



NHS
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Scotland

Scottish Ambulance Service Dementia Learning Resource



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Welcome!

Welcome to the **Scottish Ambulance Service Dementia Learning Resource.**

This resource is designed to help you develop your ability to support people with dementia, their families and carers who access ambulance services. It forms part of a broader range of learning resources produced by NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) to support implementation of the “Promoting Excellence” framework (Scottish Government, 2011a) and the “Standards of Care for Dementia in Scotland” (Scottish Government, 2011b).



Who is this learning resource for?

Ambulance clinicians are in frequent contact with people in a range of situations from those in an emergency to people receiving planned care. It is essential that ambulance clinicians are able to recognise when a person may have dementia, and are confident of their ability to provide appropriate support, care and treatment.

This learning resource will enable staff to meet the needs of the person with dementia, their families and carers while recognising the often immediate and time limited nature of their practice. It has been developed to cater for this staff group who may have various levels of expertise and experience.

Aims of the resource

By completing this resource ambulance clinicians will be able to:

- Use a screening tool to identify the presence of cognitive impairment.
- Identify the causes and distinguishing features of delirium along with the predisposing and precipitating risk factors.
- Distinguish between dementia and delirium.
- Understand how to apply appropriate interventions where dementia, confusion and/or delirium are identified.
- Communicate with the person who may have dementia, their families and carers.
- Provide positive support for the person who may have dementia, their families and carers.

How is the resource structured?

This learning resource is organised into four sections - Initial Contact, Assessment, Intervention and Care Transitions. The learning activities that appear in each section will play a key part in helping you further develop your knowledge and understanding of working with people with dementia their families and carers. The focus of the sections and learning activities is on practical applications of the learning, reflective practice and putting your learning into action. Suggested responses and key learning points related to activities are provided in Appendix 1.

The time required to complete this learning resource will be dependent on the clinician's current level of knowledge and understanding.



Section 1: Initial Contact

1.1 Introduction

Regardless of their role most ambulance clinicians will come into contact with people with a diagnosis of dementia, their families and carers as well as people with early signs of dementia who do not have a diagnosis. While this contact may be time limited it will have an influence

on the impact of the whole care experience for the person with dementia. Your initial contact is an opportunity to form a positive, engaging relationship with the person with dementia, their family or carer and gain an understanding of what is important to them in relation to care delivery.

Dementia: Some Basic Facts

As people live longer, there are more and more people living with dementia in Scotland. Statistics from Alzheimer Scotland in 2011 showed dementia affects about:

- 2% of people aged 65 to 70
- 5% of people aged 70 to 80
- 20% over 80

88,000 people in Scotland have dementia (overall, approximately 5% of people over the age of 65 years experience dementia, with the risk of developing dementia increasing with age) and this figure is expected to double over the next 25 years.

While dementia is often considered a condition of later life, people in their 40s or 50s or even younger can have dementia, and it is sometimes only one of a range of conditions people may be living with, for example:

- Dementia and depression
- Dementia and learning disability
- Dementia and heart disease

1.2 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 used to describe a large number of degenerative brain disorders. There are many types of dementia, each caused by a different disease. The most common type is Alzheimer's disease accounting for 62% of those with a diagnosis of dementia. Vascular dementia is the second most common, caused by blockages in the blood supply and therefore the supply of oxygen to neurons.

There are several other less well known or rarer types of dementia. Each different type of dementia causes different changes in the brain and can cause different responses in the person affected. Among other things, these affect the person's memory, relationships and their ability to communicate. In addition, no matter what type of dementia the person has, their personality and life experience will often contribute to how they appear to you and how their condition progresses.

There is currently no cure for dementia and although there are medicines that can improve some symptoms or temporarily slow progression, the condition is terminal. All types of dementia are progressive, though in some less common types the progression can be halted. Some symptoms are common to all types of dementia, while other symptoms are more likely to occur in one specific type.

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

similarities experienced by people with different types of dementia, no two people will experience dementia in exactly the same way and the rate of progression of dementia also varies greatly between people.

Remember...

The person with dementia is an individual and no two people with dementia are the same

1.3 Does the person need to go to the Emergency Department?

Any visit to a hospital can be distressing for the person with dementia and they can appear worse after this experience (The Alzheimer Society, 2009). Some of this may be due to the illness or injury they have experienced but it is also likely that the trauma of facing such a change in their daily life can also have an impact. Understanding the challenges for the person with dementia who requires care can be difficult, but the decision to take them to the emergency department must be based on clinical need. It is therefore vital that during this initial and often brief contact that you build as comprehensive a picture as possible of the person's life and their perspective on what is happening.

Just a thought



You have arrived at the airport to go on a trip. At first all goes well; you are familiar with your local airport and know the routine.

Unfortunately there has been a problem with the flights you booked and you have to connect to another flight, in a strange airport, during your journey.

You get off the plane and find that nobody speaks your language and you do not speak theirs. You are reduced to waving your tickets and passport while gesticulating and speaking in a loud voice to try and be understood.

The screens show flights and times but they have changed all the flight numbers from the one you have and there are four different flights going to your destination.

By now you have had no food or drink for hours and cannot even locate the toilet. You try to explain what you need to officials but they think you are being rude and aggressive.

Can you try and imagine how you would feel by now?

How would you respond to other people?

How would you behave?

The experience described in this activity will help you to understand how a visit to an emergency department may feel for a person with dementia. Their feelings and actions may be the same as yours might be in that imaginary situation. Imagine what it must be like for a person with dementia, when the world is not making sense, people around you are not responding in a way you expect, and you cannot get the words out to explain yourself. To support the person and work with them in a person centred way we need to see the world from their point of view. We can do this through effective communication, empathy and relating directly to them to understand their individual needs.

1.4 Effective Communication

Usually we do not necessarily give much thought to how we communicate; it is very much an automatic process. As we spend much of our time communicating, perhaps we consider ourselves as fairly skilled in this respect. We adapt our communication without thinking, to explain or get across what we want to say, but this is a two-way process, with others adapting to how we communicate. As a result the gaps in our capabilities can become more evident when interacting with people with dementia. We may struggle to establish lines of common understanding and find our messages become distorted and misinterpreted.

A person's communication skills are progressively affected as dementia develops. In the early stages they may have difficulty in finding words and the person may try to talk around the word they are looking for. They may be less fluent and language requires more thought and effort from them. The loss of language skills for the person

with dementia starts with those words we use least and those we learned last and this can be a useful guide to our use of language when we communicate with them. Communication that uses health related jargon and words that have become more popular recently are least likely to be understood. This means that the shorter the sentence and the more everyday words we use, the more chance there is that the person will understand what we are trying to say. In short, we should try to match our level of communication to theirs.

As dementia progresses the person may develop a range of more specific language problems. Some people experience expressive dysphasia, where they may understand what is said to them but are unable to express this understanding. They may also develop receptive dysphasia, where they are unable to understand what is being said to them. In the early stage of dementia, the person will be aware of some of their communication difficulties and putting pressure on them by rushing will only make the situation more difficult. Reinforcing verbal information with written and other visual materials may also help the person understand what is going on.

As the person moves into the later stages of dementia we need to attend more carefully to communication with them. Here arguing or reasoning with them only has the effect of making them more distressed and confused. Instead it is helpful to try and follow their line of thought as this can make your communication more effective. Use gestures and facial expression as well as words to reinforce your message. In the advanced stage of dementia the person may not understand words at all, but they may still recognise facial expression and tone of voice. A gentle tone can mean more than words here.

Practice Point



Here are some key ideas about communication from a person with dementia.

Christine Bryden was diagnosed with dementia at the age of 46 and has written extensively on this experience. These quotes are selected from some of Christine's tips on communication.

"Give us time to speak, wait for us to search around that untidy heap on the floor of the brain for the word we want to use. Try not to finish our sentences. Just listen, and don't let us feel embarrassed if we lose the thread of what we want to say."

"Don't rush us into something because we can't think or speak fast enough to let you know whether we agree. Try to give us time to respond - to let you know whether we really want to do it."

"When you want to talk to us, think of some way to do this without questions that can alarm us or make us feel uncomfortable."

"Don't try too hard to help us remember something that just happened. If it never registered we are never going to be able to recall it."

Christine Bryden

1.5 Communication that could disadvantage the person with dementia

The way we communicate can disadvantage the person with dementia. It is therefore important to avoid the following:

- Interrupting the person while they are trying to speak
- Contradicting or arguing with them
- Speaking for the person, perhaps to another professional
- Reinterpreting what you think the person has said in your 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. This can lead to distressed reactions such as agitation and aggression.

- Negative non-verbal communication such as sighing, turning away and frowning can be easily recognised by the person with dementia, who still understands non verbal communication.

Remember...

Never assume that the person with dementia cannot understand you.

1.6 Top Communication Tips

Gain the person's attention

It is important to gain the person's attention first, before you begin to speak. Approach them from the front so they can see you coming towards them. Try and make eye contact, 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 on being touched and that it does not frighten them.

Use the person's name

Importantly, use the person's name when you address them. Using the person's name may help them understand that you know them and are not a stranger and this can be very reassuring.

Remind the person who you are

It is very helpful to remind the person who you are each time you return to them 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 that they are with someone who is caring for them.

Keep the noise down

Reduce distractions such as activity and noise wherever you can. Try and find a quiet area where the person with dementia can concentrate on what you are trying to communicate.

Do not rush

Take your time with the person. It is tempting to hurry when you are busy but this will inevitably mean that you will take longer in the long run, as the person with dementia may not co-operate 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.

Listen to the person

Taking time to really listen is important as the person with dementia may be struggling with their words and any pressure from you may increase their anxiety; making it much more difficult to communicate their needs.

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 with dementia 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 these one at a time. Open questions can be very challenging for the 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 example rather than saying "sit there" you could try saying "sit in this blue chair".

Use prompts and cues where possible

Written or photographic prompts can help a good deal as it provides another cue for the person who may not understand what is being asked of them.

Use humour when appropriate

Humour can be a very useful way both of communicating and diffusing tense situations, however it must be used very carefully as it can misfire where the person with dementia 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 e.g. families and carers, friends, support workers, or health/social care professionals involved with their care – in fact anyone who knows the person well. For example using the person's first spoken language, Makaton or communication aids such as pictures or speech mats.

Talking mats is a communication tool which uses a mat with picture symbols attached as the basis for communication. It is designed to help people with communication difficulties to think about issues discussed with them and to provide them with a way to effectively express their opinions.

It enables the person with dementia to express their views and remain involved in planning their lives. It can also support families, friends and carers to communicate with the person. If you access the following website on www.talkingmats.com you can watch a video clip of a person with dementia using a talking mat.

1.7 Summary

This section provided an introduction to dementia and the potential impact of admission to an emergency department for the person with dementia. We have highlighted the critical role communication skills play in supporting the person with dementia and the way communication has the potential to reduce distress or conversely, to trigger it.

