Generally unaffected.</td>
<td>Hyperactive – speeded up – or hypoactive – slowed down.</td>
<td>Slowed or agitated.</td>
</tr>
<tr>
<td>Perception</td>
<td>May misperceive objects in the environment.</td>
<td>May see/hear/feel things vividly that are not there and are frightened or distressed by these experiences.</td>
<td>May have a negative view of the world, themselves and people around them; in extreme depression, hallucinations and delusion may occur.</td>
</tr>
</tbody>
</table>
### Module 2 Person-centred assessment and screening

<table>
<thead>
<tr>
<th>Domains</th>
<th>Dementia</th>
<th>Delirium</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical function</strong></td>
<td>Slow progressive changes in physical function.</td>
<td>Sudden loss or change in normal physical functioning.</td>
<td>General slowness or agitated physical functioning develops over time.</td>
</tr>
<tr>
<td><strong>Memory</strong></td>
<td>Short and immediate memory reduction. Difficulty learning new information.</td>
<td>Reduced immediate and short-term memory.</td>
<td>Some short-term memory deficits may be present due to poor concentration. Person may report their memory is deteriorating.</td>
</tr>
<tr>
<td><strong>Thinking</strong></td>
<td>Reduced problem-solving abilities, reasoning and ability to understand abstract concepts.</td>
<td>Disorganised, leaping from one subject to another.</td>
<td>Feelings of helplessness, worthlessness, guilt and hopelessness. Thinking may be slowed or at times people report being unable to think.</td>
</tr>
<tr>
<td><strong>Speech</strong></td>
<td>Decreased ability to name things, find words or engage in long conversations.</td>
<td>Significantly different to what is usual for that person: very loud, upset, angry or quiet, slow, difficult to understand.</td>
<td>May be slowed or absent. Expression may be quiet and with short sentences, single words only.</td>
</tr>
<tr>
<td><strong>Causes</strong></td>
<td>Dementia is an overarching word for a group of illnesses whose origins are based in organic changes in the brain: Alzheimer's disease, vascular dementia, dementia with Lewy bodies (DLB).</td>
<td>Infection, dehydration, medicine toxicity, renal failure, head injury, sepsis, hyponatraemia, hyperglycaemia, malnutrition.</td>
<td>Recent losses of any nature. Medicine side-effects. Ongoing chronic illness, particularly with uncontrolled pain.</td>
</tr>
</tbody>
</table>
Delirium and dementia

Mary’s story

Ambulance clinicians have reported to you that care home staff have informed them that while Mary has had memory difficulties over the last year, she has been more confused over the past couple of days. She has not been eating or drinking very much but has been attempting to walk without assistance. The ambulance clinicians also report that they suspect Mary may have delirium.

The risk of developing delirium is increased:

- when a person is older;
- when a person has a combination of multiple precipitating and/or predisposing factors, such as frailty, physical health problems and cognitive impairment.

We know that Mary has COPD and peripheral vascular dementia. In addition, she has not been eating or drinking: this puts her at risk of dehydration and constipation, which further increase her risk of developing delirium. If Mary has a fractured femur, she will be at greater risk of developing persistent delirium that can result in serious consequences and poor outcomes.

Evidence suggests that delirium occurring during admission with hip fracture is associated with increased hospital stay and increased mortality in older people. When a person appears to have signs of cognitive impairment or seems confused and reports suggest a rapid change in his or her condition, it is essential to ‘Think Delirium’ and treat it as a medical emergency.

Activity

What would help you to determine whether Mary has delirium?

Record your answer here:

Remember

'Think Delirium' and treat as a medical emergency

It is vital that all staff working in acute care hospitals recognise the potential long-term impact of delirium and ensure screening and assessment is carried out as a priority when an older person, or a person with dementia, is admitted.
Admission to hospital, which is an unfamiliar environment, may be sufficient to trigger delirium in older people and those who already have a diagnosis of dementia.

Points to note

- Just having a diagnosis of dementia will increase the person’s risk of delirium fivefold.
- It is suggested that some two-thirds of people with dementia in an acute setting will have delirium.
- The consequence of this is often acceleration in the progress of dementia, loss of independence in physical function and increased mortality, particularly if it is persistent and there are repeated episodes of delirium.
- Older people who have frailty and are experiencing repeated and persistent episodes of delirium are at increased risk of developing dementia.
- Delirium is preventable when staff are aware of the triggers and risk factors and deliver appropriate person-centred care.
- It is also treatable when identified quickly and care and treatment approaches are put in place. When a person appears to have signs of cognitive impairment or seems confused and reports suggest a rapid change in his or her condition, it is essential to ‘Think Delirium’ and treat as a medical emergency.

As part of their Care of Older People in Acute Care work programme, Healthcare Improvement Scotland (HIS), in collaboration with NHS Boards across Scotland, has developed a range of tools and resources for healthcare professionals to help improve the identification and immediate management of delirium in clinical settings.

This includes the Delirium Pathway developed by the Scottish Delirium Association (SDA) in collaboration with HIS and recommended assessment and monitoring tools for use in acute general hospital settings. You can access these resources from the Healthcare Improvement Scotland website.

If it is suspected the person has delirium it must be treated as a medical emergency and an initial assessment using the 4AT assessment tool carried out.

This tool is designed to be used by any health professional at first contact with the person and at other times when delirium is suspected. It incorporates the AMT4, the brief screening tool for general cognitive impairment referred to earlier. It takes less than two minutes to complete. A copy of the 4AT assessment tool is available in Appendix I of this module.
Where it is not possible to carry out an assessment and there is someone present who knows the person’s baseline function (that is, their mobility, cognition and social support network), you should use the Single Question in Delirium (SQiD), as this may be the only trigger to suspecting delirium.

**Single Question in Delirium (SQiD)**

Do you think (name of person) has been more confused in the last two weeks?

You can find out more about the SQiD on the HIS Older People in Hospitals Improvement Programme website.

To further enhance your knowledge in the identification, care, treatment and prevention of delirium, you should access the NES Delirium Resources on LearnPro and complete the module that is appropriate to your role.

**Dementia and depression**

Depression is common in dementia and in older people with other health problems. As the symptoms of depression and dementia can be similar and can co-exist, an older person with dementia can sometimes wrongly be thought to have depression, and vice versa. It is important to note that depression is common among people at all stages of their dementia journey.

Other impairments typically experienced by people with dementia, including those relating to language, visual perception and the ability to orientate themselves in time and space, are found less often in depression. A person with depression will occasionally complain of an inability to remember things, but is more likely to recall information when prompted. In contrast, depending on their diagnosis and severity of symptoms, a person with dementia is less likely to benefit from such cues to aid recall and will tend to experience more significant memory problems and/or lack of insight into them.

The powers of reasoning and memory may be significantly affected in severe depression, and it is this state that is most easily confused with dementia. In a person with depression, however, this impairment is mainly due to poor concentration. The condition is reversible with appropriate treatment or if the depression improves spontaneously, but this is not the case with dementia.

**Frailty and dementia**

Frailty is a complex problem associated with ageing that substantially increases the person’s risk of poor health outcomes, longer stay in hospital, repeated admissions, increased admission to residential care and a markedly higher mortality rate. Many factors are involved, including multiple long-term conditions and health problems. When these are combined with an acute illness in a frail person, the result is impaired physical or psychological function.

Frailty is often associated with:

- falls
- malnutrition
- muscle weakness
- fatigue
- difficulty carrying out activities of daily living independently.

When the person’s condition is already compromised, a small additional problem can trigger an acute episode of disability and frailty.

Cognitive impairment is likely to be another key aspect of frailty, and the risk of poor outcomes increase tenfold for people with an existing dementia. Evidence suggests, however, that outcomes can be improved for the person when hospital staff rapidly identify frail older people and carry out a Comprehensive Geriatric Assessment (CGA).
Comprehensive Geriatric Assessment

CGA is a diagnostic process that involves holistic, multidimensional and interdisciplinary assessment of the person by a specialist team skilled in working with older people and rehabilitation. The focus of CGA is on establishing a frail person’s medical, psychological and functional capability. This will inform the development of a coordinated and integrated plan for care, treatment, discharge and ongoing follow-up and review and is likely to involve delivery of care, treatment and support across primary and secondary care, as well as the health and social services interfaces. It is essential that the person and their family and carers are fully involved in this process.

Screening for frailty

The decision to carry out screening for frailty is based on the person’s age, condition on admission and any recent deterioration in their ability to carry out activities of daily living. It will be informed by the person-centred approach to your general assessment of the person described earlier in this module, as well as the result of the 4AT score.

There is no set screening criteria, but HIS has developed a ‘Think Frailty’ screening tool (see overleaf) as part of their Care of Older People in Acute Care programme to support early identification, care and treatment of people who are admitted to hospital and who have frailty. The tool indicates the age criterion as 75 years and over or 65 and admitted from nursing/residential care or community hospital.

It also lists the following five criteria that would indicate a need to consider referral for CGA:

- functional impairment in the context of significant multiple conditions (new or pre-existing);
- resident in a care home;
- acute confusion (‘Think Delirium’) (for example the 4AT screening tool – is there a diagnosis of dementia or a history of chronic confusion?);
- immobility or falls in the last three months;
- list of six or more medicines (polypharmacy).

As we can see from Mary’s story, she is also potentially at risk of frailty. While you may not be able to carry out screening of her cognitive function, there are a number of other potential risks that would warrant further assessment.
Module 2 Person-centred assessment and screening

Frailty screening tool

Name: __________________________
Date of birth: __________________________
CHI number: __________________________
Practitioner name: __________________________
Practitioner signature: __________________________
Designation: __________________________

Step 1
Would this person benefit from Comprehensive Geriatric Assessment?
Aged 75 and over age 65+ from nursing or residential care or admitted from community hospital

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>F</td>
<td>Functional impairment in context of significant multiple conditions (new or pre-existing)</td>
</tr>
<tr>
<td>R</td>
<td>Resident in a care home</td>
</tr>
<tr>
<td>A</td>
<td>Acute confusion (Think Delirium), for example the 4AT screening tool – is there a diagnosis of dementia or a history of chronic confusion?</td>
</tr>
<tr>
<td>I</td>
<td>Immobility or falls in last 3 months</td>
</tr>
<tr>
<td>L</td>
<td>List of six or more medicines (polypharmacy)</td>
</tr>
</tbody>
</table>

Are any of the above criteria met?
If YES to any of the above, move to Step 2

Step 2
For those potentially being referred for Comprehensive Geriatric Assessment
Would this person be better managed by another speciality team at present?
Indicator for care by another acute speciality regardless of age

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need for HDU/ITU (including non-invasive ventilation)</td>
<td></td>
</tr>
<tr>
<td>Suspected new stroke or TIA thrombolysis and care in stroke unit</td>
<td></td>
</tr>
<tr>
<td>Trauma with suspected fracture</td>
<td></td>
</tr>
<tr>
<td>Head injury with loss of consciousness</td>
<td></td>
</tr>
<tr>
<td>Acute abdominal pain with collapse</td>
<td></td>
</tr>
<tr>
<td>Chest pain with suspected MI</td>
<td></td>
</tr>
<tr>
<td>Clear need for other speciality input, for example flare-up of known chronic condition</td>
<td></td>
</tr>
</tbody>
</table>

Are any of the above criteria met?
If YES to anything in Step 2:
– please ask for specialist multidisciplinary review while in their current unit, but do not transfer directly to the geriatric assessment service

If NO to the list in Step 2:
– prioritise for transfer of care to specialist geriatric assessment service
Importantly, this approach should also support identification of when palliative, rather than curative, approaches may be required. We will look at the specific palliative and end-of-life care needs of people with dementia in Module 4.

As the specific criteria for screening and assessment differ across Scotland, you should find out what screening and assessment arrangements are in place in your own NHS Board.

For further information on frailty, you may wish to access the Healthcare Improvement Scotland Older People in Acute Care website.

Remember

If you are working with older people who have confusion or dementia, the areas of assessment and screening described here are part of a wider comprehensive assessment process that also includes nutrition and hydration, falls prevention and tissue viability.