Section 2: Assessment

2.1 Introduction

For ambulance clinicians working with the person, the identification of possible dementia is vital to ensure that the person receives the appropriate care. A diagnosis of dementia only occurs following a specialised assessment either in a Memory Clinic, by a Liaison Mental Health Service or by a Consultant Psychiatrist or Geriatrician. However, pre-hospital and emergency care staff have a role in identifying the person who they suspect may have dementia and making sure that this is communicated to the relevant triage or medical team. They also have a vital role to play in the identification and treatment of illness or injury which is causing delirium and the avoidance of unnecessary admissions to hospital.

2.2 Understanding what is normal for that person

In order to identify the presence of dementia or delirium, ambulance clinicians need to rapidly establish what is normal for that person. The main sources of this information include the person themselves, their family and carer 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.

You will need to establish:

- If the person already has a diagnosis or a history of dementia or delirium;
- If the person is able to give a good personal history, or do they need a family member or carer present;
- What are the normal behavioural responses, speech, mobility and mental abilities for this person?
- How does the current problem differ from what is normal for this person?
- How long has this been a problem for the person?
- Is there anything else different or unusual that the family, carer or others have noticed about the person?

2.3 Practice guide to assessment

During assessment the person with dementia can often give good information but simply needs more support to provide this. Using the top communication tips described earlier will help the person and ensure a more focussed approach to addressing their needs. In addition it is important to:

- Engage with the person's family or carer if they are available;
- Arrange for one person to engage with the person directly;
- **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 on which to base care decisions.

Do not talk too quietly, screech at them or flap your arms about. Find the level at which the person can hear you clearly and maintain that level.

The pace is equally important. Do not talk too fast, nor talk slow like this; Good...morning...how...are...you... today. It is demeaning.

**Mr. James McKillop
A person with dementia**

2.4 Screening for cognitive impairment and delirium

There may be difficulties when the person has no diagnosis but the clinical picture suggests dementia. The assessment process and reaching a diagnosis of dementia is very complex, and can take several months involving different professionals as well as extensive tests and assessments. Therefore it is more appropriate for ambulance clinicians to use a screening tool to identify the presence of cognitive impairment which serves to raise awareness of potential memory problems and does not mean someone has dementia. The term cognitive impairment is an overarching one for the person who may be experiencing problems with the mental processes of memory, perception, judgement and reasoning. Identification of cognitive impairment can help you deliver appropriate care at the time and provides a prompt to refer on for further assessment for dementia.

It is recommended that you use **The Four Item Abbreviated Mental Test (AMT4)** to identify the presence of cognitive impairment.

AMT4

1. How old are you?
2. What is your date of birth?
3. What is this place?
4. What year is it?

A score of one should be awarded for each correct answer and a score of three or less on this scale would indicate the possible presence of cognitive impairment and could lead to a referral for further assessment.

When a person appears to have signs of cognitive impairment or seems confused and reports suggest a rapid change in the person's condition it is essential to Think Delirium and treat as a medical emergency.

2.5 What is Delirium?

Delirium (previously known as acute confusion) is a common and serious condition that is characterised by disruptions in thinking, consciousness, attention, cognition and perception. It develops over a short period of time (hours or days), and usually fluctuates during the course of the day. The person may have difficulty sustaining focus or shifting attention and will typically be disorientated to time and place. Perceptual changes include auditory, visual and tactile hallucinations. The person may become more restless and agitated, or they may become drowsy, withdrawn and difficult to wake. Anyone can develop delirium but older people, people with dementia or other neurological disorders, and people with co-morbid conditions are at much greater risk.

2.5.1 Key Features of Delirium

The way in which delirium develops will differ from person to person as well as throughout the day in one person. There are three main types of delirium which have been identified:

- **Hyperactive Delirium** – where the person becomes hyper alert and agitated. They may be intensely anxious with an enhanced sensory sensitivity making the person easily startled. They may also be restless, easily distracted, irritable, angry or frustrated and unable to sit still. Their speech may be loud but incoherent and jumping from one topic to another.

- **Hypoactive Delirium** - where the person is lethargic, apathetic, slow in movement, sleepy, withdrawn and difficult to wake.
- **Mixed Delirium** – where the person alternates between hyperactive and hypoactive delirium. This can change throughout the day.

It is suggested that if the person has a pre-existing dementia, they are more likely to experience the **hypoactive** type of delirium, resulting in someone who is quiet, withdrawn and apathetic but in severe distress.

The **key indicators** of delirium are **rapid changes** in:

- **Cognitive function** where the person is confused and less aware of their surroundings, they are unable to focus attention on any one thing and their speech may become either slowed down or faster than their usual depending on the type of delirium.
- **Perception or false beliefs** where the person experiences hallucinations. As well as seeing and hearing things that are not there, they may feel things that are not there such as a sense that their skin is crawling and may respond by picking at clothing or scratching their skin. They may also become suspicious or believe that people are trying to harm them and have difficulty tolerating eye contact or they may feel threatened by being touched. Paranoia and suspiciousness can often be associated with hearing and sight impairment.
- **Physical function** - in hypoactive delirium the person may have changes in appetite, reduced mobility and reduced movement. In hyperactive delirium the person may be

restless, agitated and be unable to stay still. Their usual sleep pattern may change. The person will often sleep during the day, but wake up at night.

- **Social function** - the person may become more agitated, irritable, frightened and angry than usual or more sleepy, withdrawn and difficult to wake. Their mood or attitude may change and they are mistrustful and suspicious.

With all types of delirium the person may be distressed even if this is not immediately evident.

Think Delirium if there is:

- Acute onset and fluctuating course **and**
- Inattention **and, either**
- Disordered thinking or altered level of consciousness

Remember...

It is always safest to assume delirium and treat as a medical emergency

2.5.2 Consequences of Delirium

Early identification and recognition of delirium is essential and if treated promptly it is reversible in up to 50% of cases. Delirium can last a few days or continue for weeks. In older people and people with dementia it may last for several months. The consequences of persistent delirium are that the person may:

- Be admitted to hospital and stay there for longer than necessary;
- Have an increased risk of developing dementia;
- Be at greater risk of falls and pressure sores;
- Have a permanent deterioration in physical function;
- Be more likely to go into long term care sooner than necessary;
- Be more likely to die (NICE, 2012).

2.5.3 What Causes Delirium?

Delirium can be difficult to recognise as it does not have a single clear presentation. Anything that interrupts normal brain function can cause delirium and it can be precipitated by almost any medical condition or pharmaceutical treatment. Inflammation or toxic substances can interfere with brain function, for example, by disturbing the neurotransmitters that nerve cells use to communicate. In many instances there are multiple factors involved and in approximately 30% of cases the cause cannot be found.

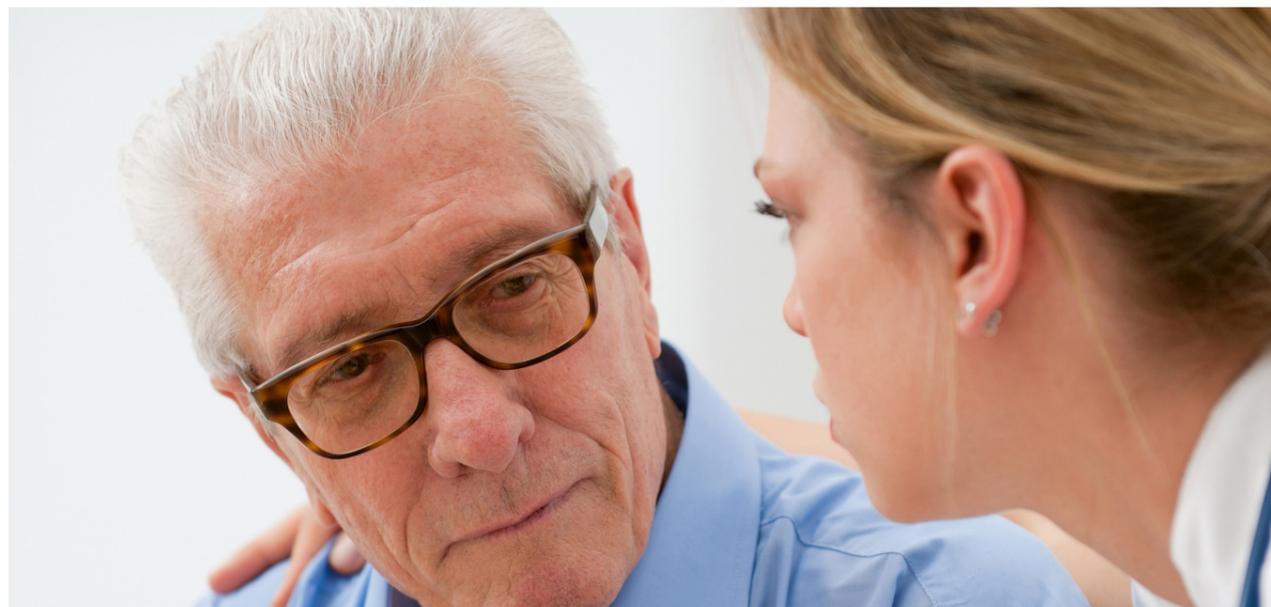
The most common causes are:

- Infection - eg. urinary tract infections, pneumonia, or fever from a viral infection
- Medicines such as anticholinergics, analgesics and corticosteroids
- Serious medical condition – eg diseases of the liver, kidney, lungs, and heart
- Suddenly stopping drugs or alcohol
- Major surgery
- Acute stress
- Epilepsy
- Chemical problems in the body such as dehydration and low salt levels
- Brain injury or infection
- Terminal illness
- Constipation
- Urine catheter
- Immobility

Older people and people with dementia or other neurological disorders are known to be at greatest risk of developing delirium. While the cause of delirium is not fully understood one explanation for this increased risk involves the neurotransmitter acetylcholine. For example, if blood sugar levels fall too low because of poor nutrition or the brain does not receive enough oxygen (hypoxia), acetylcholine transmission plummets.

Medicines with anticholinergic activity (that reduce the effect of acetylcholine) are commonly associated with delirium such as opioids, benzodiazepines and corticosteroids. This can include medicines the person has been taking for some time, particularly if they are taking 3 or more different medicines. It can more frequently be caused by new medicines, increase in dose of medication or medication being stopped suddenly.

As people get older the level of acetylcholine decreases but this in itself does not lead to delirium, there needs to be other precipitating events. However the greater the number of risk factors a person has means that it will only take a minor precipitant to trigger delirium. For example, when an older person has dementia and also has hearing or sight impairment it could only take being moved to an unfamiliar environment or admission to hospital to cause an acute stress response and trigger delirium. The development of delirium depends on a complex interaction of multiple risk factors. It is often a combination of multiple precipitating and/or predisposing factors that places a person at increased risk of developing delirium. Although not the cause of the delirium they are the catalysts to it developing.



The following table provides some examples of how the combination of factors may lead to delirium.

Predisposing factors	Precipitating factors may include
Over 65 years old Physically frail Severe illness	Stressful event, e.g. admission to hospital or unfamiliar environment
Pre existing cognitive impairment Diabetes Vision or hearing impairment	The current illness (including infection, hypoxia, hypoglycaemia, hypotension, electrolyte abnormality and metabolic disturbance)
Over 65 years old Hip fracture Dehydration	Survey for hip fracture
Existing illness such as heart disease, cerebral vascular disease, chronic kidney failure, anaemia, chronic obstructive airways disease	Anticholinergic drugs Benzodiazepines
Malnourishment	Antihistamines
Sleep deprivation	Corticosteroids
Pre existing cognitive impairment Pain High dose Codeine	Constipation

2.5.4 Why is Delirium under recognised?

There are many reasons why delirium is not recognised or identified but it is mainly due to its fluctuating course, failure to routinely screen and assess the person as well as signs and symptoms being attributed to other conditions.

For example:

- Different terms are used such as ‘confusion’ or ‘acute confusional state’ which are symptoms rather than a diagnosis;

- There may be a misperception that the changes noted are normal for an older person;
- Where a person is experiencing hallucinations and delusions this may be wrongly attributed to mental health problems;
- The cognitive changes may be wrongly attributed to dementia and particularly as vascular dementia can have a sudden deterioration and dementia with Lewy bodies also has a fluctuating course similar to delirium;

- Where the person is known to have dementia a superimposed delirium is frequently attributed to dementia and left untreated;
- Low mood and withdrawal may be attributed to depression.

These three conditions of dementia, delirium and depression may have a confused and blurred presentation in an older person and the person may have one, two or all three.

Accurate identification of delirium, dementia and depression is vital to ensure timely and appropriate treatment. Some of the key distinguishing features are in relation to onset, progression, attention and thinking.

Onset and progression

Dementia tends to develop gradually, while delirium develops rapidly within hours or days and presents in a fluctuating pattern. Vascular dementia, however, can present with sudden deterioration and dementia with Lewy bodies also has a fluctuating course similar to delirium.

Attention

The person's attention span will vary in both dementia and delirium, but in the latter the person will not be able to focus even for a limited time.

Thinking

In dementia, the person may have difficulty with abstraction, thoughts and difficulty finding words. A person with delirium will have disorganised, distorted incoherent and either slow or accelerated thinking.

When a person has depression the changes develop gradually over weeks and months but the person may have a fluctuating sleep pattern and may have difficulty with memory and concentration similar to dementia and delirium.

2.5.5 Co-morbidity Issues

It is not uncommon for an older person to have a number of physical healthcare needs; the same can be said for mental health care needs. It is known that people can have:

- Both forms of delirium, hypoactive in the day and hyperactive at night
- More than one form of dementia
- More than one form of dementia and a delirium state
- Dementia and depression
- Depression and delirium
- A combination of all three: dementia, delirium and depression. (The three D's)

2.5.6 Assessment for delirium

Your initial assessment is crucial in identifying if there are predisposing and precipitating risk factors to the person developing delirium. Thereafter it is important to assess the person for indicators of delirium to respond appropriately and allow you to put prevention measures in place. Prevention measures are discussed later in this section.

If you suspect the person may have delirium treat as a medical emergency and carry out initial assessment using **the 4AT assessment tool**. 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 2 minutes to complete.

4AT



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

Patient name: (label)

Date of birth:

Patient number:

Date: Time:

Tester:

[1] ALERTNESS
This includes patients who may be markedly drowsy (eg. 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

CIRCLE

[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
	Untestable (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 (eg. 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
1-3: possible cognitive impairment
0: delirium or cognitive impairment unlikely (but delirium still possible if [4] information incomplete)

4AT SCORE

GUIDANCE NOTES Information and download: www.the4AT.com

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), eg. your own knowledge of the patient, other staff who know the patient (eg. 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).

Where it is not possible to carry out an assessment and there is someone present who knows the person's baseline function i.e.(mobility, cognition and social support network) you should use the 'Single question in delirium' (SQID) - Do you think (name of person) has been more confused in the last two weeks? As this may be the only trigger to suspecting delirium.

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Learning Activity 2.1

Jean's Story

Jean is 80 years old and has lived in a care home for one year. She has Parkinson's disease and needs assistance with dressing, walking, eating and drinking.

You respond to an emergency call that Jean has had an unwitnessed fall and sustained superficial cuts and bruises as well as a suspected fractured femur.

When you arrive at the care home the member of staff working with Jean reports that Jean has had increasing memory difficulties over the past year and she frequently attempts to walk without assistance. She also reports that Jean has not been eating or drinking very much over the past couple of days and is more confused than usual. They had requested a GP visit this morning as they suspect she may have a UTI.

On examination of Jean you find her vital signs are normal including blood sugar and temperature. Head to toe examination shows an obvious # (R)NOF. Jean does not appear to notice when you speak to her and she is drowsy and lethargic.

What will be the key consideration in your assessment?

What would help you determine if Jean has delirium?

What action would you take if you suspect Jean has delirium?

2.6 Summary

This section explored how to recognise when a person has delirium, the importance of early detection and how to distinguish between delirium, dementia and depression.

We emphasised best practice in assessment and the ambulance clinician's role in screening for cognitive impairment and delirium.

Section 3: Intervention

3.1 Introduction

In most instances it will be necessary to carry out treatments or interventions before and during transfer of the person to hospital or other care environment as well as when you are supporting the person to remain at home. It is therefore important to consider how this may affect the person with dementia. We all experience stress at some time and for the person who has dementia, stress can be overwhelming leading to distressed behaviour which is perhaps challenging for staff.

communicate using speech and the person may have impairments in expression while still able to understand what is being said. As dementia progresses the different areas of the brain are damaged and a variety of communication challenges are the result. These may include some of the following:

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 this may help them move their communication on again. Distracting the person may also help.

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 they are 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 or badge if they can understand these cues.

Reflection point



Think about a really stressful and busy shift you have had recently. It may even be today.

- Did you remember to do everything you intended to do that day?
- How did you feel by the end of the shift?

3.2 Changes in Communication with Dementia

The person with dementia can often have extreme communication challenges both in expressing and receiving information. These challenges are complex involving neurological, psychological and interpersonal elements as well as the individual's personality, history, ethnicity and spirituality. Not all people with dementia can

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 Guide to Communication provided here and try again. Repetition may not be within the person's control and it may 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 this. You could point to objects or people in the environment if you cannot guess the word.

Understand people are reticent to open up to a stranger. Do you tell a stranger personal things about yourself? It is difficult.

Mr. James McKillop
A person with dementia

3.3 Working with the person with dementia who is distressed

Stress is a very important and often underestimated aspect of the experience of dementia which can be both caused by and impact on the person's physical health care needs. The main sources of distress for the person are as follows:

Tiredness - Tiredness and fatigue are a major source of stress for the person with dementia. They are already facing enormous challenges because of their compromised brain function and

have to expend tremendous effort to make sense of the world around them. This can be exhausting for them and they may become easily tired.

Noise, light and activity - Multiple sources of stress from noise, lighting, people and activity can become incomprehensible to the person with dementia, who will struggle to make sense of all this new material they have to process.

New experiences - Change in daily routine is a challenge to the person with dementia who requires stability and familiarity in their daily life to reduce the stress on their ability to remember and find their way. It is important for the person with dementia to have familiar people around them who know them well; family, friends or carers should be encouraged to remain with them as much as possible. Some people have familiar objects that are very comforting and these should not be removed from them if at all possible.

Complex demands, instructions and questions - Complex demands, instructions and questions can become overwhelming for the person with dementia who is unable to process these but understands instinctively that others are becoming impatient with their apparent lack of cooperation.

Illness, injury and pain - If the person is being transferred to an emergency department all of the demands placed on the person with dementia will be exacerbated by their current physical healthcare needs. They may be in pain or distress and unable to explain how they feel. They may also experience a number of physical needs that they are unable to express because of their increasing distress. These can include thirst, hunger or a need to go to the toilet.

If stress is not reduced or managed for the person with dementia their level of distress will escalate and they may become angry, agitated or aggressive. It has to be remembered that each person with dementia is an individual and therefore no single explanation of their behaviour and no single intervention can be provided. The following are some responses you may see in a distressed person with dementia:

Agitated Behaviour - This response is an indicator that all is not well with the person who has dementia. Where there is a decline in communication skills then agitated behaviour can be the only form of communication. The person who is caring for or treating the person with dementia should understand that agitated behaviour is a response to an unmet need. **It is therefore very important that the reason for their behaviour is sought. In particular, agitation can result from delirium. Where an older person with dementia is agitated then it is vital to exclude physical causes.**

Agitation can be a motor, verbal or behavioural activity that does not always have an obvious reason. Although it is not necessarily caused by dementia alone it is likely to be more frequent in advanced dementia where the person can still speak but cannot make him or herself easily understood or in the later stages where the ability to speak at all is lost.

Repetitive Questioning - The person may ask the same question over and over again. This is usually related to memory loss and they simply cannot remember the answer you gave them. If they are also feeling anxious or unwell this can make the situation worse. It is important to respond sensitively as any suggestion that you have already answered the question can increase the person's feelings of anxiety. Try helping the person to find the answer for him or herself. 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 an ambulance or in hospital etc.

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

Suspicion - Sometimes the person with dementia may accuse people of stealing from them or talking about them. This is often due to the memory problems they have and the struggle the person can have at times trying to make sense of the world around them. This is 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. Focusing on the feeling the person is expressing is a more appropriate intervention. By showing that you understand why they are distressed they may become calmer and willing to cooperate with staff.

However the person may well be at risk and their suspicions or accusations should not be discounted as a symptom of their condition. You should document the person's concerns in case there is any follow up due to actual wrong doing using your agreed reporting protocol.

Misperceptions and Hallucinations - Visual hallucinations are often associated with more advanced dementia and it is suggested that they are more common in women who are older and with a longer duration of dementia. The severity and frequency varies but they are often worse later in the day. Firstly it is important to assess

the environment when the person starts to react to something you do not perceive is there. If there are objects and sounds that they may be misunderstanding these should be removed if possible. In addition, lighting should be bright and shadows should be eliminated if possible to reduce the effects of figures or objects.

Aggression - Fear, pain, frustration, embarrassment and a strange environment can all compound the challenges the person with dementia faces as result of their condition. Sometimes this can spill over into aggressive language or behaviour. At times this can seem out of proportion to the situation they find themselves in.

What could cause an aggressive reaction from the person with dementia?

- They do not recognise where they are;
- They do not recognise the people there;
- There is too much stimulation from noise and light;
- They are ill, in pain, cold, hot, hungry, thirsty or need the toilet;
- They are embarrassed or their dignity is offended;
- They are afraid.

How should you respond to an aggressive reaction?

- Try to find out what is upsetting them;
- Reduce the stress or demands made on them;
- Explain what is happening by frequently using their name and explaining who you are;
- Give them time to respond;
- Try not to show criticism or irritation and do not confront them;
- Watch for warning signs that they are becoming more anxious or agitated. Get help if the situation does not calm down quickly;
- Include their family, friend or carer if available; they may know how to manage the situation;
- Do not make sudden movements or use a sharp tone, remain calm and keep your voice low.