You should ensure you are familiar with the Healthcare Improvement Scotland (HIS) Care of Older People in Hospital Standards that can be accessed on the HIS website.
Module summary

We have explored how early identification of key risks, such as delirium, undiagnosed dementia and depression, is vital to ensure that the person receives timely and appropriate care. A person-centred approach to screening and assessment is essential and may improve outcomes for the person. We have discussed approaches to communication that support the person and stressed the importance of finding out what is usual for him or her and recognising indicators of possible dementia, delirium and depression. We will develop many of these issues as we look at person-centred care of people with dementia in later modules.

Module assessment

Reflective activity

What did you learn from completing this module?

How did you change or improve your practice as a result?

How is this relevant to your Code of Professional Practice?
Appendix 1. 4AT screening tool

The 4A Test: screening instrument for cognitive impairment and delirium

[1] ALERTNESS
This includes patients who may be markedly drowsy (e.g., difficult to rouse and/or obviously sleepy during assessment) or agitated/hyperactive. Observe the patient. If asleep, attempt to wake with speech or gentle touch on shoulder. Ask the patient to state their name and address to assist rating.

- Normal (fully alert, but not agitated, throughout assessment): 0
- Mild sleepiness for <10 seconds after waking, then normal: 0
- Clearly abnormal: 4

[2] AMT4
Age, date of birth, place (name of the hospital or building), current year.

- No mistakes: 0
- 1 mistake: 1
- 2 or more mistakes/untestable: 2

[3] ATTENTION
Ask the patient: “Please tell me the months of the year in backwards order, starting at December.” To assist initial understanding one prompt of “what is the month before December?” is permitted.

- Months of the year backwards
  - Achieves 7 months or more correctly: 0
  - Starts but scores < 7 months / refuses to start: 1
  - Unstable (cannot start because unwell, drowsy, inattentive): 2

[4] ACUTE CHANGE OR FLUCTUATING COURSE
Evidence of significant change or fluctuation in: alertness, cognition, other mental function (e.g., paranoia, hallucinations) arising over the last 2 weeks and still evident in last 24hrs

- No: 0
- Yes: 4

4 or above: possible delirium +/- cognitive impairment
0: delirium or cognitive impairment unlikely (but delirium still possible if [4] information incomplete)

4AT SCORE

GUIDANCE NOTES
The 4AT is a screening instrument designed for rapid and sensitive initial assessment of cognitive impairment and delirium. A score of 4 or more suggests delirium but is not diagnostic: more detailed assessment of mental status may be required to reach a diagnosis. A score of 1-3 suggests cognitive impairment and more detailed cognitive testing and informant history-taking are required. Items 1-3 are rated solely on observation of the patient at the time of assessment. Item 4 requires information from one or more source(s), e.g., your own knowledge of the patient, other staff who know the patient (e.g., ward nurses), GP letter, case notes, carers. The tester should take account of communication difficulties (hearing impairment, dysphasia, lack of common language) when carrying out the test and interpreting the score.

Alertness: Altered level of alertness is very likely to be delirium in general hospital settings. If the patient shows significant altered alertness during the bedside assessment, score 4 for this item. AMT4 (Abbreviated Mental Test - 4): This score can be extracted from items in the full AMT if done immediately before. Acute Change or Fluctuating Course: Fluctuation can occur without delirium in some cases of dementia, but marked fluctuation usually indicates delirium. To help elicit any hallucinations and/or paranoid thoughts ask the patient questions such as, “Are you concerned about anything going on here?”; “Do you feel frightened by anything or anyone?”; “Have you been seeing or hearing anything unusual?” In general hospital settings psychotic symptoms most often reflect delirium rather than functional psychosis (such as schizophrenia).
Module 3
Holistic approaches to supporting the healthcare needs of people with dementia
Module 3 Holistic approaches to supporting the healthcare needs of people with dementia

Introduction

In this module, we will describe holistic approaches to supporting the person, including the importance of the environment of care. We will consider general principles that can be applied when supporting people with dementia. Specifically, we will examine issues regarding the meaningful involvement of families and carers, and explore the issue of human rights and the importance of protecting them, including capacity and consent.

Learning outcomes

By the end of this module, you should be able to:

- describe and apply some common principles in working with people with dementia in a person-centred way;
- appreciate the importance of working in partnership with families and carers;
- appreciate the impact of the hospital environment on people with dementia and how environmental adaptations can improve the experience and outcomes of care and treatment;
- apply the concept of human rights to the care you provide by understanding how people’s rights might be violated, and also protected.

Links to the 10 Care Actions

Learning in this module links to the following 10 Care Actions for Acute General Hospitals:

- develop and embed person-centred assessment and care planning;
- develop a safe and therapeutic environment;
- promote a rights-based and anti-discriminatory culture;
- work as equal partners with families, friends and carers.

General principles to apply when working with people with dementia in a person-centred way

Many people live well with dementia, either on their own or with families or carers. They will have made adjustments in response to their diagnosis to maintain their independence and ensure they have the best quality of life possible. Many will still have:

- a sense of control over their life and environment;
- made choices with regard to routines and predictability in their daily life that provide security;
- environments they know well and which have been adjusted to enable them to live well with dementia;
- regular contact with friends, family and supportive relationships;
- social contact with their local community;
- the ability to engage in activities that are meaningful and rewarding for them.
As outlined in earlier modules, admission to hospital can place one or all of these elements at risk, leading to a long-term risk to the person’s health and well-being. In earlier modules, we outlined some of the risks people with dementia might face when being admitted to an acute general hospital. In adopting a holistic approach to supporting the healthcare needs of someone living with dementia, we need to maximise their independence and provide the level of support appropriate to their ongoing needs.

A person with dementia should be encouraged and supported to self-care as much as possible. It will always be less stressful for the person to try to complete activities for him- or herself. Stepping back a little and providing simple one-stage instructions can help the person feel calmer and in control of their situation. It is not about leaving the person to ‘get on with it’, but instead is about focusing on their strengths and abilities and supporting the person to maintain them while they are in hospital. This also ensures we respect people’s dignity.

When we are supporting someone with physical health care, we need to remember we are potentially invading their personal space and they may not understand what is happening. Just like any of us, people with dementia will find it difficult when others invade their personal space. You have a choice when this happens to you – you can move away from the other person or tell them to move away from you. This choice is not always the same for a person with dementia in an acute ward.

Just a thought

Imagine you are in a shop and are looking at the clothes on display. You are minding your own business when a salesperson comes over and tries to persuade you to have a makeover. Apparently this person wants you to take off your clothes and he or she will put a dressing gown on you. You will have your new outfit chosen for you and you will be dressed to make you look good. Before that, however, your face will need attention. If you are a woman you will have your skin cleansed, if you are a man you will have a shave.

How does this seem?

If you are in an expensive shop that offers this type of service, you may be thrilled by this offer, especially if it is free.

What if you had no choice and had to submit to this person taking off your clothes and dressing you in clothes that are not your own?

How would you feel about them washing or shaving you, even when you said no?

If a person with dementia is not able to understand the care that is offered, or does not agree with it, they may become distressed as you move closer to them to provide personal care.

Activities like washing, dressing, bathing or repositioning may cause the person to feel they are being harmed. Any attempt to continue will make the situation worse. This can be difficult for staff trying to provide good care to the person. It can also be very distressing for the person with dementia when more invasive procedures, such as catheterisation, cannulation or wound dressings, must be carried out – we will explore these issues more in Module 4.
Module 3 Holistic approaches to supporting the healthcare needs of people with dementia

General principles to apply in supporting people with dementia with care interventions – key tips

Take time

It is tempting to hurry when you are busy, but this will inevitably mean you will take more time in the long run, as the person may not engage with you. Simply slowing down your rate of speech and movement can help. Taking time to really listen is important, as the person may be struggling with words and any pressure from you may increase their anxiety, making it much more difficult to communicate their needs. Your movements should be deliberate with no sudden reactions. If you role-model calm behaviour, the person may respond in the same way.

Explain and listen

We may believe we have explained clearly what we are going to do with the person, but it is important to listen carefully to ensure the person has understood what you have said. If they have no memory of the explanation you have given and someone touches them in an unexpected way, a negative response is understandable.

Plan your approach

People with dementia are often very sensitive to non-verbal behaviour and reactions; they will sense if the member of staff is anxious, rushed or annoyed and respond negatively.

- It is very important to be calm and relaxed in your approach, to smile and use the person’s name.
- Follow the good practice principles, as discussed in Module 2, in your communication.
- Keep external stimuli to a minimum if you can.
- Chose a quieter time of day to carry out care and have as few staff involved as possible.
- If it is safe, only one staff member should provide the care. If more than one person needs to be involved, only one should make the initial approach and the other(s) can then come in to help.
- It is really important to be organised and have everything you need ready. If you have to leave the person and return, they may have forgotten you have been there and you will have to start again. Alternatively, they may believe you have already carried out the care and refuse to be washed or shaved again!
- Noise reduction is very important (see below).
- Careful planning of care around peak periods of ward activity may reduce demands on the person and improve the care experience.
Module 3 Holistic approaches to supporting the healthcare needs of people with dementia

Previous experience
It is important to know something about the person’s usual routine, likes and dislikes and how they carry out their activities of living. It will help to talk to family and carers – their knowledge of the person can be invaluable here, especially if they have been providing care at home. They may be able to provide practical help or give you pointers to make the process less stressful for all concerned.

Environment of care
The person may have hearing and visual difficulties and will benefit from a reduction of noise and an increase in light. Low noise levels reduce agitation and ensure that the person with dementia is not distracted by other noises and voices in the environment and has a better chance of hearing you. Care may be compromised when there is a lot of activity in the ward. This can include shift changes, meal times, medical rounds, receiving times and visiting hours.

As we age, we need more light to see well. Lighting should be bright and shadows should be minimised. Access to natural daylight can also be beneficial. It is important for the person to be able to see your face clearly and also see what you are doing. Clutter in the immediate environment should be at a minimum. We will explore this in more detail later in this module.

Delay unwelcome care
Most care episodes can be delayed for a short period without any risk. If the person is not wanting care at that time and is becoming upset and distressed, stop and move away, after making sure they are safe. Leave the person for five to ten minutes and then try again using a different approach or perhaps a different member of staff. Continuing to try and provide care for a person with dementia who is distressed may not only create difficulties for the current care episode, but might also affect how they respond in the future. The person may not always be able to remember specific actions or incidents, but can often retain the emotions that were generated and could react negatively when placed in similar situations subsequently.
Module 3 Holistic approaches to supporting the healthcare needs of people with dementia

Working in partnership with families and carers to promote person-centred care for the person with dementia

Important issues to consider

Carers and families can be an essential source of support to enable the person with dementia to have an improved experience and outcome of admission to an acute general hospital.

If a person with dementia is supported by a carer, such as a family member or close friend, it is important that they are an integral part of the assessment and care planning process.

It is also important to remember that carers may experience distress and even depression as a result of the pressures associated with the caring role. Added to this, carers often describe a feeling of frustration at not being involved as an equal partner in discussions about care and support, even though they are often directly affected.

NHS Education for Scotland and the Scottish Social Services Council have developed core principles for working with carers and young carers.

Core Principles
for Working with Carers and Young Carers

- Carers are supported and empowered to manage their caring role
- Carers are enabled to have a life outside of caring
- Carers are recognised and valued as equal partners in care
- Carers are free from disadvantage or discrimination related to their caring role
- Carers are identified for Working with Carers and Young Carers

Supporting People with Dementia in Acute Care
Find out more at the Equal Partners in Care website on the Knowledge Network, where there are a number of e-learning modules and wider learning resources that can help you further develop your knowledge.

Some families and carers may:

- be clear about their caring role, introduce themselves as a carer, and have positive links to support them in their role;
- have taken on the role without knowing what supports are available to them;
- be working exceptionally hard in difficult circumstances but not see themselves as, or want to be called, ‘carers’;
- may not ‘fit’ with the expected spouse or adult carer you may expect – many people under 18, partners in same-sex couples and families from ethnic minority groups are providing daily care.

The potential consequences of being in hospital for people with dementia will also have an effect on families and carers. If the person they look after returns home with deterioration in their mobility or self-care skills, increased disorientation or higher levels of distress, stress for the carers may increase, leading to a potential breakdown in the caring relationship with life-changing outcomes for everyone concerned.