Try to bear in mind that the person is not being deliberately difficult but is often trying to get help in the only way they know how.



Learning Activity 3.1

George's Story

George is 75 years old and lives with his wife Mary who is 74 years old. George was diagnosed with dementia 3 years ago. He continues to engage in a range of social activities but requires instruction and prompting from Mary to complete daily living tasks. Mary who is on anti hypertensive medication feels unwell and phones NHS 24 for advice. Due to her report of chest pain NHS 24 staff advise they will send an ambulance.

You arrive and while you are undertaking an assessment of Mary's condition and gaining a history of events and general medical history, George becomes very distressed, repeatedly asking what is happening and what is wrong with Mary. You explain what you are doing and continue with your assessing and treating Mary. Her symptoms and 12 lead ECG confirms she is having a STEMI. At the same time George continues to repeat his earlier questions and also shouts at you to stop – "you do not need to do that Mary is fine".

While you will need to follow your protocol for someone having a STEMI you need to consider your care and support for George.

What may be causing George to be distressed?

How can you support George to reduce his distress?

Mary needs to be admitted to hospital as an emergency and George cannot be left at home without support. What are the potential support options in this situation?

3.4 Pain and Dementia

Detection of pain in many older adults is not without problems: some older people themselves believe that pain is an inevitable part of ageing and some public and professional attitudes can reinforce that. Having dementia only adds to the person's difficulties.

Detection of pain in the person in the earlier stages of dementia where the person can respond verbally is similar to any other person in pain. Most can describe current pain fairly accurately. However, as a result of their memory difficulties they may not be able to provide any history of pain. Like many other older adults they may not self-report voluntarily. Some may not report pain because of fears that any admission of disability or frailty may lead to hospitalisation or even institutionalisation.

My name is Mary and I don't know this place. I don't know how I got here but I don't like it. There are other people sitting nearby but they don't speak to me.

My back is sore ---my legs are sore-----my head hurts.

Two young ones came up to me and said "we're taking you to see the doctor" They don't need to shout, I can hear them fine. I won't be telling them anything anyway; I'll just end up in the hospital if I say I'm sore. I want to go home, I don't like it here.

Older people and those with dementia respond better to a standardised assessment tool rather than vague enquiries that may be misunderstood.

Pain intensity scales and visual analogue scales may be useful but some people may have

difficulty distinguishing between the levels of pain displayed on these depending on their degree of cognitive impairment.

Of course as they progress through dementia they will require more time to respond to questions and memory difficulties may preclude assessment of pain history, eventually it may become necessary to encourage them to move their body during your assessment to help them recognise current pain.

We know that pain is a multi-dimensional subjective experience and is considered to be whatever the person says it is. In principle this is an excellent guide to understanding the patient's lived experience of pain and treating them in a person-centred way. However there may come a time in the course of dementia when the person can no longer describe their pain in words or may not wish to.

The person with dementia may experience pain differently and they may not react to it immediately. They may not exhibit behaviours that are recognised by family, friends or carers or their behaviours may only be interpreted in the light of their dementia. Some communication problems also lead to difficulties in their ability to self-report their needs.

Collateral reports from family and friends and carers, especially about the person's usual behaviour when experiencing pain, are helpful.

Care in assessment is crucial to the appropriate treatment and management of pain. There are a number of assessment tools available to assess pain when the person with dementia is unable to communicate verbally. The one used by the ambulance service is the **Abbey Pain Scale** which is an observational rating scale and can be a very useful addition to the assessment processes used for detection of pain.

Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalise.

How to use scale: While observing the resident, score questions 1 to 6

Name of resident:

Name and designation of person completing the scale:

Date: **Time:**

Latest pain relief given was.....**at****hrs.**

Q1.	Vocalisation eg. whimpering, groaning, crying <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q1	<input style="width: 40px; height: 25px;" type="text"/>
Q2.	Facial expression eg: looking tense, frowning grimacing, looking frightened <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q2	<input style="width: 40px; height: 25px;" type="text"/>
Q3.	Change in body language eg: fidgeting, rocking, guarding part of body, withdrawn <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q3	<input style="width: 40px; height: 25px;" type="text"/>
Q4.	Behavioural Change eg: increased confusion, refusing to eat, alteration in usual patterns <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q4	<input style="width: 40px; height: 25px;" type="text"/>
Q5.	Physiological change eg: temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q5	<input style="width: 40px; height: 25px;" type="text"/>
Q6.	Physical changes eg: skin tears, pressure areas, arthritis, contractures, previous injuries. <i>Absent 0 Mild 1 Moderate 2 Severe 3</i>	Q6	<input style="width: 40px; height: 25px;" type="text"/>

Add scores for 1 – 6 and record here ➔ **Total Pain Score**

Now tick the box that matches the Total Pain Score ➔

0 – 2 No pain	3 – 7 Mild	8 – 13 Moderate	14+ Severe
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Finally, tick the box which matches the type of pain ➔

Chronic	Acute	Acute on Chronic
----------------	--------------	-------------------------

Dementia Care Australia Pty Ltd
 Website: www.dementiacareaustralia.com
 Abbey, J; De Bellis, A; Piller, N; Esterman, A; Giles, L; Parker, D and Lowcay, B.
 Funded by the JH & JD Gunn Medical Research Foundation 1998 – 2002
 (This document may be reproduced with this acknowledgment retained)

3.5 Capacity and Consent

It will be normal practice for you to seek consent from the person you are caring for before undertaking any intervention or treatment. **In many instances you will be responding to an emergency and in such situations, healthcare professionals may provide treatment to the person without consent, provided that the treatment is necessary to preserve life or to prevent a serious deterioration in their condition.**

Accurate and detailed recording of both the decision and the decision-making process is essential. In non emergency situations you will get informed consent on the presumption that the adult has capacity to consent.

Scottish law works on the same presumption that all adults 16 years and older have sufficient capacity to decide on their own medical treatment. This presumption of capacity can only be overturned on evidence of impaired capacity, even where the person has a diagnosis that may affect his or her ability to make decisions, for example dementia.

In Scotland the main piece of legislation used to protect the rights of a person who lacks capacity to consent to treatment is **Part 5 of the Adults with Incapacity (Scotland) Act (2000)**.

The Adults with Incapacity (Scotland) Act (2000); (AWI), created a legal framework for making decisions on behalf of a person who does not have the capacity to make decisions. It covers the person's welfare, property, financial affairs and medical treatment. It also enables a person to make their own arrangements about how their affairs should be managed in the future if they lose the capacity to make decisions.

The Adults with Incapacity (Scotland) Act (2000) sets out clear statements of Principles that inform the ethical basis for the provisions of the legislation and the values underpinning it. They place a duty on the person or bodies intervening to have regard for the principles which may be the subject of judicial review.

3.5.1 The Principles of the Adults with Incapacity (Scotland) Act (2000)

Any intervention under the Act must take account of the principles and must be followed in any action taken. If not, the action may be subject to legal challenge. The principles are as follows:

- Any action taken on behalf of the person **must benefit** the person.
- Any action must be the **least restrictive option** that will achieve the desired effect.
- Before making a decision on behalf of a person, account should be taken of the person's **past and present views and preferences**.
- Account should be taken of the **views of specific persons** such as guardian, attorney, relatives and any other person appearing to have an interest in the person.
- Anyone acting under the act must **encourage the adult to develop and exercise as much skill as possible** in making decisions or taking actions. All steps must be taken to enhance the person's decision making ability.

3.5.2 What is Capacity and Incapacity?

'Capacity' means the ability to use and understand information to make a decision. The person should be given appropriate information provided in a way that they can understand and can make a decision based on this information. Capacity in relation to consent to treatment means people are capable of understanding the nature, implications and consequences of their decisions. 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 in order to arrive at a decision;
- Can communicate that decision to others, and;
- 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, they make a consistent decision. This makes their decision valid.

3.5.3 Factors that may influence capacity

We also need to consider the many factors that may influence capacity both internal and external to the person such as environment, previous hospital experience, quality and form of information provided, communication and co-existent health problems.

There are multiple factors that may potentially affect and compromise people's capacity to make decisions. These include:

- Personal, physical, psychosocial and situational demands placed on the person;
- The resources and supports available;
- The impact on the person's capacity to make decisions if they are suffering pain or discomfort or taking medication that causes drowsiness;
- Conditions that can affect decision making capacity and these include infections such as pneumonia, urinary tract infection or influenza, delirium, endocrine disorders, cardiovascular disease and chronic pain.

Relationships between people may have a significant impact on decisions made and, therefore, may influence the capacity of someone to make a decision. **For example**, in a relationship where the person is at risk or feels threatened by another person, they may be put under undue pressure to consent or refuse treatment rather than making an autonomous decision. If you suspect that is the case **you must** follow local adult protection procedures, in line with the Adult Support and Protection (Scotland) Act (2007).

Equality and diversity issues, such as someone's ethnic background or disability also needs to be a major consideration in capacity assessment to eliminate the risk of misinterpreting indicators of cultural difference as incapacity and reduced cognitive function. This will require sensitivity to the person's specific cultural needs which may include for example, the use of interpreters or referral for specialist assessment.

There are however, very specific additional requirements for the assessment of capacity when it relates to consent for medical treatment under Part 5 of the Act. It must be determined whether the person:

- Is capable of making and communicating their choice;
- Understands the nature of what is being asked and why;
- Has memory abilities that allow the retention of information - if the person has advanced dementia they may not be able to retain information for the duration of treatment / intervention but if they consistently give the same response when information is provided this can be accepted as consent or refusal.
- Is aware of any alternatives;
- Has knowledge of the risks and benefits involved;
- Is aware that such information is of personal relevance to them;
- Is aware of their right to, and how to, refuse, as well as the consequences of refusal;
- Has ever expressed their wishes relevant to the issue when greater capacity existed;

- Is expressing views consistent with their previously preferred moral, cultural, family, and experiential background;
- Is not under undue influence from a relative, carer or other third party declaring an interest in the care and treatment of the adult.

Consent to care and treatment is therefore dependant on the person's capacity. Valid consent must be:

- Given freely without coercion;
- Given by a person who is considered competent to make the decision;
- Specific to the intervention or procedure;
- Informed, so the person understands what is involved;
- Is continuous for the duration of the treatment or procedure.

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 need support in other areas. For some the ability to make decisions can vary depending on their capacity at any point in time and this can be influenced by the many factors described earlier.



Learning Activity 3.2

David's Story

David is 70 years old and lives alone in his own home. He has a diagnosis of dementia and requires home care support to assist with personal care needs and organising meals.

David has been having recurring chest infections over the past couple of months. His GP has visited and requested an urgent admission to hospital for IV antibiotics.

You arrive to take David to hospital. He refuses to go and states that he is not leaving his house. All attempts by you and care staff present to encourage him to go to hospital fail. He also refuses to have any observations taken despite obvious respiratory distress and becomes quite insistent that he is not going anywhere and asks everyone to leave his house.

How will you establish if David has Capacity to refuse Treatment?

What action can you take to support David?

3.5.4 Proxy decision makers under the Adults with Incapacity (Scotland) Act (2000)

A significant feature of the Adults with Incapacity (Scotland) Act that pertains to obtaining informed consent is the introduction of proxy decision

makers, additional provisions and new roles. Prior to this legislation, under common law, no other person could consent to treatment on behalf of another person.

3.5.5 Power of Attorney

'Power of Attorney' is the name given to a person or persons granted the authority to make decisions on behalf of a person who becomes incapable of making decisions on their own. A Power of Attorney is taken out in the same way 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 granting the power immediately before the document was signed. This certificate confirms that, in the solicitor or medical practitioner's opinion, the granter is capable of making the decision about Power of Attorney, knows and understands what they are doing and, importantly, is free from duress or pressure in making that decision.

It is obviously important that a person gives Power of Attorney to someone they trust, to make decisions when they are no longer capable of making them. We can support people by ensuring they have information about the different powers within the Act to empower and enable them to make decisions and draw up advanced plans.

The legal terms relating to Power of Attorney are:

- **Granter** - the person giving permission to someone else
- **Attorney** (also known as **proxy**) - the person who is given the powers

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

Continuing Attorney

A person with Continuing Power of Attorney can only manage the finances and property

of another person and 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. For example, when continuing Power of Attorney is in place, the Attorney would have access to the person's finances and could arrange to do things like pay household bills.

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, for example, physical and mental health and protection from abuse and harm (other than financial harm). Powers can include choice of medical care and treatment, choice of diet, personal care, choice of clothing, meaningful social contact with friends, families or communities, and even where the person lives.

Welfare Attorneys can only start making decisions on behalf of the person, once the person has been assessed and it is agreed they no longer have capacity.

All Continuing and Welfare Powers of Attorney must be registered with the Public Guardian. In return, the Public Guardian issues the Welfare Attorney with a Certificate of Registration. The office of the Public Guardian was created by the AWI Act and anyone can contact them for information:

<http://www.publicguardian-scotland.gov.uk>

3.5.6 Intervention Orders

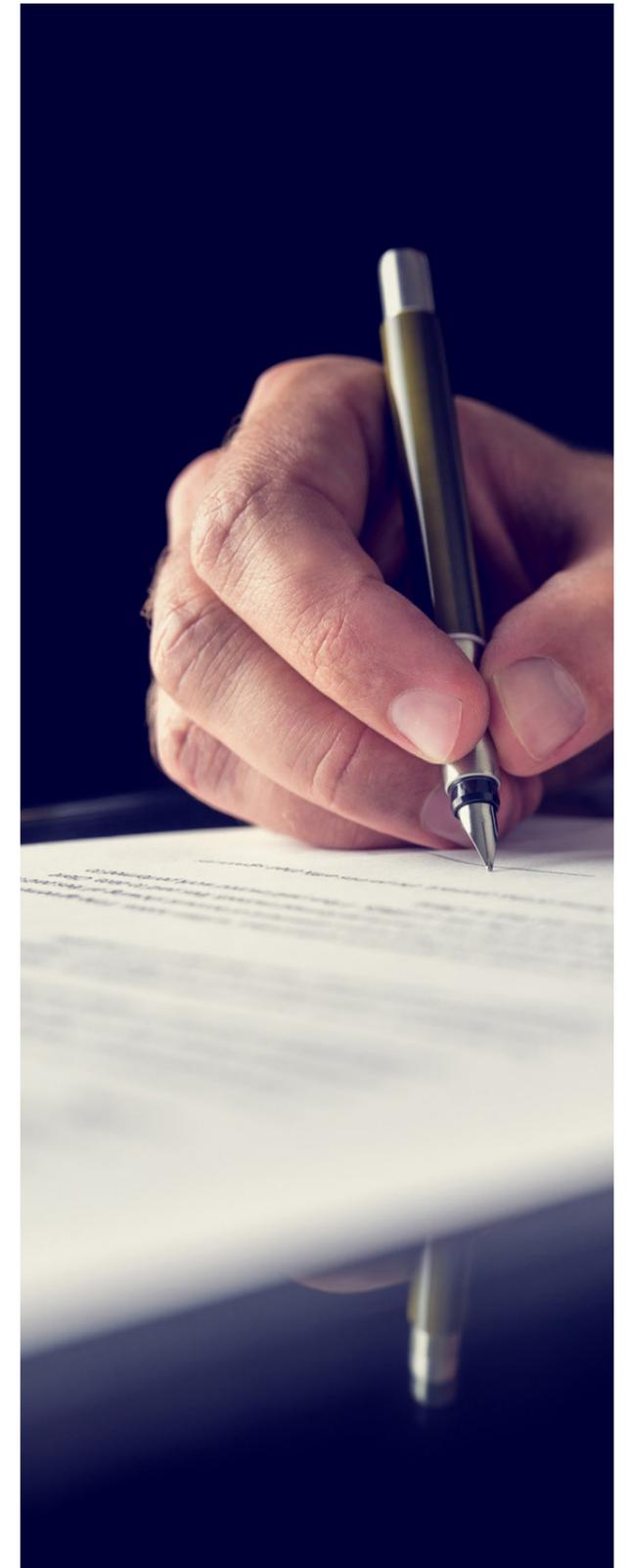
Intervention orders give permission for one-off decisions which the person does not have the capacity to make. The decision may be to do with property, finance or personal welfare. For example, when dealing with income tax or selling a property the person making an application to the court for the order would not have to have power of attorney or guardianship. The person would have to have an interest or concern about the person in question. The local authority in the area the person lives may make an application in certain circumstances. A welfare intervention order may be relevant when a person is assessed as not being able to consent to a complex medical treatment, although they can still make most other decisions.

3.5.7 Guardianship Order

Guardianship is different to Power of Attorney in that it can only be applied for when the person is assessed as not having capacity to make decisions. It can cover property and financial matters or personal welfare, including health, or a combination of all of these. Anyone with an interest in the person may apply to the courts for guardianship e.g. a family member or the local authority. The guardian can then make decisions on behalf of the person in the same way as the Attorney.

The decisions the Attorney or Guardian can make will be specified in the order granted and it should not be presumed that they have the power to make all decisions regarding the care of the person.

Other key elements of the AWI Act that may be relevant to you in your practice are described at **Appendix 2**.





Learning Activity 3.3

Margaret's Story

Margaret is 75 years old and lives at home with her husband James. She has a diagnosis of dementia, type 2 diabetes mellitus and peripheral vascular disease. You respond to an emergency call that Margaret has had a fall and sustained a head injury. When you arrive you observe that Margaret has a laceration to her left eye which is red and inflamed. Margaret is very distressed and screams when you approach to assess her. Her husband James is also very distressed and insists she needs to go to hospital. All attempts to encourage her to go to hospital fail. James then states that he has Power of Attorney and can consent to treatment on Margaret's behalf.

Should you accept James's proxy consent for Margaret?

Should Margaret's capacity to consent to treatment be assessed?

When a person refuses treatment or to travel to hospital clinicians may be concerned that their assessment of the person's capacity to consent and subsequent decision could later be examined critically in a court of law. This could be either from the perspective of forcing a capable adult to have treatment they do not want resulting

in a criminal charges of assault or for omitting necessary treatment of a person who lacks capacity. **It is important to remember that you are assessing the person's capacity to make a decision at the time it needs to be made and any change or fluctuation in capacity at another time will not apply to this decision.**

Essentially you need to establish if the person is:

- taking in the information;
- they are retaining the information; and
- they can weigh up the risks and benefits.

In addition, the level of capacity required has to match the seriousness of the decision to be made. For example, the person may have capacity to refuse treatment for a minor laceration, but not to refuse life saving treatment.

To be confident if you are following best practice in reaching a decision you should:

- Follow the steps to assessing capacity discussed earlier in this section.
- Take account of the principles of the Act
- Record in detail your assessment and how you arrived at your decision, including names of other parties present or informed who can provide corroboration. For example, a GP telephone contact or professional to professional advice.

If your assessment leaves you in any doubt about the person's capacity and they are refusing treatment you should seek medical or professional to professional advice to provide alternative pathways of care.

3.6 Summary

In this section we considered the impact of stress and distress on the person with dementia and how this can be both caused by and impact on the person's physical health care needs. It also provided essential information about the application of Part 5 of the Adults with Incapacity (Scotland) Act (2000) and in particular safeguarding the rights of people who lack capacity to consent to treatment.



Section 4: Care Transitions

4.1 Introduction

The nature of your contact with the person with dementia will vary and this may be when:

- treatment is concluded in hospital and they are returning home.
- you have treated the person and they are remaining in their own home.
- you have treated the person and need to transfer them to hospital or another facility.

This may result in the person having to be prepared for hospital or waiting for various time periods. There are some important considerations particularly passing on any indication of cognitive impairment where the person is not known to have dementia and ensuring they are in a calming and supportive environment.

Dementia results in a marked change in how the person interacts and interprets the environment. This varies depending on the severity of the

dementia, the type of dementia and other sensory deficits the person may experience. Because of this the person with dementia has been described as having a lowering stress threshold. The result of this is that stressors normally taken for granted by others using health and social care services can be unbearable to the person with dementia.

It is important that the way the person with dementia behaves is not viewed in purely pathological terms. The conditions of agitation and anxiety that are often viewed as 'challenging' behaviours can be reframed as distress and a consequence of being in an environment that is disabling for the person with dementia. Making an effort to reduce their anxiety and stress as far as possible can result in a calmer and more positive experience for the person, their family, friends and carers.



Just a thought

Scene one

You are in your local hospital and have injured your leg; you are being transported in a wheelchair. Fortunately, the hospital is an enabling environment. The doorways are wide enough to allow the wheelchair to pass. There are toilets not only with wide doorways but rails to allow you to use them without help;

no need for embarrassment there. If you need to move around there are slopes to allow the chair to move easily from one level to another and there is a large lift if you need to go to different parts of the hospital. Your supporter was able to park right at the door in the disabled parking bay.

Scene two

You are in your local hospital and have injured your leg; you are being transported in a wheelchair. Oh! You have dementia.

The doors are just as wide but you can't see any signs and you don't know where you are going. There are no toilets that you can see, so the wide doors and rails are no use to you. The signs are all too high to see and you are not going in the lift as the floor is really dark and shiny and you are sure you will fall into that hole they are pushing you towards.

Shadows can form shapes and for the distressed person these can be misperceived leading to fear, agitation and distress. The person with dementia can appear to be hallucinating when they are in fact experiencing an illusion created by this misunderstood visual stimulus. Not only shadows can be misperceived in the environment.

In the case below it was an everyday object in the environment that was misperceived by a distressed and visually impaired older person.