Remember

You will need to be skilled at recognising the needs and wishes of families and carers while ensuring the rights of the person with dementia remain paramount. It can be difficult to get the balance right, but you will find it easier to build a positive relationship based on empathy and understanding if you work with families and carers in a person-centred way.

Involving families and carers in direct care delivery for the person with dementia

A number of excellent initiatives are being taken forward across NHSScotland to support families and carers to be involved as equal partners in care in supporting the person with dementia when admitted to acute general hospitals. These include:

- open/flexible visiting times;
- the use of the ‘Getting to Know Me’ document to enable families and carers to identify how they wish to be involved in care and helping them to support the person with dementia with care activities such as personal hygiene and eating and drinking;
- enabling families and carers to ‘be there’ and support the person with dementia when they are stressed or distressed.
Module 3 Holistic approaches to supporting the healthcare needs of people with dementia

Important issues to consider when involving families and carers in direct care delivery for people with dementia

You should:

- value the person as a carer and understand that many carers are expert in working with the person they support;
- remember all experiences of caring are different – you should ask the carer about theirs;
- do not make assumptions about what their usual caring role is – the family member/carer may advocate strongly for the person but may not want to help with intimate care delivery, such as taking the person to the toilet or meeting personal hygiene needs;
- be aware that carers may also have support needs due to their age and experience of the stressors of caring;
- check on family members/carers regularly if they are spending long periods of time on the ward supporting someone, so they don’t have to leave the person to come and find you;
- make sure they get regular breaks if they have been in the ward for a while – help them to find tea, coffee and something to eat and make sure they are comfortable;
- do not assume that families and carers have the knowledge to deal with every situation – if the person with dementia is very distressed, this may be a completely new situation for the family or carer to cope with;
- find out if any family member/carers is a Welfare Power of Attorney with powers relevant to health care and treatment – we will discuss this in more detail later in this module.

Remember

Involving families and carers in direct care delivery is not about abdicating care to them – they often have significant support needs that you also need to address.

Activity

If you do not already know, find out what improvement activity is being taken forward in your NHS Board to support implementation of Care Action 8:

- ‘work as equal partners with families, friends and carers’.

Record your answers here:
Module 3 Holistic approaches to supporting the healthcare needs of people with dementia

The impact of the hospital environment on people with dementia

The acute care hospital environment – physical, social and cultural – can have a profound effect on the quality of life and experience of people with dementia. Something that might seem simple to a person without cognitive impairment can feel difficult, frustrating, confusing and even frightening for someone with dementia. Multiple sources of stress from noise, light, people and activity can become incomprehensible to someone with dementia. It may be difficult for them to make sense of what is happening. This can be compounded by the attitudes of staff and how they approach the person.

Changes the person experiences as their dementia progresses may alter how they interpret what they see, hear, taste and smell. While these changes will be unique to each person, people with dementia may generally find it difficult to orientate to an unfamiliar environment and have a reduced stress threshold to many environmental stimuli.

We will discuss the stress and distress people with dementia can experience while in hospital in more detail in Module 4.

There are some aspects of the hospital environment that are particularly amenable to change, such as sound, light and design. These can promote independence and social interaction.

Sound and noise

Many older people experience hearing loss, which can be made worse if the person has dementia. Not only will people with dementia have difficulty responding to sounds, they may also misinterpret what they hear. Noise can make concentration difficult and increase feelings of anxiety for the person.

Hospital settings can be noisy and unpredictable places. Noises can be insistent, unfamiliar and incessant, which can be more difficult when the person has come from their own home where they have some control over their environment. Most of the conversations they hear in hospital may be disjointed, with background noise from machines and telephones. People constantly moving around can also add to the pressure of the multiple sounds they experience, increasing anxiety which in turn can lead to increased distress.

Sudden noises can also startle the person and increase their insecurity and fear. If this continues, it can lead to the person becoming anxious and distressed by the care and treatment being provided.

Remember

It is crucial that the hospital environment is enabling for, and is not a barrier to, people with dementia. The physical environment can play an important part in improving the lives of people with dementia. A few simple changes can have a significant positive impact.
**Module 3 Holistic approaches to supporting the healthcare needs of people with dementia**

**Practical things that can help with sound and noise**

- Be aware of noise from specific devices, such as alarms, doorbells or telephones.
- Try to minimise these types of noises, which can be intrusive, especially when combined with other background noise and at night.
- Monitor sound levels in the ward or clinical area. For example, a device called a ‘yacker tracker’ can be used to measure sound decibels. It uses a traffic-light system so staff can see immediate results if they reduce the noise.
- Use sound-absorbing materials – soft-closing bins, floor tiles, and ceiling and wall panels, for example.
- Use floating floors to reduce impact noise from footsteps, trolleys or doors closing.
- Use noiseless pagers.
- Organise work patterns so that staff are working quietly rather than in a hub, such as a nurses’ station.

**Light**

It is estimated that older people need three times more light than those who are younger. Even natural light may not be sufficient for the needs of an older person; it may have to be substantially boosted by artificial light sources. Lighting should be direct and come from an overhead source to minimise shadows being cast over the visual area.

While it is vital to have good lighting for the person with dementia to see clearly, there can be devastating effects from glare. Glare is the sudden change that occurs in the light when moving from a dark environment to a bright one. It can also occur with reflection from glass or other highly polished surfaces. The older person’s eye takes considerably longer to accommodate to changes in light levels or react to sudden flashes from reflective surfaces. This can mean that the person is temporarily blinded and can lead to unsteadiness and falls.

The four photographs below are good examples of different light sources. The picture on the top left has the light directly on the face, almost obliterating the features. The light from behind on the bottom left photograph casts a shadow over the whole face, making the features hard to make out clearly.
Module 3 Holistic approaches to supporting the healthcare needs of people with dementia

Someone with dementia can sometimes have additional deficits in visuospatial ability. This can cause further misperceptions in relation to highly reflective surfaces, which appear to be 3- rather than 2-dimensional in appearance. For example, someone with dementia looking at a highly polished floor may ‘see’ what appears to them to be puddles of water. Similarly, speckles or pebble effects on flooring could look like pieces of litter. If the person tries to avoid these, it can lead to loss of balance and falls.

### Colour and contrast

A person with dementia may have progressive difficulty with colour discrimination and sensitivity to contrast in colours. The older person’s eye may have difficulty seeing pastel shades and the so called ‘cold’ colours of blue, grey and lilac. In contrast, ability to identify the ‘hot’ colours of yellow, red and orange is more likely to be preserved.

People with dementia may have additional deficits in visuospatial ability that can cause them further misperceptions. Considering colour and contrasts is important if you wish the person to clearly find some areas in the ward, such as toilets.

Below are some examples of the impact of colour and contrast. Those that are effective exaggerate the contrast and colours used.

### Practical things that can help with colour and contrast

- If you wish the person with dementia to see something clearly, use strong colours that stand out from the background.
- If you need to disguise something, use pale shades that blend into the background.
- Cover trolleys and equipment with drapes to minimise the contrasts of trolley surface and equipment: the area is then less likely to be attractive to touch.

### Signage and other design features

The principles relating to colour and contrast extend to other design aspects of hospital departments and to signage, where the use of strong colours and high contrast is very important to the person with dementia.

Being able to move around is important to support the person’s recovery and return home. You can promote this by:

- providing strongly colour-contrasted handrails and small seating areas where they can rest;
- ensuring access to quiet spaces and outdoor areas away from the busyness of the ward or unit;
- providing displays of artwork, which may encourage mobility and meaningful engagement and promote orientation, but this needs to be carefully considered, as strong patterns may be misinterpreted;
- using calendars, large-faced clocks and signage to support the person to remain orientated, but clutter and distractions, including notices, can cause added confusion.
For maximum impact, signage should include a photographic image and written words large enough to read. These should be placed at an appropriate height for the person to see, taking into consideration the needs of people being transported in a wheelchair, whose vision is even more limited.

Someone with dementia can be very disadvantaged by the environment – not being able to find the toilet, for example, can create anxiety and distress. Leaving doors open so the toilet is clearly visible is an effective way to direct a person with dementia. Toilet signs should be realistic and placed on the door rather than beside it and at a height that can also be seen by someone using a wheelchair. The use of traditional and familiar designs will also reduce anxiety and promote self-care. Signs on the floor can help, as many people may be looking down to prevent falling in the unfamiliar environment.

Taking steps to increase colour contrasts and stronger colours will not only be beneficial for people with dementia, but will also help anyone with visual impairments, such as cataract or glaucoma.

The red toilet seat is easily seen here, but the main consideration is making sure there is a strong contrast between the seat and the floor covering. It is more important to have a strong contrast than any particular colour. Indeed, the use of red contrast might not be the best approach, as people may associate this colour with blood and this could be alarming for them.

Where possible, plain rather than patterned surfaces should be used, particularly in relation to flooring. Strong patterns, tiled surfaces or sudden or dramatic changes in floor colouring can create the effect of different floor levels. This will cause the person to stop suddenly or stumble, increasing the risk of falls.

Activity

Consider your learning from this section.

- How dementia-friendly is your ward/unit environment?
- Which of the features described above are already in place in your ward/unit?
- What improvements should be made?

Record your answers here:
Module 3 Holistic approaches to supporting the healthcare needs of people with dementia

Protecting the human rights of people with dementia when they are in hospital

In Scotland, and worldwide, human rights are something people expect to enable them to live an acceptable quality of life. ‘Human rights’ are not about privileges or being allowed to do something – they are a ‘given’ and are generally thought of as protected.

Legislation in Scotland and relevant codes of professional practice ensure that most staff in acute hospitals have a role in making sure that people’s rights can be protected to maximise their potential for a good quality of life.

The Charter of Rights for People with Dementia and their Carers in Scotland

In 2009, the Scottish Parliament cross-party group on Alzheimer’s disease published the Charter of Rights for People with Dementia and their Carers in Scotland. The Charter reflects protection laws that already exist in Scotland and uses them to focus on rights specific to people with dementia. It describes how people with dementia, their families and carers can be empowered and supported to exercise these rights at every stage of their journey and wherever they live in Scotland.

If you want to find out more about the Charter of Rights for People with Dementia and their Carers in Scotland, visit the Scottish Government or Alzheimer Scotland websites.

Below are some practice examples adapted from the Charter that relate directly to people with dementia. They will help you to recognise if they might be at risk of being disregarded in an acute general hospital.

Examples of human rights that may be disregarded for people with dementia in practice

The right not to be treated in an inhuman or degrading way.

- Leaving a person in soiled or unchanged clothing or bedding.
- Leaving food for the person without offering help when they are unable to eat or drink without assistance.
- Speaking about people in a derogatory way or in a way that labels or stereotypes them, such as ‘walkers’, ‘feeders’, ‘wanderers’, ‘demented’.
- Using symbols on ‘bed boards’ or using ‘different’ cutlery, plates, drinking jugs and tumblers that identify the person as having dementia or a cognitive impairment. While these ‘identifying’ interventions can be helpful, we also need to think about them in terms of protecting people’s human rights. This could be viewed as a way of ‘labelling’ someone, however benign the intent.
- A person experiencing multiple bed and ward moves and being ‘boarded’ in various wards because of flow or bed-pressure issues rather than his or her clinical need.
- The person being moved from ward to ward or discharged during the evening or night.
Module 3 Holistic approaches to supporting the healthcare needs of people with dementia

Examples of human rights that may be disregarded for people with dementia in practice (continued)

<table>
<thead>
<tr>
<th>The right to respect for private and family life, home and correspondence.</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Separation from families and other key people with whom the person has relationships due to admission to hospital.</td>
</tr>
<tr>
<td>- Not receiving support to participate in meaningful activities to promote recovery while in hospital.</td>
</tr>
<tr>
<td>- Hospital staff controlling people's access to phone calls without authority by, for instance, not allowing the use of a mobile phone.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The right to freedom or liberty.</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Detaining a person who lacks capacity to consent to admission to hospital without using legal and safeguarding processes.</td>
</tr>
<tr>
<td>- Excessive and inappropriate use of restraint while in hospital, including the use of technological devices without consent.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The right to a fair trial.</th>
</tr>
</thead>
<tbody>
<tr>
<td>This does not just apply to criminal proceedings, but also to a broad range of areas where a person's civil rights or responsibilities are influenced, including:</td>
</tr>
<tr>
<td>- the person's or their family's or carers' complaint not being investigated by an organisation;</td>
</tr>
<tr>
<td>- the person not being made aware of the right to complain and not being given information about the procedure to enable them to make a complaint.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The right not to be discriminated against.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discrimination can be direct or indirect. This right does not apply on its own. A person can only use the Human Rights Act 1998 to argue discrimination if another human right is breached, such as:</td>
</tr>
<tr>
<td>- a person is not given access to medical treatment or community care services based on age, disability, gender or ethnic origin or because they have dementia;</td>
</tr>
<tr>
<td>- a person with dementia is not offered physiotherapy treatment in the belief that they will not be able to follow exercise instructions;</td>
</tr>
<tr>
<td>- information or options are provided in a way that is inaccessible to the person;</td>
</tr>
<tr>
<td>- a person's cultural nutrition requirements, such as the need for kosher or halal foods, are not taken into account.</td>
</tr>
</tbody>
</table>
Module 3 Holistic approaches to supporting the healthcare needs of people with dementia

Activity

Reflect on your own work environment and practices and how you contribute to protecting the rights of a person with dementia.