Jean has been sent to A&E by her doctor after a fall at home. She has not been too well lately her daughter reports. She is distressed at the moment by the 'little girl in the red dress who

has her hand over her eyes and is crying for her mum'.

Jean is getting very angry with everyone because they are ignoring this child. What kind of people are they?

Examination of the environment shows an upright red fire extinguisher with a hose folded from the middle to the top of it. Half close your eyes and it does look like someone small with their arm raised.

Jean is already distressed and in pain and she has clearly transferred these emotions to a misperception in her environment. That is, the red fire extinguisher.

What can be done to reduce Jean's level of distress?

Try moving Jean, if possible, away from the stimulus. If that is not feasible, a bin or trolley could be moved between her and the extinguisher so she can no longer see it from her position in the room.



4.2 The person with dementia who has to wait

As you work through this section you may feel that you have little influence over what happens with the person in the time they are waiting. However you should consider how some of these factors could relate to the experience of being in an ambulance for the person with dementia.

4.2.1 Going to the toilet

The person with dementia may not be able to let you know that they need to go to the toilet. Even if they normally manage to go by themselves at home, they may not, for example, be able to find their way around a busy emergency department. Leaving doors open so the toilet is clearly visible is the most successful way to direct the person with dementia. Toilet signs should be realistic and placed at a height that can be seen even by

the person in a wheelchair. Signs on the floor can also help as many of the patients 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 the person with dementia but those patients with other 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 toilet seat and the floor covering. It is more important to have a strong contrast than any particular colour.



Read their body language and non verbal messages. If they are giving out distress signals or seem not to be understand you, it may be something is troubling them such as needing the toilet, or they simply cannot hear you clearly. They can be become distracted, anxious or discombobulated. Remain alert at all times.

Mr. James McKillop
A person with dementia

4.2.2 Eating and drinking

One of the problems related to memory loss, is that the person with dementia may not remember when they last had something to eat and drink. They may not ask for anything and may need to be prompted by being asked.

Remember...

You have to ASK about eating and drinking.

Ask a direct question to get a positive reply. For example in my mother's care home they would ask her if she wanted a cup of tea, to which she would reply "yes", as she was thirsty. However if they said do you want tea or coffee, she would have said coffee.

Mr. James McKillop
A person with dementia

4.2.3 A quiet environment

It would be ideal to have a quiet waiting area for the person with dementia with calming colours, good signage and materials to occupy them, which are appropriate to their age. This may be achievable in some departments and is best practice. However, even in those departments with limited space or opportunity to provide a designated space for the person with dementia there is still a good deal that may be achieved if good dementia design principles are adopted.

4.2.4 Waiting time

The person with dementia may not be aware of time passing and is unlikely to remember that they have been told they may have to wait. If their family, friend or carer is available they are likely to be the best companion for them. If they are alone it is best if someone can be assigned to stay with them.

Practice Point

Check these three examples of information sheets below:

1) *Each patient will have a named nurse who will be responsible for the planning of their care. You will be introduced to your named nurse when you arrive on the ward*

2) **EACH PATIENT WILL HAVE A NAMED NURSE WHO WILL BE RESPONSIBLE FOR THE PLANNING OF THEIR CARE. YOU WILL BE INTRODUCED TO YOUR NAMED NURSE WHEN YOU ARRIVE ON THE WARD**

3) Each patient will have a named nurse who will be responsible for the planning of their care. You will be introduced to your named nurse when you arrive on the ward

Are they all easily understood? Could you read these if you had a visual problem? Can you read them without your glasses, if you wear them?

Adapted from Top Tips for Achieving Clear Print (RNIB)

Text size should be 12-14 pt. 14 pt is preferred.

Avoid elaborate printing fonts.

The text should be aligned to the left.

Keep the layout clear and simple.

Use bold highlighting sparingly; only on a few words not full paragraphs.

Do not use all capital letters and avoid italics and underlining.

Do not put text on top of an image.

The paper should not be glossy or reflective; avoid laminated effects.

Use paper thick enough to avoid the letter showing through to the underside

Use a high contrast between the text and the background colour.

For further information see the website for the Royal National Institute for the Blind.

http://www.rnib.org.uk/professionals/accessibleinformation/text/Pages/clear_print.aspx

4.3 Environmental considerations

Providing an environment that is enabling for the person with dementia has three main benefits; it makes it easier for the person with dementia to settle, it may have an impact on the experience of other vulnerable and disabled patients who attend and it will reduce the stress of caring for the staff; enabling them to release care and treatment time.

In particular there are two aspects of the environment that can be amenable to change, these are sound and light. These two aspects of the environment can be a source of over or under stimulation for the person with dementia and are likely to be controlled to a degree by staff and can often be managed during the working day.

4.3.1 Sound and noise

Many older people experience hearing loss and this can be made worse when the person has dementia. Not only will they have difficulty responding to sounds, they may also misinterpret what they do hear.

Many health care settings can be noisy and unpredictable places. Noises can be insistent, unfamiliar and incessant and this can be more challenging when the person has come from their own home where they have some control over their environment. Most of the conversations they hear will 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. This can increase anxiety and in turn can lead to increased agitation. Sudden noises can also startle the person and increase their insecurity and fear. If this continues it can lead to the person becoming resistive to care and treatment.

Remember...

Sensory overstimulation can increase agitation and confusion

4.3.2 Light

It is estimated that older people need three to five times more light than younger people do. Even natural light may not be sufficient for the needs of the older person; it may have to be substantially boosted by artificial light sources. Lighting should also 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 older person with dementia to see clearly, there can also 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 the reflection from glass or other highly polished surfaces. The older eye takes considerably longer to accommodate the changes in light levels or react to sudden flashes from reflective surfaces. This can mean 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 left has the light directly on the face almost obliterating the features. The light from behind on the right photograph casts shadows over half the image making the features hard to make out clearly.



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?

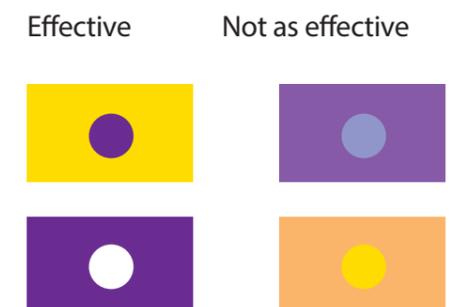
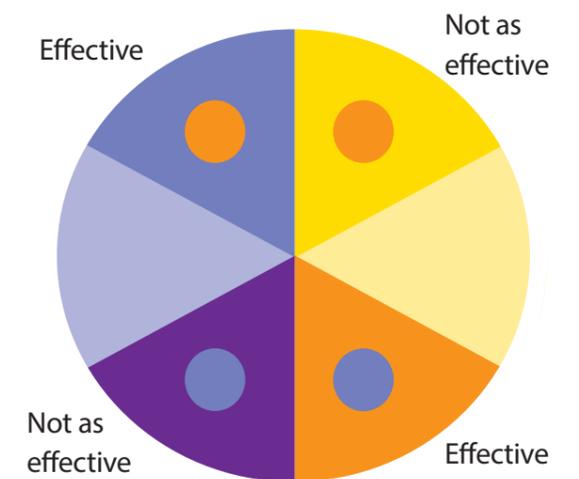
The person with dementia has sometimes additional deficits in the visiospatial ability; this can cause further misperceptions in relation to highly reflective surfaces. These appear to be three rather than two dimensional in appearance. Looking at a highly polished floor for example, the person with dementia may 'see' what appears to them to be puddles of water on the floor. If they try to avoid these, this can also lead to loss of balance and falls.

Where it is possible, plain rather than patterned surfaces should be used. This is particularly important in relation to flooring. Strong patterns, tiled surfaces or sudden or dramatic changes in floor colouring can be raised or lowered with the appearance of a step up or down. This will cause the person to stop suddenly or to stumble, increasing the risk of falls.

4.3.3 Colour and contrast

The person with dementia may have progressive difficulty with colour discrimination, and sensitivity to contrast in colours. The older eye may have difficulty seeing pastel shades and the so called 'cold' colours of blue, grey and lilac. In contrast the 'hot' colours of yellow, red and orange are more likely to be preserved. This can be useful if you wish the person to clearly find some areas in the department such as toilets and perhaps there are other areas that they would be at risk in.

In addition to considering colour it is important to also consider contrast. The contrast between light and dark colours also affects the image we see. Below are some examples of the impact of colour and contrast. Those that are effective exaggerate the contrast and colours used.



Remember...

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.

4.4 Medication

If you attend a person who appears confused, check their repeat prescription or medications. Typical memory enhancing drugs used include donepezil hydrochloride, rivastigmine, galantamine and memantine. Many people are likely to have been prescribed these along with a wide range of other drugs to assist with symptom management including anti-psychotics, anti-depressants, anxiolytics, hypnotics or anti-convulsants. As highlighted earlier in section 2 these may be risk factors for the development of delirium.



Learning Activity 4.1



John's Story

John was diagnosed with a dementia five years ago and has continued to live at home with his wife. Over the five years he has managed well at home but has slowly deteriorated, becoming more forgetful and sometimes agitated.

As a form of respite John attends the local day care unit that is designed for people with dementia, they take part in activities and have their lunch. This gives his wife an opportunity to have a break and complete tasks such as shopping which she finds difficult when caring for John.

Patient transport services pick John up each morning to take him to the unit, but over the last few weeks John hasn't been ready when they go to pick him up, he seems to be very sleepy and on occasions has got aggressive with the crew and his wife when they try to rush him. On several occasions you have had to leave him.

Why is this situation not ideal?

What could be causing this?

What could be done to make things easier?

4.5 Summary

This section explored the importance of the environmental design on the person with dementia. It highlighted the factors that need to be considered when the person is waiting for

care, treatment or to transfer elsewhere and how these can contribute to the person's level of stress and distress.

References

Alzheimer's Society (2009) Counting the Cost. London, Alzheimer's Society.

Bannarjee, S (2009) The use of antipsychotic medication for people with dementia: Time for Action. London, Department of Health.

Knapp and Prince (2007) Dementia UK: The full report. London, Alzheimer's Society.

Luengo-Fernandez R, Leal J, Gray A (2010) Dementia 2010. Cambridge, Alzheimer's Research Trust.

Mental Welfare Commission (2011) Right to treat? Delivering physical healthcare to people who lack capacity and refuse or resist treatment. Accessible at; www.mwscot.org.uk

Morrison RS, Sui AL (2000) A comparison of pain and its treatment in advanced dementia and cognitively intact patients with a hip fracture. *Journal of Pain and Symptom Management* Vol 19 pp240-8.

Schofield I, Stott DJ, Tolson D, McFadyen A, Monaghan J, Nelson D (2010) Screening for cognitive impairment in older people attending accident and emergency using the 4 item Abbreviated Mental test. *European Journal of Emergency Medicine* Vol 17(6), pp 340-342.

Scottish Government (2010) Scotland's National Dementia Strategy. Edinburgh, The Scottish Government.