- Can you identify any risks, or examples, that might suggest that people with dementia you are working with may have their human rights disregarded?
- What changes or improvements could you make to contribute to protecting the rights of a person with dementia?

Record your answers here:

Protecting people’s rights – the Adults with Incapacity (Scotland) Act 2000

The Adults with Incapacity (Scotland) Act 2000 provides a legal framework for making decisions on behalf of a person who does not have the capacity to make decisions. Without proper legal authorisation, the person’s right to make decisions about their care can be violated. The Adults with Incapacity (Scotland) Act 2000 places an obligation on all staff to understand legislation and apply it appropriately.

In this section, we summarise some key issues from the Adults with Incapacity Act.

It is important that you learn about this in more depth and you should also study the resource ‘Think Capacity: Think Consent’ that is available on the NES website.

Capacity and incapacity to make decisions and consent to treatment

Under the Adults with Incapacity Act, all adults are presumed to be legally capable of making personal decisions and managing their own affairs unless it is established that they lack capacity to do so.

Capacity means the person’s ability to use and understand information to make a decision. The person needs to be given appropriate information provided in a way they can understand so they can make a decision based on the information.

Capacity in relation to consent to treatment means people are capable of understanding the nature, implications and consequences of their decisions.
Supporting People with Dementia in Acute Care

A person is considered to have capacity to consent to treatment if they:

- understand in simple language what the treatment is, its purpose and nature and why it is being proposed;
- understand its principal benefits, risks and alternatives and be able to make a choice;
- have a general understanding of what the consequences will be of not receiving the proposed treatment;
- can retain the information long enough to use it to weigh up the possible outcomes to arrive at a decision;
- can communicate that decision to others;
- can hold this decision consistently: this includes occasions when a person has difficulty in remembering a decision but, given the same information at another time, can make a consistent decision – this makes their decision valid.

The Adults with Incapacity Act refers to ‘incapacity’ rather than ‘capacity’ and defines incapacity as when a person is incapable of:

- acting
- making decisions
- communicating decisions
- understanding decisions
- retaining the memory of decisions.

Remember

Capacity is not an all-or-nothing concept – a person may not have capacity at a particular point in time or for a particular decision, but this does not mean that they will never have capacity to make any decisions.

The ability of a person with dementia to make a decision can vary enormously. Most people can make decisions about some aspects of their lives, but may need support in other areas.

Power of Attorney

Power of Attorney is the name given to a person who has been granted the power to make decisions on behalf of a person who is incapable of making decisions on their own. A Power of Attorney is taken out in the same way as a person creates a will by providing a statement in writing, usually with legal help. The document must include a certificate from a solicitor or medical practitioner who has interviewed the person immediately before the document was signed.

The Power of Attorney works by a person giving permission to someone they trust to make decisions when they are no longer capable of doing so. A solicitor or medical practitioner has to agree that the person has capacity and knows and understands what they are doing when they sign the statement.
Module 3 Holistic approaches to supporting the healthcare needs of people with dementia

There are two types of **Power of Attorney**: *Continuing* and *Welfare Attorneys*.

**Continuing Attorney**
Continuing powers of attorney mean others can only manage the **finances and property** of another person. Their powers can start immediately after the agreement is signed. The person giving permission (the granter) may not want this to happen and can specify that the powers should start only when they have lost capacity to manage their own financial affairs. When continuing attorney is in place, the ‘Power of Attorney’, when necessary, would have access to the person’s finances and could arrange to do things like pay household bills and collect pension payments.

**Welfare Attorney**
Welfare Attorneys have power over the person’s personal welfare. These are things that affect the person’s physical and emotional well-being, such as their physical and mental health and protection from abuse and harm (other than financial harm). It can include choice of medical care and treatment, diet, hygiene, clothing, meaningful social contact and where the person lives.

**Assessment of capacity under the Act**
The Act gives medical practitioners the main responsibility for deciding whether a person is incapable of making particular decisions or taking specific actions. Nurses can also assess capacity and authorise treatment, but only within their own specialty: for example, a nurse can only authorise nursing interventions. The assessment of whether the person is incapable of certain decisions or actions is central to most parts of the Act.

The medical practitioner makes the final assessment of capacity but he or she will be expected to use multi-disciplinary and multi-agency information and reports as part of the overall assessment. Under the principles of the Act, the doctor must also consider the person’s past and present wishes and feelings and, where reasonable and practicable, seek the views of significant others.

People with dementia can retain capacity to make decisions until the very late stages in their journey. Their ability may fluctuate from day to day and hour to hour, however, and this needs to be considered during assessment. It is often the staff that work directly with the person on a regular basis who will notice these fluctuations and they have a central role in contributing to assessment of capacity.

**Consent to medical treatment**
It will be normal practice for you to seek consent from the person you are working with before undertaking any intervention or treatment. In many instances, this may be implied consent. For example, if you are supporting a person to wash and ask if they would like to have a bath, the person may not respond verbally but accompany you to the bathroom: their action implies that they consent. Or if you ask a person if you can take a blood sample and the person puts their arm out, this implies consent. If the

**Remember**
It is crucial that you establish if the person with dementia you are working with has a family member, carer or friend who is a Welfare Power of Attorney with relevant powers.
person refuses or resists, however, their decision must be respected – you cannot continue with the intervention or procedure without an assessment of capacity under the Adults with Incapacity Act.

The Act defines medical treatment as ‘any healthcare procedure designed to promote or safeguard the physical or mental health of the person’. This could include the provision of: nutritional care and fluids; skin care; continence care; pain relief; help with mobility; communication aids; eyesight and hearing support; dental care and oral hygiene; and medication.

If a person is assessed as not having capacity to consent to the treatment, the responsible medical practitioner (or other health professional) will complete and sign a **Section 47 Certificate of Incapacity** and a **Treatment Plan** detailing all the care and treatment covered by the certificate. This will allow the person to receive the daily treatment/interventions without having to get consent for each one when it is needed.

**Decisions about care and treatment when the person lacks capacity**

The Act aims to protect people who lack capacity to make particular decisions, but also to support their involvement in making decisions about their own lives as far as they are able to do so. Anyone authorised to make decisions made on behalf of someone with impaired capacity must apply the following principles.

### Principles of the Adults with Incapacity Act

**Principle 1 – benefit**

Any action or decision taken must benefit the person and only be taken when that benefit cannot reasonably be achieved without it.

**Principle 2 – least restrictive option**

Any action or decision taken should be the minimum necessary to achieve the purpose. It should be the option that restricts the person’s freedom as little as possible.

**Principle 3 – take account of the wishes of the person**

In deciding if an action or decision is to be made, and what that should be, account must be taken of the present and past wishes and feelings of the person, as far as this may be ascertained. The person must be offered help to communicate his or her views. This might mean using memory aids, pictures and non-verbal communication, providing advice from a speech and language therapist or support from an independent advocate.

**Principle 4 – consultation with relevant others**

Take account of the views of others with an interest in the person’s welfare. The Act lists those who should be consulted whenever practicable and reasonable. It includes the person’s primary carer, nearest relative, named person, attorney or guardian (if there is one).

**Principle 5 – encourage the person to use existing skills and develop new skills**

Encourage and support the person to make their own decisions and manage their own affairs as much as possible and to develop the skills needed to do so.
Part 5 of the Act allows treatment to be given to safeguard or promote the physical or mental health of an adult who is unable to consent. The principles apply to medical treatment decisions and other areas of decision-making. Where a Welfare Attorney or Guardian has been appointed with healthcare decision-making powers, the doctor must seek his or her consent where it is practicable and reasonable to do so. Where the adult has no proxy, a doctor is authorised to provide medical treatment, subject to certain safeguards and exceptions.

**Covert medication** is the administration of any medical treatment in disguised form. This can involve disguising medication by administering it in food and drink. Sometimes it may involve medicines being administered in an altered form, such as crushed tablets or opened capsules. However, other medicines, such as patches or liquid preparations, can be given covertly without being altered or mixed with food or drink. The essence of covert administration is that the person is unknowingly taking medication.

### Application to practice

We will now explore issues of capacity and consent further in relation to specific issues.

### Medication issues

Consider Charlie’s story in the activity below.

**Activity**

**Charlie’s story**

Charlie is 70 years old and lives at home with his wife, Jane. He has a diagnosis of dementia and has been admitted to hospital with suspected unstable angina.

Charlie can become distressed when being given medication for his angina and it appears he does not want to take it. His wife Jane has said staff can give it to him crushed up in his food. You are working in the ward one afternoon and when you offer Charlie his medication, he pushes your hand away. A senior member of staff asks you to give Charlie some bread and jam with his medication crushed up inside.

What do you need to consider in this situation?

**Record your answers here:**

**Remember**

You need to be aware that altering medication in this way can mean it will not have the desired effect, or it could result in serious health consequences for the person.
You should **never give medication covertly** even if the person’s family or carers request or insist you do so without ensuring proper assessment has taken place and safeguards are in place. **Otherwise it is regarded as an assault on the person.**

Medication can only be given covertly when it has been agreed with a pharmacist and the health team working with the person.

It must be detailed and recorded in the prescription as a means of administration.

While there may be occasions where giving covert medication is medically and ethically justified and there is no alternative, it must never be given to someone who is capable of deciding about medical treatment.

Every effort to gain consent must be recorded. Details of multi-disciplinary discussion and the pharmacist’s recommended approach must be inserted in the person’s care plan and the prescription, which must be signed on each occasion, issued.

More guidance about covert medication is available on the Mental Welfare Commission for Scotland’s website. You should also take time to identify guidance in your local area.

**Restraint**

At times, actions taken by staff or families and carers with the intention of minimising risk in effect amount to either ‘direct’ or ‘indirect’ restraint. The Mental Welfare Commission for Scotland describes restraint as:

- the planned or unplanned, deliberate or unintentional actions of staff to prevent a person from doing what he or she wishes to do;
- placing limits on the person’s freedom of movement;
- being defined in relation to the degree of control, consent and intended purpose of the intervention.

Being restrained can be frightening, potentially dangerous and undignified. Restraint may be regarded as a **criminal offence** committed by an individual worker rather than their employer, unless carried out within the legal processes described earlier in this module. It may take the form of: direct physical/mechanical restraint; modification of design; medication; or psychological restraint. All these methods prevent or restrict the person’s movements within their own home, a care home or hospital.

Physical and mechanical restraint may include:

- laying a hand on the person to stop them moving;
- use of a restraining chair;
- trays fixed to chairs;
- bed sides;
- restricting the person’s movement while they are in bed by, for example, tightly tucking in bed clothes;
- modifying the design of items, which includes locked doors, doors with code number pads, electronic tagging devices and video surveillance.

Restraint also includes the use of covert medication (which we discussed previously).

**Remember**

The use of sedative or tranquillising drugs purely to prevent someone moving can never be justified.
Module 3 Holistic approaches to supporting the healthcare needs of people with dementia

Psychological restraint refers to a number of things, including what could be seen as bullying attitudes like shouting at or excluding the person, and leaving the person afraid to ask for help. An example would be telling the person they are not allowed to get out of bed in an unfriendly or brusque manner, or placing their walking aid out of reach.

It is also important to be aware of the impact of restraint on the person. As well as being traumatic, it may also lead to feelings of shame, loss of dignity and self-respect and social isolation. In addition, the person is likely to become anxious and distressed.

Restraint should only be used if the Adults with Incapacity Act is applied and in accordance with the principles of the Act and its supporting guidance.

The use of technology

Many acute general hospitals now use a range of technological devices associated with preventing older people falling in hospital, including movement alarms attached to chairs or beds and the use of ‘ultra-low’ beds.

We do not cover the range of interventions being put in place to reduce falls in older people in hospital in this resource, but we recognise that people with cognitive impairment and dementia are at increased risk of falls in hospital. We will therefore explore the use of the following in relation to the potential restraint of people with dementia in hospital and the ethical and legal issues that need to be considered:

- the ‘wander guard’ bracelet (a fob that can be attached to clothing or in the form of a bracelet that emits an alarm if the person wearing it crosses a particular boundary)
- chair and bed movement alarms.

The Mental Welfare Commission for Scotland published very useful guidance in 2015, ‘Decisions about Technology’: you can access this on their website. The content below is reproduced from this guidance, but we strongly recommend you read the full document.

Activity

Charlie’s story revisited

Charlie has become increasingly confused. He is anxious and agitated and has walked out of the ward without staff noticing. His mobility is reduced, his balance is poor and he needs supervision when walking.

He has been assessed as being at risk of falling. At present he is disorientated and forgets that he is in hospital. Staff are concerned that he may leave the ward again without them noticing; it is a very busy ward and the hospital is surrounded by potential hazards, including a busy road and a river.

His wife has Welfare Power of Attorney.

- What technology do you think would help in Charlie’s situation?
- Would a ‘wander guard’ bracelet be useful?
- Would a chair alert alarm be the best approach?
- Would a combination of both be best?

Record your answers here:
Key issues to consider

The hospital has a duty of care towards Charlie to keep him safe. His current physical and mental condition is increasing the likelihood that he could come to harm by leaving him unsupervised, either through leaving, or falling in, the ward.

- While technology could be helpful in this situation, great care would need to be taken to ensure that it was not stigmatising in any way (keeping the alarms as discreet as possible) and a clear process about who responds to alarms was established.
- If Charlie could not consent to the use of the technology because he was assessed as lacking capacity to do so, staff would need to check if the Welfare Power of Attorney held by his wife included appropriate powers.
- There should be a discussion with her explaining the reasons why staff felt this was necessary and the benefit it may bring to her husband.
- If there was no one with powers to consent on Charlie’s behalf, there would need to be careful discussion within the team and recording in the care files to explain why a decision was taken to use the technology and the benefits it would bring to Charlie, rather than to staff or others.
- The assessment and rationale for using the technology should be clearly recorded in the care file and regularly reviewed.

Activity

Know your local policy

The Mental Welfare Commission for Scotland state any hospital wards that use technology should have a specific policy on its use for patients or residents who lack capacity to consent to it to ensure that they are treated with dignity and respect.

If you are not already familiar with your NHS Board policy, you should access it and find out more.

Key issues to consider when using technology

The use of technology should be used as a last, rather than first, resort as it has the potential to violate the human rights of people with dementia. Using it must be carefully considered. It is important to note that technology is not a replacement for human contact and person-centred care and in some cases could make the hospital experience for a person with dementia even more distressing.

Technology has its place, but with provisos:

- alarms can be useful for patients who need help to walk, to alert nurses to the fact that they are on the move;
- the use of technology is not intended to tell or remind people to sit down and not move, or restrict their freedom to walk around;
- any alarms should be audible to staff on the ward and must be quickly responded to;
- alarms should not disturb other patients’ rest;
- we must remain aware that alarms could cause further distress and confusion for the person who has dementia or delirium;
Module 3 Holistic approaches to supporting the healthcare needs of people with dementia

- There may be a number of reasons for a person with dementia being distressed or agitated that need to be carefully assessed, including: pain; boredom; hunger and thirst; environmental issues; constipation; infections; and delirium.

We will explore these issues in more detail in Module 4.

Remember

Careful consideration needs to be given to the legality of the use of technology, particularly when a person lacks capacity to consent – in this case, decision-making to use technology must be informed by the principles and safeguards provided by the Adults with Incapacity Act and the guidance on ‘Decisions about Technology’ provided by the Mental Welfare Commission for Scotland.

Bed moves and transitions

Older people, particularly those with dementia and cognitive impairment, are more likely to have adverse outcomes, including increased mortality, longer stay in hospital and poorer experiences, when they are inappropriately moved in hospital (at night or multiple moves, for example) or when discharge is delayed.

The practice of ‘boarding’ describes a situation in which a patient’s care and treatment are delivered in hospital areas that are not designed to meet their care needs.

- Boarding of any person with dementia must be avoided.

- People with dementia or cognitive impairment should not be moved to another room or ward unless clinically necessary for their treatment or to manage clinical risk.

Activity

You should ensure you are familiar with the Healthcare Improvement Scotland (HIS) Standards for the Care of Older People in Hospital in relation to ‘Patient Pathways and Flow’. You can access the standards on the HIS website.

Managing risk and risk enablement

Risk is inevitable; it is part of daily life regardless of medical conditions, age, gender and social background. Taking measured risks for people with dementia when they are in hospital can contribute to their quality of life and improved outcomes when they are discharged.

Removing risks can negatively impact on well-being and, for some people, create new risks, challenges or distress. While some risks pose an unacceptable level of danger to a person with dementia, it is important to take a balanced and individualised approach to risk assessment and management to ensure that positive risk-taking is supported whenever appropriate.

‘Nothing Ventured, Nothing Gained: Risk Guidance for People with Dementia’ is a useful framework for risk enablement for people with dementia you can access from the Department of Health England website.

Many NHS Boards have/are developing detailed guidance for staff to assist them to identify and balance the potential benefits against the risks of an adverse event occurring.
Remember

It is important you keep up to date with policies being developed in your NHS Board in relation to risk enablement for people with dementia while they are in hospital.

Any decisions about managing risk and risk enablement for people with dementia who may not have capacity to consent must be informed by the principles, provisions and safeguards provided by the Adults with Incapacity Act.

Decisions about cardiopulmonary resuscitation

Decisions about the care and treatment of people with dementia towards the end of life, including ‘Do Not Attempt Cardiopulmonary Resuscitation’ decisions and preferred place of death, must be informed by the ‘Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Integrated Adult Policy’, available on the Scottish Government website.

Importantly, any decisions about resuscitation for the person with dementia should address any advance plans and wishes the person might have in place.

Decisions about DNACPR for people with dementia who may not have capacity to consent must be informed by the principles, provisions and safeguards provided by the Adults with Incapacity Act.

We will discuss palliative care and end-of-life issues for people with dementia in hospital in more detail in Module 4.
Module 3 Holistic approaches to supporting the healthcare needs of people with dementia

Module summary
In this module, we have explored common principles in working with people with dementia in a person-centred way, and the importance of working in partnership with families and informal carers. We have also discussed the impact of the hospital environment for people with dementia and how environmental adaptations can improve the experience and outcomes of care and treatment. Importantly, this module has also examined how the concept of human rights should inform the care you provide by understanding how people’s rights might be violated and also protected.

Module assessment

Reflective activity

What did you learn from completing this module?

How did you change or improve your practice as a result?

How is this relevant to your Code of Professional Practice?
Module 4
The care experience
Introduction

This module builds on the previous content of the learning resource. We will explore specific approaches you can use to support the care and treatment of people with dementia in acute hospital environments. This will include considerations of very practical approaches you can implement when carrying out person-centred care to specific care situations and interventions across the care pathway.

Learning outcomes

By the end of this module, you should be able to:

- further appreciate stress and distress experienced by people with dementia in acute hospital care environments and how this should inform your practice, as a basis for further learning;
- appreciate the wider health and well-being issues people with dementia may experience and how this should inform your practice;
- build on previous learning to apply common principles to working with people with dementia in a person-centred way, to specific care situations and interventions and across the care pathway.

Links to the 10 Care Actions

Learning in this module links to the following 10 Care Actions for Acute General Hospitals:

- develop and embed person-centred assessment and care planning;
- develop a safe and therapeutic environment;
- promote a rights-based and anti-discriminatory culture;
- work as equal partners with families, friends and carers;
- minimise and respond appropriately to stress and distress;
- plan and prepare for admission and discharge.

Stress and distress experienced by people with dementia in acute care hospital environments

Stress and distress is an underestimated aspect of the experience of people with dementia when they are in an acute general hospital.

Consider the scene that can face a person with dementia being treated in an acute general hospital.

The person may have memory and other thinking problems that will often be exacerbated and compounded by:

- the noise and bustle of a busy hospital ward or unit;
- feeling unwell or perhaps injured;
- the trauma of facing such a change in their daily life.
It is important that we try and prevent stress and distress for the person with dementia when admitted to hospital, and when this is possible, respond to the distress as quickly and as effectively as we can.

**What is stress and distress experienced by the person with dementia?**

Throughout this resource we have explored the difficulties people with dementia may have with communication, including expressing their emotions. The way they may act when feeling distressed may be viewed as ‘difficult’ by other people, including families and carers.

It is important for us to understand the causes, triggers and ways of responding to stress and distress in a person with dementia. If not dealt with in an appropriate manner, it can cause further emotional distress for the person and/or significant distress for families and carers.

Distressed behaviour can be seen as an attempt to communicate an unmet need and may be the only way the person with dementia can communicate this need to us. Hopefully, we can identify and meet the person’s needs to prevent them from feeling distressed in the first place – identifying and treating a hearing impairment early through fitting a hearing aid, for example, can reduce social isolation, improve mood and prevent distress.

Our perceptions of something that is ‘difficult to manage’ can differ from those of other people. It can therefore be helpful to ask yourself the following questions first.

- Is it really a problem?
- Who is it that finds the distressed behaviour problematic?
- Are there external factors that are difficult for the person with dementia?

- Is the behaviour compromising the safety of the person or others?

**Specific examples of behaviours that can be the result of distress**

There are some specific behaviours that can be the result of distress. Guidance on how to respond to them and intervene is outlined in the following section.

**Agitated behaviour**

This response is an indicator that all is not well with the person who has dementia. Where the person has a decline in communication skills, agitated behaviour can be their only form of communication. If we are caring for or treating the person with dementia, we should understand that agitated behaviour:

- is often a response to an unmet need, so it is very important that the reason for the behaviour is explored and understood;
- can indicate the person has delirium or other physical causes – if a person with dementia is agitated, it may be that they are experiencing changes and a deterioration in their health condition, rather than the agitation being caused by their dementia.

Agitation can be a motor, verbal or behavioural activity that does not always have an obvious reason. Although it is not often caused by dementia alone, it is likely to be more frequent if the person cannot make themselves easily understood or when their ability to speak is lost.

Agitated and aggressive behaviours are not the same. Agitated behaviour tends to include pacing, restlessness, lifting and moving items and undressing inappropriately. Verbal behaviours can include repetitive questioning and constant requests for attention. Agitated behaviour can have serious consequences for the person with dementia, as it can pose a risk to themselves and others in the environment.
Walking about

Many people with dementia may walk about constantly in what appears to be an aimless manner. This was previously referred to as ‘wandering’, but this is an unhelpful and negative term as it suggests it is aimless and without purpose.

There are two types of ‘walking about’ behaviour that can be difficult when the person is in hospital. One is where the person leaves the ward because they want to go home or get away from the ward setting. The second is related to persistent walking around the ward or unit and not knowing where they are. These may improve as the person becomes more familiar with the environment and any delirium is treated successfully.

It is important to remember that walking is not in itself a problem, and it can help to relieve stress and boredom as well as provide exercise. When the person is in an acute general hospital, they are likely to be more disorientated than in their own home. It can become a problem, however, when the person is on the ward and attempts to leave, or is walking about persistently and putting him or herself and others in danger.