Nightingale S, Holmes J, Mason J et al (2001) Psychiatric illness and mortality after hip fracture. *Lancet*, 357, 1264–5.

Brauer C, Morrison RD, Silberzweig SB, and Siu AL. The cause of delirium in patients with hip fracture. *Arch Intern Med.* 2000;160(12):1856-60.

Scottish Government (2010) Adults with Incapacity (Scotland) Act 2000 Code of Practice for Practitioners authorised to carry out medical treatment or research under Part 5 of the Act. (Code of Practice, 2010, pp9 –10) Available at www.scotland.gov.uk/Topics/Justice/law

Appendix 1

Suggested responses and key learning points related to activities

The suggested responses to selected learning activities provided in this appendix set out examples of what learners may be expected to include in their answers to the activities.

Learning Activity 2.1



Jean's Story

What will be a key consideration in your assessment?

A key consideration will be delirium, as the risk of developing delirium is increased when a person is older and a combination of multiple precipitating and/or predisposing factors exists, such as frailty, physical health problems and cognitive impairment. If Jean has a fractured femur she will be at greater risk of developing persistent delirium that can result in serious consequences and poor outcomes for the person. Evidence suggests that delirium occurring during admission with hip fracture is associated with increased hospital stay and increased mortality in older people.

What would help you determine if Jean has dementia or delirium?

Some of the key distinguishing features between dementia and delirium are as follows:

Onset and progression

Dementia tends to develop gradually, while delirium develops rapidly within hours or days and presents in a fluctuating pattern. Vascular dementia, however, can present with sudden deterioration and dementia with Lewy bodies also has a fluctuating course similar to delirium.

Attention

The person's attention span will vary in both dementia and delirium, but in the latter the person will not be able to focus even for a limited time.

Thinking

In dementia, the person may have difficulty with abstraction, thoughts and difficulty finding words. A person with delirium will have disorganised, distorted, incoherent and either slow or accelerated thinking.



The changes in Jean have developed quite suddenly and the fact that she is drowsy and lethargic could suggest hypoactive delirium. This type of delirium is frequently missed because the person is quiet and can easily go unnoticed in a busy environment. It is also important to be aware that when a person is known to have dementia, a superimposed delirium is frequently attributed to dementia and left untreated.

A further indication may be that Jean has been not eating or drinking very much over the past couple of days putting her at greater risk of dehydration and constipation leading to delirium. It is also important to be aware that when a person is older dehydration can develop rapidly or within hours.

As Jean's vital signs are normal it will also be important to establish if she has had any recent changes in medication.

As a guide you should think delirium if there is: acute onset and fluctuating course **and** inattention **and either** disordered thinking or altered level of consciousness.

What action would you take if you suspect Jean has delirium?

You should complete a 4AT assessment as part of your overall assessment and pass on Jean's 4AT score to triage and/or medical staff in the emergency department. While you will also do the F.A.S.T test as part of your routine assessment it is always safest to assume delirium and seek medical advice and treatment.

Learning Activity 3.1

George's Story

What may be causing George to be distressed?

For some people with dementia they may have a reduced threshold for stress and be less able to tolerate multiple demands. It maybe the combination of shock with Mary being unwell, fear of what is happening and overstimulation caused by strange people, noise from equipment and sense of urgency of the situation. George may be feeling a need for safety and security, or a need for affection, privacy or comfort and be unable to express this verbally. His thoughts will be affecting his feelings and as he begins to feel anxious this triggers a fight or flight response causing an increased release of adrenaline and reduced concentration and reduced ability to communicate effectively which will result in repeated questioning and shouting.

How can you support George to reduce his distress?

To support George and reduce his distress it is essential to listen to his feelings as well as the words he is using. If you are to respond appropriately, actively listening and hearing the emotional message behind the words is, in effect, more important than the words themselves. Acknowledging the person's feelings and taking time with them to offer support so that he knows his feelings are being heard will diffuse their distress.

In this situation there is limited time but you can speak with Mary to establish what would help. Also as communication is often more effective when there is a tangible focus, you could distract George from the over stimulated situation; again explain what is happening using the communication tips described in section one of this learning resource. Then ask George to help you organise medicines etc that Mary will need to take to the hospital.

Mary needs to be admitted to hospital as an emergency and George cannot be left at home without support. What are the potential support options in this situation?

Potential Options

1. Organise for a neighbour or family member or someone close by that George trusts to come and stay with him. Mary may already have arranged this.
2. Organise for another ambulance to attend to assist George until alternative arrangements are made.
3. You may have no alternative but to take George with you but you need to be aware that once at the hospital he will need ongoing support as he will be separated from Mary. Also as Mary is likely to be transferred using emergency systems this may exacerbate George's distress.



Learning Activity 3.2

David's Story

How will you establish if David has Capacity to refuse Treatment?

While you do not need to formally assess David's capacity to consent to treatment under the Adults with Incapacity (Scotland) Act (2000) you could use the additional requirements listed below as a guide to your conversation with him before requesting that he signs a refusal form.

- Is capable of making and communicating their choice.
- Understands the nature of what is being asked and why.
- Has memory abilities that allow the retention of information.
- Is aware of any alternatives.
- Has knowledge of the risks and benefits involved.
- Is aware that such information is of personal relevance to them.
- Is aware of their right to, and how to, refuse, as well as the consequences of refusal.
- Has ever expressed their wishes relevant to the issue when greater capacity existed.
- Is expressing views consistent with their previously preferred moral, cultural, family, and experiential background.
- Is not under undue influence from a relative, carer or other third party declaring an interest in the care and treatment of the adult.

It will also be important to establish if there is something which is compromising his ability to consent such as delirium. If he does not cooperate with the 4AT assessment you could use the SQID to establish from home care staff, if this is a rapid change for him. The predisposing and precipitating factors present (age, dementia and severe illness) would also indicate a likelihood of delirium. He may be misinterpreting what is happening or be suspicious and not reveal this or be distressed by the number of people present.

The fact that he has dementia does not in itself mean that he lacks capacity to consent to treatment and the requirement that he needs to have memory abilities that allow the retention of information will not automatically apply if his answer with regards to his view on treatment remains consistent when repeated at different times.

Also, disagreeing with a suggested line of treatment does not necessarily mean that the person lacks capacity. It is important to assess capacity in relation to the treatment decision that the person is facing. "Presumption in favour of capacity" must be interpreted with care. It does not mean that a person is "assumed to have capacity unless there is a certificate that states otherwise". A presumption of capacity can be challenged if there is evidence to the contrary.

Refusal and resistance may be based on a lack of understanding. Healthcare professionals have a duty to give information in a way that the person can understand. Even where the person lacks capacity, well-presented information can overcome resistance to a necessary procedure. It is particularly important to involve others who know the person well, e.g. relatives and carers. Explanation, support and reassurance by someone the person trusts is often enough to overcome resistance. Also, where the person has a specific fear of hospitals or specific procedures, there should be attempts to "desensitise" the person's fear by gradual exposure and measures to combat anxiety.

What action can you take to support David?

The alternative care pathway arrangements available for you to action may be:

- Contacting the GP direct or, if out of hours, professional to professional line to advise of your concerns for the ongoing care of David.
- Some areas now have hospital at home services and it may be appropriate to access this service for David.
- As a result you may be required to await the GP or other medical response.

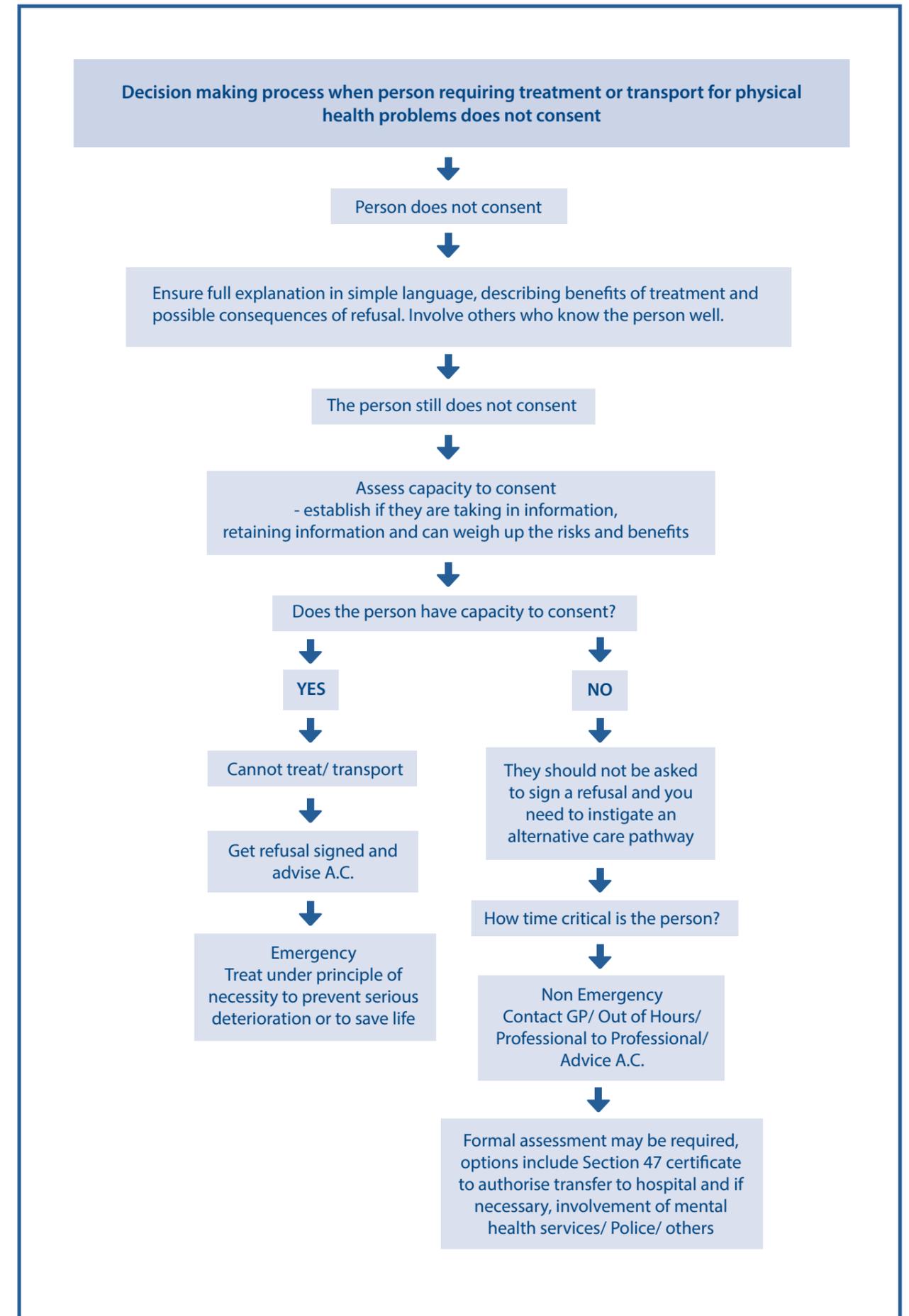
Medical practitioner responsibility and authority

The medical practitioner attending will have authority to formally assess his capacity and where it is established that he lacks capacity to consent to treatment he/she would sign a section 47 Certificate of Incapacity authorising his transfer to hospital. There may still be difficulties in transferring him to hospital if he resists as the use of restraint or other force is an interference with the person's right to physical integrity, and as such should only be on the basis of law, in pursuit of a legitimate aim, and should also be the least restriction necessary to achieve that aim (i.e. it should be proportionate). The "section 47 certificate" cannot authorise force except where immediately necessary and only for as long as is necessary.