As the person with dementia may be walking about for any number of reasons, a full assessment is needed to identify what they are trying to achieve and ways to meet their needs. A person with dementia who has to stay for long periods in the ward may become restless and begin to pace around. They may be hungry, thirsty, need to use the toilet, or be in pain but be unable to express this. They may simply feel unwell. The noise and busyness around them may be upsetting them. If you have tried to deal with all of these, it may be helpful to try and find a quieter area for them (if possible) and let them move around safely.

It may be that their room is near the exit and they see people leaving all the time. The fundamental needs of the person, such as the need to go to the toilet, hunger, thirst, pain, feeling too cold or too hot, have to be identified and addressed. The environment around them may be too noisy or too quiet.

The person with dementia may be at considerable risk when walking about in a hospital setting and some more specific measures may be required. Their room should not be near exits but easily observed by staff. Involve the family and carers if you can, especially at peak activity periods in the ward when the person may not be missed so quickly.

Repetitive questioning

The person may ask the same question over and over again. This is usually related to memory loss – they simply cannot remember the answer you gave them. If they are also feeling anxious or unwell, this can make the situation worse. Try not to be insensitive when you respond: do not say things like, ‘I’ve already told you that’, as this can increase the person’s feelings of anxiety.

Try helping them to find the answer for themselves. For example, if they keep asking where they are, try prompting them to look at your uniform and badge and reminding them in words and by cues that they are in hospital. If they are too distressed for this, try and distract them. Distraction can be a very effective way of managing distress that people with dementia might experience. The general idea is to talk about something that is not related to what is distressing the person. It is important to use short and simple sentences and to stay calm. Use events happening around them or something in another part of the ward. This is particularly effective if you know something of the person’s life history, such as their hobbies or previous occupation.
Module 4 The care experience

The main aim of distraction is to try and refocus the person on to something that is less distressing or anxiety-provoking. If you find yourself becoming irritated by their repetition, it can help to leave them with someone else for a short time until you feel more responsive.

The person can also become stressed by future events, such as going to X-ray departments. In this case, it is often better to tell them about it just before it happens, so they don’t become anxious and worried. Another way to help the person may be to involve family and carers.

Repetitive phrases or movements

Some people may repeat the same phrase or movement time after time. This is called perseveration. It is more evident in certain types of dementia, particularly fronto-temporal dementia, but can also be caused by physical discomfort. It is made worse when the person is in pain or unwell and can also be exacerbated by the demands of noisy, busy environments. Treating the person’s physical condition and reducing the demands of the environment may help. Repetitive behaviour such as moving the chairs around or trying to empty bins or trolleys can be caused by anxiety or boredom. Having something safe for the person to occupy themselves with may help here.

Disinhibited behaviour

A person with dementia who is very stressed and confused may become disinhibited. They may try and undress, lift up or undo their clothes. Sometimes they are trying to communicate something by this – they may need the toilet, be too hot or simply be unaware where they are.

Sexually inappropriate behaviour, such as inappropriate touching of others or touching their genitals in public settings, should be gently discouraged and some assessment of the person providing care should be made. Perhaps a male patient would be happier to be assessed by a male member of staff. It is also helpful for the member of staff to repeat frequently who they are and why the person with dementia is on the ward, and to understand what the person’s usual routine/behaviour is. For example, if a gentleman’s usual behaviour is not to wear pyjamas at home, he is unlikely to do so while in hospital, so this should not be interpreted as disinhibited behaviour.

Suspicion

The person with dementia may sometimes accuse people of stealing from them or talking about them. This is often due to memory problems and their struggle to make sense of the world around them. It becomes worse when they find themselves in a strange environment and are unwell or injured.

It is important to appreciate that the person cannot control their beliefs and that these are real to them. There is little to be gained from arguing with them about these beliefs, and doing so is likely to increase the person’s level of distress. It is, of course, also important to check the accuracy of any assertions the person may make, but if these are clearly unfounded, then it is equally important to support the person with dementia, who is likely to be very distressed by his or her beliefs.

Focusing on the feelings the person is expressing is a more appropriate intervention. Showing you understand why they are distressed may have a calming effect that means they may be more likely to engage with the proposed intervention or care activity. Distracting them rather than discussing their beliefs and reassuring the person that you are there to help may ease the situation.
Misperceptions and hallucinations

A hallucination is an experience of something that is not really there. The person may see, hear, smell, taste or feel things that do not exist. The most common type of hallucinations for people with dementia are visual, where they see things that are not there. Although less common, the person with dementia may experience auditory hallucinations, such as hearing noises or voices that are not there. This can cause the person not only to talk when no one is there, but also to shout at the perceived voice or noise.

Many people with dementia may never experience hallucinations, but might be incorrectly assumed to be doing so when in fact they are making a mistake about what they have seen. For some types of dementia, however, hallucinations are more common – dementia with Lewy bodies, for example.

You can support the person by remaining calm and reassuring them. Try to stay with the person and:

- explain that you cannot see or hear what they are referring to, but you want to know what they are experiencing;
- listen carefully to what they describe, focusing on the emotion they are expressing and not what the person is saying;
- confirm their emotion – they may be frightened, angry, anxious or frustrated – by saying, for instance, ‘You seem frightened’, ‘How can I help?’; you may not need to confirm if the person is angry, but reassure them that you want to help them;
- repeat the explanation that you cannot see or hear what they are describing if the person cannot retain information or is distressed, but avoid arguing with them or trying to convince them that what they see or hear is not there;
- perhaps distract the person or try to identify if they are misinterpreting something rather than experiencing hallucinations.

Misperceptions are common, particularly when the person with dementia also has visual or hearing impairment and is unwell or injured. The ward environment is full of strange equipment and sounds that can easily be misunderstood. It is important to assess the environment first when the person starts to react to something you do not perceive as being there. If there are objects and sounds that may be causing misunderstandings, remove them if possible. Lighting should be bright and shadows should be eliminated if possible to reduce the effects of figures or objects. This may be enough to resolve the problem, as these can often be misinterpreted as real objects or people.

When auditory or visual hallucinations are troublesome and there are no obvious causes, including delirium, the person should be referred for a mental health assessment.

Aggression

Fear, pain, frustration, embarrassment and a strange environment can all compound the difficulties the person with dementia faces as a result of their condition. Sometimes this can manifest as aggressive language or behaviour. At times, this can seem out of proportion to the situation they find themselves in. It can appear that a very minor incident can set off a catastrophic reaction. If seen through the eyes of the person with dementia, however, the reaction can become understandable.

Aggression can involve kicking, hitting, throwing objects, swearing and screaming. It must be borne in mind that for the person with dementia, who finds themselves in a strange environment with people they do not know who are physically
touching and treating them, the aggression they exhibit may well be an understandable response.

To complete your learning and develop your understanding of how to recognise, prevent and respond to stress and distress in dementia, you will need to access the NES Module 'Stress and Distress in Dementia-Acute' on LearnPro.

**Using medication to manage distress in the person with dementia**

Medication may be used for people in hospital who have distressed behaviour associated with dementia or delirium in the following circumstances:

- if it is the person’s regular medication;
- to manage safety and risk when the person is posing a risk to themselves or others;
- to reduce stress and distress when all other interventions have proved ineffective.

The most commonly used medications for managing distress in dementia are the typical antipsychotic (neuroleptic) medications, such as haloperidol. While there is some indication that this medication can have an effect in reducing distressed behaviour, it has a number of unwanted effects that warrant caution when considering this approach: it can lead to increased risks for the person, including the risk of falls, constipation and swallowing difficulties.

Medication should always be used as a last resort. Most NHS Boards have their own pharmacological guidelines that you should be familiar with.

In particular, there can be serious unwanted effects when this group of medicines are given to people with dementia with Lewy bodies. The medicines can make the person’s symptoms worse.

If the person is unable to understand or consent to the use of these medicines, it is vital to use the guidance and safeguards contained in the Adults with Incapacity (Scotland) Act 2000 to protect the person’s rights.

**Remember**

**Distressed behaviour? Think pain first**

Caution must always be employed in the use of antipsychotic medicines with people with suspected dementia and many older people due to the risk of serious side-effects. There is no medication that will work in every situation. It can be useful to consider pain relief before using other medicines to manage distressed behaviour.

**Health and well-being issues for people with dementia**

**Physical and mental activity**

Activity is beneficial for physical and mental health and can improve quality of life for people in all stages of their dementia journey. It can also provide opportunities for people to socialise and engage with other people, reduce any feelings of isolation they might be experiencing, and help support them to improve or maintain their independence.

When a person with dementia is initially admitted to an acute general hospital, they will need acute care and treatment for their immediate health problem: keeping active will not necessarily be a priority at this time. However, many people with dementia have
protracted stays in acute general hospitals and it is important that they are enabled to keep as active as possible to maintain their independence, cognitive abilities and physical health.

Many NHS Boards in Scotland have introduced a range of initiatives to support people with dementia to stay mentally and physically active when in acute general hospital, including:

- reminiscence work;
- the use of ‘rummage boxes’;
- therapeutic gardens;
- dog therapy;
- introducing social mealtimes where people can eat together in a communal area;
- doll therapy;
- the use of music;
- engagement in social activity.

Find out more about what is happening in your NHS Board area.

**Visual difficulties**

Dementia often causes problems with visual perception. Although the person may still have good eyesight, they may experience problems in recognising what they see.

As we saw in Module 3, it is common for people with dementia to experience a decreased ability to perceive colour contrasts and depth. This can make it hard for people to recognise the edges of objects or to interpret patterns or shadows. Because of these difficulties, an apparently normal environment can become extremely difficult for a person with dementia.

Vision difficulties can sometimes result in a variety of ‘visual mistakes’ that can cause a person with dementia to misinterpret their environment and what is in it. These visual difficulties can be severe for people with dementia as they may not know, or remember, that they are making these mistakes.

Some people with dementia can also have age-related deterioration in their vision. A number of visual disorders are commonly associated with ageing, including cataracts, glaucoma, macular degeneration and retinal complications from diabetes. Illness, medication and the type of dementia the person has can all impact on their vision in a range of ways.

We discussed the impact of the hospital environment on people with dementia and how environmental adaptations can support people with dementia who experience visual problems in Module 3.

**Oral health**

It is important to support a person with dementia to maintain their oral health, as dental pain can often be a cause of stress and distress that goes unrecognised. A regular programme of dental and gum care should be undertaken – poor oral health can lead to pain and tooth loss, which can negatively impact on self-esteem and the ability to eat, laugh and smile.

Wearing dentures can sometimes be a problematic issue and a great source of discomfort for a person with dementia, particularly if the dentures are not cared for properly. It is important to look after them appropriately and regularly review them to ensure they fit properly. You can find more information on this in the Alzheimer’s Society worksheets on oral health for people with dementia. The NHS Health Scotland ‘Caring for Smiles – Guide for Care Homes’ may also be of interest.
Hearing difficulties

Despite being common conditions, dementia and hearing loss are not an inevitable part of getting older. Families, carers and staff should nevertheless remain vigilant and be aware of any signs that the person is experiencing hearing difficulties.

A major source of hearing difficulty is impacted wax, so it is important to eliminate this as a possible cause. It is also important to find out if the person with dementia uses a hearing aid and, if so, check that it is working and the batteries are charged. If you suspect the person may have other hearing conditions that require further investigation, they should be referred to an audiologist.

Use the most favourable strategies to support communication

- Find out how the person usually communicates. For example, do they use speech, British Sign Language (BSL), lip-reading, the Deafblind Alphabet or other means? This information should be available in the person's life history or support plan. If alternative communication methods are used, you should seek further assistance from local sensory support services. You can find more information about these alternative means of communication on the ‘Action on Hearing Loss’ website.

- Check for any sight issues or problems with glasses, especially if the person uses BSL or lip-reading. Ensure the person's sight is checked regularly.

- Avoid turning away or covering your mouth as you speak.

- Ensure you are at the same eye level and facing each other.

- Arrange yourself to be within one metre of the person.

- Do not sit in front of a window (you may appear as a silhouette if the light coming through the window is strong), and make sure your face is well lit.

- Make sure the room has good acoustics – a room with lots of hard surfaces such as large windows, bare floors and tables will make it difficult for the person to hear speech.

- Reduce distractions and background noise.

- Remember that someone may cope well on a 1:1 basis but have difficulty in a group situation.

- Do not shout, as this can look aggressive and frightening and does not help the person to hear any better.

You should also consider the key communication tips listed in Module 2.
Supporting people with dementia in specific care situations and interventions

Planned admissions to hospital

Pre-admission planning and support

There are many occasions when people with dementia will have a planned admission to hospital. Working with the person, their family and carers to support them to prepare for admission can decrease stress and distress, length of stay in hospital and the risk of readmissions.

The pre-admission planning process should include:

- identifying a key member of the team to work with the person with dementia, their family and carers to coordinate and plan the admission to hospital;
- identifying a named nurse and key contacts within the hospital for additional information and support being identified;
- fully involving the person with dementia in the planning process;
- providing the person with dementia, their family and carers with written information, including an explanation of the planned treatment or procedure and the care pathway;
- establishing if community services and support are already in place and making contact with them before the person is in hospital to plan for discharge;
- organising a visit to the ward for the person to meet staff and become familiar with the environment;
- conducting all investigations and tests on an outpatient basis where possible to prevent unnecessary time in hospital;

Consider the common health and well-being issues people with dementia may face we have discussed in this section of the module.

Review the assessments and care plans of people with dementia in your ward/unit.

- Has the assessment addressed areas of activity;
- visual and hearing difficulty?
- Is there a person-centred care plan in place to address these issues using a risk-enabling approach?
- Are there any improvements that can be made to support people and enhance their health and well-being?

Record you answers here:
Module 4 The care experience

- assessing the person’s capacity to consent to investigation and completing a Section 47 certificate if required: it is important to remember that the assessment of the person’s capacity to consent to treatment will need be repeated when they are admitted;

- supporting the person, their family and carers to complete the ‘Getting to Know Me’ documentation and completing the pre-admission assessment;

- ensuring a record of the medication review relevant to the planned procedure or treatment accompanies the pre-admission assessment;

- suggesting that the person takes reassuring and familiar objects with them, such as photographs, an iPad or iPod and books;

- establishing how they, their family and carers wish to be involved in day-to-day care and support, visiting and staying with the person – this should also include involvement of friends and wider networks;

- arranging admission at a time when the ward is likely to be quieter but avoiding evening and night-time admissions.

Supporting good nutrition for people with dementia

For many people with dementia, eating and maintaining a healthy weight can become more difficult as their dementia journey progresses. For some people, the changes they have experienced can have an impact on their ability to eat and drink, which can result in weight loss, malnutrition, constipation and dehydration, or even weight gain.

Malnutrition Universal Screening Tool (MUST)

The Malnutrition Universal Screening Tool (MUST) provides useful information to guide nutritional care for older people and people with dementia.

MUST is a five-step screening tool to identify adults who are malnourished and at risk of malnutrition (undernutrition). It also includes management guidelines that can be used to develop a nutritional care plan.

As with any one of us, the appetite of a person with dementia may vary from day to day. We should nevertheless remain aware of some of the changes that can occur as their dementia progresses.

Potential nutritional difficulties people with dementia may experience include:

- difficulties with, or forgetting how to use, cutlery – food may fall off cutlery, for example, which can be frustrating for the person;

- communication difficulties may make it difficult for the person to explain what food or drink they want or what they dislike;

- difficulties with sight and visual perception, which can mean the person is unable to see or recognise cutlery, crockery or the food;

- inability to associate the names of food with the actual food itself;

- lack of memory for all the options given to them, or forgetting what they ordered in advance;

- a noisy environment that can make it difficult for the person to concentrate on eating;

- the person with dementia being uncomfortable eating with other people or in an unfamiliar environment;
Module 4 The care experience

- the person experiencing pain or being afraid they may choke on the food;
- dentures, or dental plates, no longer fitting correctly, making chewing difficult and painful;
- the person experiencing difficulties chewing and swallowing as their dementia progresses.

It is very important that you are vigilant to any signs that people may be experiencing swallowing difficulties, as this can lead to serious health difficulties.

Signs that someone is experiencing swallowing difficulties include:
- repeated coughing, throat-clearing or choking after swallowing food or drink;
- a wet-sounding voice after swallowing;
- reluctance to eat and drink, or simply not swallowing food and drink.

Helping people with dementia to have good nutrition – key tips

- Always adopt a person-centred approach – we should not assume that a person who is not eating does not want to, and it is up to us to try to identify what the difficulties are. The more we know about a person with dementia, the easier it is to meet their nutritional needs.
- Regularly monitor their weight – completing and appropriately responding to the MUST assessment can help to alert us to changes.
- Use the information contained in the person’s ‘Getting to Know Me’ documentation to encourage conversation about food if they are struggling with a poor appetite.
- Ask people with dementia about their mealtime preferences. Families and carers can be a valuable source of information if the person with dementia has difficulty communicating their eating habits and preferences for food and drinks.
- The environment where people are having their meals needs to be calm and relaxed.
- Ensure that food and drink is visible and available throughout the day so that people can eat and drink whenever they feel hungry or thirsty.
- Use clear jugs with a coloured fluid to prompt drinking and snack plates to encourage eating.
- Using bold contrasting primary colours for crockery and cutlery can help make them more obvious and visible.
- Showing the person with dementia the food, or a picture of the food you are offering, and naming it can help the person connect the words with their memory.
- Finger foods can help a person who has difficulty with cutlery to eat independently, and are also useful for someone who is unable to sit down for long enough to complete a plated meal.

Remember

If you think someone has swallowing difficulties, the person will require urgent referral to a speech and language therapist for specialist assessment and support.
Providing soft textured foods for people who cannot chew can help. Do not assume that a pureed diet is the answer when a person with dementia declines food, or if they appear to show difficulties chewing and swallowing food and drinks. This can make things worse if given inappropriately and people are reluctant to eat it.

It may be that someone needs to be present at mealtimes to, for example, sit beside the person to demonstrate eating and drinking actions or to encourage and prompt the person to eat and drink.

Some people can benefit from small frequent meals every 2–3 hours, or to have longer to eat a meal. In this instance, plate-warmers or pre-heated ceramic plates can be a good way to keep food warm.

Providing high-calorie/high-protein and nourishing foods based on milk can be ways of supporting a person with dementia to improve their nutritional intake.

**Supporting people with dementia with their personal hygiene and continence**

The person with dementia may become distressed during physical care activities if they are not able to understand the care that is offered, or how you are trying to help them. Activities like washing, dressing, bathing or helping to move or reposition may cause the person to feel they are being harmed. This can be very difficult for staff who are trying to provide good care to the person.

As we have seen in Module 3, people with dementia can be very sensitive to the non-verbal behaviour and reactions of others, so it is likely that the person will sense if you are anxious, rushed or annoyed. It is very important to be calm and relaxed in your approach and use the communication approaches outlined in Modules 1 and 2 and general principles discussed in Module 3.

**Things you should consider.**

- Is it essential that this care activity is done?
- If so, is it essential that it is done at this point in time?
- Is there a time that better suits the person?
- Is this activity causing any pain?

**Remember**

Seek specialist help if there are any concerns about a person with dementia and their nutritional status.

**Remember**

Where there are particular personal care activities that seem to cause distress for the person, it is essential that these are examined to try and find out why this may be the case and resolve the problems.
Module 4 The care experience

- How many staff are present when it is carried out?
- Where is it being carried out?
- Would it be appropriate for family or carers to be present during the care activity?

Washing and bathing

For most of us, washing and bathing are personal and private activities. When assisting someone with dementia to wash or bathe, it is important to be sensitive and respectful of their dignity, while helping them to maximise their independence and manage their own care as far as they are able. Washing and bathing can become a source of great distress for the person with dementia. There can be a number of reasons for this, which may include some of the following:

- pain as a result of illness and musculoskeletal conditions;
- weakness caused by frailty and ill health;
- anxiety and misunderstanding because of memory impairment;
- loss of understanding or recognition of the bathroom, or previous negative bathing experiences;
- fear of falling, especially when being moved around in lifting equipment and hoists;
- noisy, cold or unfamiliar environments;
- being naked in front of a stranger – the person with dementia may not understand that you are there to care for them;
- having care carried out by someone of a different gender;
- unfamiliar environments and bathing equipment such as ‘wet rooms’ and ‘Arjo’ baths;
- unfamiliar routine that differs from their usual at home.

Care tasks such as washing, bathing or changing their clothes can be very difficult for people at a progressed stage of their dementia journey and for the staff supporting them.

The person may continually grasp at people and objects in the environment. This hand grasp is often a reflex action the person cannot help. If you try to prise their hand off, they will automatically try to grip harder, often causing pain and injury.

Practical tips

- A possible solution may be to give the person something to hold.
- If the person already has a hold of something and you want them to release their grasp, they may respond if you demonstrate the action of opening your hand where the person can comfortably see it.
- At the same time, give the person a one-word instruction, such as ‘open’ or ‘release’.

Knowing the person and using the communication approaches described in Modules 2 and 3 will also support this intervention.

How to support a person with dementia with continence when in hospital

Incontinence is not an inevitable symptom of dementia, but there are a number of reasons why someone with dementia could become incontinent when they are admitted to an acute general hospital.
Module 4 The care experience

Remember

The person with dementia may have profound difficulties performing tasks in a sequence or pattern. This loss of ability can also affect the person finding their way around. For example, to find the toilet, you need to:

- know where you are now;
- know that you are looking for the toilet;
- know how to get to the toilet;
- recognise it when you get there;
- know how to remove and replace the appropriate clothing.

Practical tips

- Sometimes leaving doors open so the toilet is clearly visible can be a successful way to direct the person with dementia.
- As previously discussed in Module 3:
  - toilet signs should be realistic and placed at a height that can be seen even by a person in a wheelchair;
  - signs on the floor can also help as many people may be looking down to the floor to prevent falling in the unfamiliar environment;

  taking steps to increase colour contrast and stronger colours can help not only people with dementia, but also those with other visual impairments, such as cataract or glaucoma.

Activity

- Have a look around your ward or unit. Can you see any way that you could improve the physical environment to make it easier for people to remain continent?

Record you answers here:

There are also various medical conditions, all of which are amenable to treatment, that can contribute to a person with dementia becoming incontinent, including:

- urinary tract infections;
- various conditions related to the prostate gland for men;
- side-effects of medication;
- constipation can put pressure on the bladder and can also lead to faecal incontinence – eating high-fibre foods, drinking plenty of fluids and keeping physically active can help prevent this.
It may be that everything has been tried to support the person with dementia to remain continent, but without success. In this case, the use of aids can help maintain the person’s comfort and dignity. Simple aids include incontinence pads, pull-up pants for day and night wear and male continence sheaths.

The use of an indwelling urinary catheter should only be considered when all other avenues have been exhausted: there is a high risk of infection associated with their use, which can lead to the development of delirium.

To further explore issues about continence and people with dementia, access the ‘Caring about Continence’ resource on the Care Inspectorate website.

Helping with mobility and preventing falls

When the person with dementia is admitted to hospital, being immobile can increase their length of stay and pose risks to their morbidity and mortality. A dementia-friendly physical environment, as described in Module 3, will support the person to mobilise independently.

The person may be afraid to move around, however, particularly if they have had a fall or the environment does not feel safe. It is important to be aware that maintaining the person’s ability to walk even a couple of paces and moving from one seat to another will have positive impacts on their health and well-being. Exercises can range from changing position from sitting to standing, walking a short distance into another room or moving to sit in a different chair throughout the day. A daily routine involving moving around and walking rather than using a wheelchair whenever and wherever possible can help to maintain muscle strength and joint flexibility which, in turn, can reduce the risk of falls. Evidence suggests that remaining active in these ways helps to reduce the incidence of falls.

A balance needs to be struck by helping the person with dementia to stay mobile and independent and preventing the risk of falls. In-hospital falls are estimated to occur at a rate of 3–5 per 1,000 occupied bed days in acute hospitals, with higher rates in areas such as older people’s care settings. A fall in hospital can result in significant harm and poor outcomes for the person.

While the person with dementia may have been identified at risk of falls in hospital, it remains important to encourage a culture of risk enablement, recovery and rehabilitation to maximise their independence and well-being. It is particularly important to consider if it is helpful for the person to walk about, as this can help prevent stress and distress and enable them to retain their mobility and independence.