The best legal option may be the use of reasonable force using a section 47 certificate under the Adults with Incapacity (Scotland) Act 2000 where treatment is not an immediate emergency but still urgent and where there is no time to obtain authorisation under part six of the 2000 Act. If the person refuses to attend hospital, there may be a need for a warrant for removal under section 293 of the Mental Health (Care and Treatment) (Scotland) Act (2003) . A Sheriff or Justice of the Peace could grant a warrant to remove the person to hospital. Treatment could be given in hospital under part five of the AWI act.

The medical practitioner must decide if the use of force is proportionate to the objective of treatment. He/she must consider the likely result of deciding not to use force, and therefore denying the person the best clinical treatment. Also, it would be inappropriate to use large amounts of force for relatively small likely benefit. This will not be an easy decision. Medical practitioners must consider the difference between best treatment using significant force, and less effective treatment where the need for force is much lower.

It is likely to be the police or mental health staff who would escort the person and it would only be in very exceptional circumstances that the ambulance clinicians would be the professionals using force. This would be minimal and based on clinical judgement where there is no danger to the person or clinicians. The decision flowchart below is adapted from the Mental Welfare Commission guidance on delivering physical healthcare to people who lack capacity and refuse or resist treatment Right to treat? and highlights the critical points in the decision process.





Learning Activity 3.3

Margaret's Story

Should you accept James's proxy consent for Margaret?

When James informs you he has Power of Attorney and he can consent to treatment, you should ask to see a copy of the Certificate of Registration issued by the Public Guardian before he can give consent. You also need to be assured that it is a Welfare Power of Attorney and not a Continuing Power of Attorney and that it contains the relevant specified authority to make decisions relating to medical care and treatment.

If James does not have a copy of the Certificate of Registration available, the Office of the Public Guardian can provide this information or alternatively the local Authority is also advised of Welfare Attorney and Guardian registrations.

However even where a Power of Attorney has authority in relation to medical treatment the Mental Welfare Commission's view is that this does not authorise the use of force.

Should Margaret's capacity to consent to treatment be assessed?

You should still assess Margaret's capacity to consent even if you find out James has a Welfare Power of Attorney as these powers do not come into force until the person has lost capacity. The process of establishing capacity to consent will be the same as for David in learning activity 2.



Learning Activity 4.1

John's Story

Why is this situation not ideal?

Whilst John is able to attend the day centre it allows him to take part in stimulating activities with people that have a similar diagnosis to himself. He also has access to staff who are specially trained to deal with individuals' dementia and they can track any issues, i.e. deterioration in his cognitive impairment on a regular basis. He would also have access to nurses/ teams with specialist skills such as dieticians/ speech therapists.

When John is at the centre it also allows his wife a break, as caring for someone with dementia on a full time basis can be difficult at times and a full time commitment. The health of the carer is also important and we need to make sure that both are cared for.

What could be causing this?

John's condition may be deteriorating further. If this is the case it may be even more important to get him to the day centre so this can be assessed and monitored.

John may have an underlying condition, such as another medical illness or condition that may be causing him to feel more tired. A dementia can often 'mask' other symptoms so it is important to rule out the possibility of other illnesses.

John may just be deteriorating with his dementia. Dementia is progressive. This means that the person's brain will become more damaged and will work less well over time, and their symptoms will tend to change and become more severe.

The speed at which symptoms get worse and the way that they develop will depend on the cause of the person's dementia, their overall health and their circumstances.

The pickup times for John may not be suitable and he may just require a little longer in the morning to get ready. Allowing him a little more time may allow him to feel more relaxed and in control of the situation so the associated agitation may reduce.

What could be done to make things easier?

Through conversation with John and his wife would it be possible to pick John up a little later, maybe make him the last pick up? This could allow him a little longer to get ready, and then allow him to carry on attending the day centre, giving him access to the facilities at the centre and giving his wife the essential respite she requires. This would also need communicating to the PTS planning in ACC.

Does John require a general medical check up? This could highlight any deterioration in his dementia or pick up any underlying medical issues/ illnesses. He could also get all his medication checked as this could be making him lethargic.

Appendix 2

Structure and Key Provisions of the Adults with Incapacity (Scotland) Act 2000

The Act is has 7 parts:

Part 1: Definitions, Roles, Responsibilities and General Principles

Part 2: Financial and Welfare Powers of Attorney

Part 3: Access to Funds

Part 4: Management of Residents Funds

Part 5: Authority to Treat

Part 6: Intervention and Guardianship Orders

Part 7: Miscellaneous Provisions

This module specifically focuses on Part 5, however, it is important to have an overall understanding of the whole Act.

Part 1 Definitions, Roles, Responsibilities and General Principles - Implemented in April 2001

This part of the Act defines the roles of the authorities that will act under the legislation; the **Sheriff, Mental Welfare Commission, Local Authorities and Health Boards**. It also created and defined the new role of **Public Guardian** and provided for **Codes of Practice** to be developed. Most importantly, it sets out the **General Principles** that must apply to any intervention in the affairs of an adult covered by the Act.

The Public Guardian

The Office of the Public Guardian has duties to register Powers of Attorney, intervention and guardianship orders, and to give permission for the withdrawal of funds from the person's bank account. It also receives and investigates complaints and has a duty to give advice and information on request.

The Mental Welfare Commission

The Mental Welfare Commission works to safeguard the rights and welfare of people with mental illness, learning disability and other mental disorders and their duties are set out in mental health law. The Mental Welfare Commission also has a duty to enquire into any potential ill-treatment, deficiency in care or treatment, improper detention or possible loss or damage to the property of a person with mental disorders.

The Local Authority

The Local Authority has a variety of duties:

- Supervise Welfare Guardians.
- Investigate complaints and circumstances in which the personal welfare of an adult with incapacity seems to be at risk.
- Provide information and advice.
- Take the necessary steps to safeguard the property, financial affairs or personal welfare of the adult.
- Apply to the Sheriff for an intervention order for the protection of the adult's property, financial affairs or personal welfare.
- Prepare reports to accompany applications for intervention and guardianship orders.
- Apply for intervention and guardianship orders if necessary.
- Recall guardianship and intervention orders in relation to the welfare of adults.

Part 2 Financial and Welfare Powers of Attorney - Implemented in April 2001

This part of the Act clearly defines the circumstances under which an adult, **who still has capacity to make decisions and can fully understand what they are doing can nominate a proxy decision maker**. It enables the person to safeguard their welfare or the management of their financial affairs, should their capacity deteriorate in the future, as detailed earlier in this learning resource.

Part 3 Access to Funds - Implemented in April 2001

This part set up a new scheme to allow access to funds belonging to an adult who lacks capacity to manage them. An individual, normally a relative or carer, can apply to the Public Guardian to gain access to accounts held either solely or jointly by the adult in banks or building societies. If the Public Guardian authorises it, the individual can then set up a designated account into which the bank will release funds as instructed, so that the money can be used to meet the adult's daily living expenses. It also allows one holder of a joint account to continue to operate the account if the other holder loses capacity to do so. The application to set up this access to funds must be accompanied by a Certificate of Incapacity and be counter-signed by someone who can confirm that the applicant is able to undertake these responsibilities. The Public Guardian monitors access to funds to ensure that the designated person acts within the rules laid down to safeguard the adult's interests.

Part 4 Management of Residents Funds - Implemented October 2003

This part of the Act allows hospital and care home managers to manage the finances of residents who lack capacity to do so themselves. These **Authorised Managers** will be able to apply to their **Supervisory Body** (either the relevant **Health Board** for NHS hospitals or the **Care Inspectorate** for registered care homes) if they need to manage a resident's funds and no other arrangements can be made. The application will need to include a **Certificate of Incapacity** and a plan of care detailing how the funds will be used to benefit the adult. If authority is granted, the managers will be able to manage funds up to a specified amount and use the money to purchase goods or services, which contribute to the adult's comfort. The Supervisory Body will strictly monitor any use of the resident's funds.

Part 5 Authority to Treat - Implemented July 2002, reviewed in 2004 and amended with effect from October 2005.

The Act allows treatment to be given to safeguard or promote the physical or mental health of an adult who is unable to **give or refuse** consent because they lack capacity to make decisions about the specific treatment being proposed.

Part 6 Intervention and Guardianship Orders - Implemented April 2001

Individuals, usually relatives or carers, (or the Local Authority if no individual applicant exists) can apply to the Sheriff Court for a Guardianship Order or an Intervention Order as detailed earlier in this learning resource.

Part 7 Contains miscellaneous provisions - Implemented April 2001

This part includes a collection of sections regarding existing processes and how they are included in the Act. For example, people appointed as **Curator Bonis** and **Tutors Dative**, which were terms used previously for people who had some financial and/or welfare powers given to them by the courts. Under the Act, these people automatically became Continuing and/or Welfare Guardians.

This part also makes clear that it is an offence (punishable by up to 2 years in prison) to neglect or ill-treat an adult who lacks capacity.

Additional Safeguards

An **advance statement** sets out the way a person wishes to be treated, or not treated, for mental disorder in the event of becoming mentally unwell and unable to make decisions about their treatment. It is intended to improve the person's participation, in line with the principles of the Act and requires tribunals and others providing treatment to take account of the past and present wishes and feelings of the person. It is one potentially important way of recording these wishes. An advance statement can be made by anyone, even if they are under 16, as long as they understand what they are putting in the statement and the effect it may have on their care and treatment in the future. In order for an advance statement to be valid it must be in writing, signed and witnessed by an 'appropriate' person as outlined in the Act.

A **personal statement** can be attached to an advance statement but does not have the same effect in law. It sets out what the person would like to happen if they, for example, have to go into hospital. Things like what to tell their employer, care arrangements for pets and other domestic matters can be included. It is helpful if a personal statement is signed and dated, but there is no requirement for a personal statement to be witnessed.

Independent advocacy supports a person's right to have their own voice heard in decisions made about their health and well being if, for whatever reason, they find it difficult to put their own case to service providers, or do not feel in a strong position to exercise or defend their rights. It is particularly helpful for people who are at risk of being mistreated or ignored, or who wish to negotiate a change in their care, or are facing a period of crisis. The Act makes it a right for people who have a mental disorder and places a duty on NHS Boards to ensure it is provided.

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