We discussed some general principles about managing risk and risk enablement for the person with dementia when in hospital in Module 3.
Supporting people with dementia to sleep well

Dementia can sometimes cause people difficulties in initially getting to sleep then managing to sleep the full night. Admission to hospital can compound sleep problems and disturbance for all people, including people with dementia, and can lead to a number of detrimental consequences.

People in more progressed stages of their dementia journey can become confused about night and day and may get up in the middle of the night thinking that it is morning. Sleep disturbance, in particular persistent wakefulness and night-time restlessness, can be distressing for the person with dementia and difficult for the people around them. It is important to establish the usual sleep pattern for the person.

Practical things that can help include:

- having a regular time for going to bed and getting up that reflects the person’s past and current sleeping habits;
- ensuring a range of stimulating day-time activities – people are more likely to nap during the day if they are bored;
- reducing fluid intake in the evening and avoiding stimulating drinks such as tea and coffee;
- engaging in relaxing activities at the end of the day and before bedtime;
- ensuring the bed area is comfortable, personal and as familiar as possible – this can be achieved by introducing personal and familiar bedclothes, photographs and objects.

If the person is awake during the night it is important NOT to try and get them to return to bed without finding out why they are not sleeping. Do not assume that it is because of their dementia. There are many different
reasons why the person may be awake – they may be in pain, feeling unwell, uncomfortable, or feeling lonely or afraid, for example.

There is also evidence that having dementia may cause the person to not experience deep sleep and as a result be more sensitive to environmental stimuli such as noise and lighting. The person may have had sleep difficulties prior to their dementia or had a routine of getting up very early – you may notice a person is getting up at the same time every night.

Knowing the person and taking a person-centred approach will help you in finding out why they are awake and responding appropriately to their needs.

**Supporting people with dementia experiencing pain**

There are many causes of pain and discomfort people with dementia may experience, but there is a risk these are often not recognised and can be poorly treated or go untreated altogether. The main reason is that people’s ability to communicate their needs becomes more difficult as their dementia journey progresses. Families, carers and staff need to work hard to observe and understand signs that the person with dementia may be displaying that suggest they may have pain.

A number of observational pain tools are available to assist staff to establish whether a person with dementia is in pain, especially if the person cannot tell you in words. It is important to use an evidence-based tool as part of the person’s overall care plan.

One example is the Abbey Pain Scale, which is quick to complete but is not always accurate in assessing pain in people with dementia. The Doloplus 2 is more widely used as it recognises the difficulty of identifying pain in people with dementia and highlights that distress may be caused by pain.

Observational tools alone, however, may not detect complex or chronic pain experienced by a person with dementia. It is therefore important to ensure that:

- you get to know as much as possible about the person’s pain history;
- the person’s family and carers who know them well are involved from the outset of care;
- you do not automatically attribute the cause of any changes to the person having dementia: pain is considered in the first instance as the cause of the person’s distress;
- appropriate tools are used to discern pain and discomfort and these are addressed.

The person with dementia’s response to the distress the pain is causing can result in verbal outbursts, non-verbal signs and/or distressed behaviours that can be perceived as ‘being difficult’. In these circumstances, attempts must always be made to explore and understand the underlying cause.
Once the existence of pain and its causes are established, a wide range of medications can be used to alleviate it, but other ways of tackling discomfort and pain can be used in addition, or as an alternative, to medication. Simple interventions such as distraction, relieving boredom, creating a calm, comfortable environment, and social contact can all help to alleviate pain. Knowing and understanding the person, their likes and dislikes, will help with choosing the most appropriate intervention.

**How to support the person when they need a catheter or cannula**

The use of invasive procedures with people with dementia should be avoided if possible, and discontinued as soon as is practical. However, it is recognised that these may be essential to the person’s treatment.

There are a few other approaches that may help:

- explain clearly what these tubes are: some people with dementia can still understand and with frequent information may well stop trying to disturb them;
- the tubing may be covered with clothes, so the person may forget about them: family and carers can distract the person from the presence of the tubes or remind them that are essential to their care.

**Surgical interventions and the person with dementia**

Surgery presents considerable stress and increased risk of delirium and other complications for the person with dementia, including further cognitive decline.

A person with dementia may also take longer to recover from a surgical procedure. There are several age-related and health and well-being factors that may contribute to this, including other long-term health conditions, undiagnosed diseases, polypharmacy and poor dietary and fluid intake. In addition to the person-centred approaches to communication, assessment, care and support described in this and earlier modules, peri-operative assessment, prevention of delirium and timely post-operative care are essential to improve outcomes for the person.
Peri-operative care

This should include:

- a pre-surgery assessment to provide an opportunity to identify potential care issues and prepare the person, family and carer for the procedure;
- discussion with the person, family and carers about the risks of post-operative cognitive decline and slower recovery, and agreeing on a plan of care to reduce this;
- multi-disciplinary assessment for the presence of pre-operative delirium;
- reduction of the impact of anaesthesia on the person with dementia (The experience of undergoing anaesthesia can have an enormous impact on the person in both the short and long term. It may not only cause post-operative delirium, but may also result in longer-term impairment. There are a number of factors that increase the risk of anaesthesia for the person, including changes in the brain associated with cholinergic deficits that will increase the effect of many anaesthetic drugs and impact on memory. If the person is older, they will be at increased risk of impaired renal and vascular systems that will cause adverse reaction to medication. They may also be taking multiple medications for a long time that will be compounded by the addition of anaesthetic drugs.);
- the need for increased oxygenation before and throughout the surgical procedure: older people have reduced muscle mass, which will increase the effect of muscle relaxants leading to hypothermia and an increased need for oxygen;
- nutritional assessment, particularly for hydration, to reduce post-operative risks: additional nutritional support should be introduced 10–14 days before planned/elective surgery;
- reduction in the wait to attend surgery: extended waiting to undergo surgery will lead to increased time fasting for the person and will heighten the risk of nutritional problems;
- enabling the family member/carer to accompany the person to theatre if possible and supporting and reassuring them during anaesthesia.

This overall baseline assessment of the person’s needs will assist in identifying any post-operative changes to ensure a timely response.
Module 4 The care experience

Post-operative care

This should include the following.

- The family member or carer should be supported to remain with the person, whenever possible. Consider enabling the family member/carer to be present in the recovery room to support and reassure them as they recover from anaesthesia.
- The person should return to a familiar environment and people as soon as possible. If the person with dementia wakes up suddenly following anaesthesia and analgesia in an unfamiliar environment, they may become very distressed. Reducing noise and increasing light may help to limit distress.
- Pain management needs to be appropriate and instigated early, although it is better to pre-empt pain than respond to it.

Planning for discharge from hospital

Discharge-planning for people with dementia should commence on admission to the acute unit. If the admission is planned, discharge-planning should happen in advance of admission.

The process involves multi-disciplinary and multi-agency teams working with the person in hospital and at home. It should also include the active involvement of the person with dementia, their family and carers. Appropriate referrals should be made to key disciplines such as occupational therapy and physiotherapy.

The key aims of discharge-planning include:

- improving the preparation and coordination of care and services;
- clarifying expectations or establishing joint goals;
- identifying potential barriers to discharge and implementing individualised solutions.

Remember

For people with dementia, discharge-planning should commence on admission to the acute general hospital. If the person is being admitted for a planned elective intervention, discharge-planning should start at the pre-admission assessment and planning stage.

The identification of the professional who will be coordinating care after discharge is critical. At the simplest level, the person may be discharged to the care of the general practitioner and family/carer, but in complex situations, the person may be referred to a hospital discharge team to liaise with community, social services and primary care services.

The person may require ongoing assessment, care and support in the community. He or she may already have someone who supports them and coordinates their care.
Key tips for discharge-planning

A comprehensive multi-disciplinary assessment of the person with dementia is very important. While documentation and discharge checklists will vary considerably across NHS Boards, core information and questions should include the following.

- **The person’s wishes and preferences.** What does the person with dementia want and hope for? Does this person require the support of an advocacy service or other legal support and protection mechanism?

- **Family and support networks.** What do the family and carers want and hope for? What support do they need? Do they know where and how to get the right support?

- **Current level/type of care.** What degree of care is being delivered at present? Will this level still be required on discharge? Should additional support be considered? How will this be arranged, monitored and reviewed? Have the person’s strengths and abilities been identified?

- **Current accommodation.** Has the home environment been assessed? How suitable is this environment? What modifications and adaptations are required?

- **Personal care needs.** What level of support is required? How and by whom will this aspect of care be delivered? If supported by family, carers or friends, do they understand what is required and are they prepared with the knowledge and skills to ensure they can do this safely and effectively? If formal care is part of the care package considered, how will this be monitored and reviewed?

- **Mobility.** Has a home assessment been completed? Are the modifications and equipment to aid safe mobility in place?

- **Food provision and preparation.** Who will be ensuring that shopping and provisions are available? Who will be preparing meals and supporting the person with eating and drinking, if necessary?

- **Medication reconciliation, organisation and concordance.** Who will be ordering and collecting prescribed medication? Who will be supporting and assisting with administration of prescribed medication? Has the person’s family and carers been involved in education about prescribed medication?

- **Sleep habits.** Does the person have an altered sleep pattern? Has a plan been made to support the person to sleep as well as possible when at home?

- **Risk and risk enablement.** Have risks been identified? Has a plan to manage these risks been agreed with the person, their family and carers?

- **Social connections and networks.** How will the person be supported to remain engaged with friends and wider networks? Is additional support required to enable them to do this?

- **Adult protection issues.** Have adult protection issues been identified? If so, has referral been made to appropriate services and support, in line with local NHS Board policy?
Palliative and end-of-life care for people with dementia

Some people with dementia will require palliative and end-of-life care when they are admitted to hospital.

Palliative care is an approach to working with and caring for a person with a life-limiting or terminal condition. It supports a person-centred approach and concentrates on the individual rather than their specific disease. It gives equal focus to the psychological, physical, spiritual and social aspects of the person’s life and aims to improve the quality of life for the person and their family and enable them to die with dignity and in a place of their choosing.

The term ‘palliative care’ is also used to describe the specialist care and interventions required as the person approaches the end of their life. This may also be referred to as ‘end-of-life care’ and aims to make the person comfortable and attend to their needs and wishes as the end of life approaches.

Working with the person with dementia and supporting them to live well includes supporting them to die well. We need to ensure the care, treatment and support they receive at the end of life reflects their decisions and expressed wishes and preferences.

We know that improvements need to be made to end-of-life care for people with dementia. Some of the reasons for this are that:

- the person may be less able to express their wishes and preferences for end-of-life care at the time they require it;
- staff may have difficulties in recognising when a person with dementia is nearing the end of their life.

There is no agreed definition of ‘end-of-life care’, but the General Medical Council suggest that people are approaching the end of their life when they are likely to die within 12 months. This can be extremely difficult to determine when a person has dementia. The progression of dementia will be very different for each person, and it is likely that other illnesses and conditions will be the primary cause of death, rather than dementia.

There is evidence to suggest that in the final months of their lives, people who are in the progressed stages of their dementia journey may experience symptoms such as pain, depression, incontinence, constipation, appetite disturbance, breathlessness, swallowing difficulties, weight loss, dehydration and pressure ulcers.

To help identify when a person with dementia is at the end of their life, it is suggested that they may experience a combination of changes and symptoms, including:

- no longer being able to walk;
- no longer being able to communicate verbally;
- requiring maximum assistance with activities such as washing or dressing;
- the development of complications such as weight loss, recurrent infections, pressure ulcers, hip fracture or pneumonia.

Everyone working with the person should be aware of the range of changes and symptoms the person may experience at the end of life and communicate sensitively with their family and carers.

Remember

It is important to seek advice from palliative care specialists when you are supporting people with dementia at the end of their life in hospital and to fully involve their family and carers.
Module summary

This module has built on the previous content of the learning resource. We have explored specific approaches you can use to support the care and treatment of people with dementia in acute hospital environments. This has included considerations of very practical approaches you can implement when carrying out person-centred care to specific care situations and interventions.

Module assessment

Reflective activity

What did you learn from completing this module?

How did you change or improve your practice as a result?

How is this relevant to your Code of Professional Practice?