

Dementia Care in the Emergency Department Learning Resource





Section one

Initial contact



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Special Considerations

- Consider your communication methods
- Adopt a calm and unhurried approach
- Involve the supporter in your care
- Reduce the person's waiting time if you can
- Minimise multiple moves and relocations

Introduction

- There are approximately 82,000 people with dementia living in Scotland (Scottish Government, 2010).
- The number of people in the UK with dementia is estimated at 683,597 and this is expected to rise to 940,110 by 2021 (Knapp and Prince, 2007).
- There are estimated to be 298,867 attendances, by people who have dementia, at Emergency Departments in the UK each year (Luengo-Fernandez, Leal, and Gray, 2010).

Dementia is considered to be a disorder of later life, although it can affect people of any age. This condition can last for several years and the journey of the person with dementia can vary considerably. Despite this being a long term condition most people live well with dementia for much of this journey.

Dementia is not a single disease but a collective term used to describe a large number of degenerative brain disorders that are characterised by impairment in cognition, behaviour and mood. These disorders range from the most common, such as Alzheimer's disease and vascular dementia, to less well known presentations. Each of these different types of dementia causes different changes in the brain and can cause different responses in the person affected. In addition, no matter what type of dementia the person has this happens to a person and that person's personality and life experience will often contribute to how they appear to you and how their condition progresses.

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Remember:

The person with dementia is an individual



We do not like the terms “dementia sufferer” or “suffering from dementia”, or “dementia victim”. These are demeaning and portray us in a negative light.

You would not want your love ones spoken about in such disparaging terms. Sadly the media love these terms, despite my protests, and I cannot blame people for being misled into using derogatory language also.

I did likewise at one time, and could kick myself for my insensitivity. Use “person with dementia”, or “people with dementia”, or “affected by dementia” please, thank you.

Mr. James McKillop
A person with dementia

This link below will direct you to a series of brief video clips from DementiaEd that may help you understand the effects of damage in different areas of the brain that result in dementia. http://www.youtube.com/profile?feature=iv&annotation_id=annotation_758333&user=DementiaEd#p/u/4/hDtQLhv4s50

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 of being a person with dementia who attends the emergency department is vital for making that experience better for all involved. This starts as soon as the person arrives.

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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?

This activity can feel very like an emergency department visit to the person with dementia and their feelings and actions may be the same as yours might be in that imaginary situation. The difference is that the person with dementia does not have the advantages you have to enable them to manage all the challenges of a strange environment.

So what can be done to make this experience less challenging for the person with dementia?

Remember:

Communicate carefully and involve the supporter right away.



Communicate carefully

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.

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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 you 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 severe stage of dementia the person may not understand words at all, but they do still recognise facial expression

and tone of voice. A gentle tone means 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. More about Christine can be found at: <http://www.alzheimers.org.au/Search.aspx?ustems=christine%20bryden>

"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

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Communication that could disadvantage the person with dementia

The following are some of the ways that we can disadvantage the person with dementia and indeed some of these would challenge any patient. Most people would manage to overcome these challenges but the person with dementia is likely to become more stressed and distressed if they are subjected to these. It is therefore important to avoid:

- 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.

Involve the supporter right away

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

Another thought

You are back in the airport, but this time you have a good friend who speaks the local language fluently and has brought a big bag with sandwiches and coffee.

- How do you feel now?

Sometimes the person with dementia arrives alone at the emergency department and it is important to contact a supporter as soon as possible. Meantime one person should be assigned to the person in order to make them feel safe.

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Practice Point

The Alzheimer's Society in collaboration with the Royal College of Nursing has produced a leaflet called 'This is Me'

http://alzheimers.org.uk/site/scripts/download_info.php?fileID=849

This could be used for information where there are no immediate supporters available for the person with dementia.

Section two:

Assessment



Section two: Assessment

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Special Considerations

- Minimise multiple assessment and reassessment
- Establish what is normal for the person with dementia
- listen to the concerns of the patient and supporter
- While managing physical problems, remember to observe and respond to behaviour and emotions

Introduction

If the person with dementia has a diagnosis of their condition and the staff know about this, their care needs can be addressed following the information in this resource. The situation for emergency department staff becomes more complicated when:

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

Just having a diagnosis of dementia will increase the person's risk of delirium five-fold and it is suggested that some two thirds of people with dementia in an acute setting will have delirium (The Royal College of Psychiatrists, 2005).

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

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Recognising dementia

Front line identification of possible dementia is vital to ensure that the older person receives the appropriate care in both the short and long term from both health and social care provision. 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, staff in the emergency department have a role in identifying the person who they suspect may have dementia and making sure that this is communicated to G.P's and medical staff. They also have a vital role to play in the identification and treatment of illness or injury which is causing delirium.

Practice guide to assessment of the person with dementia

- Carry out the assessment in a quiet, calm area.
- Ensure the person's supporter is with them at all times.
- Try to arrange that **one person** works with them during their time in the department.
- Try not to move the person to different areas in the department.
- **ASK** what the person needs, **LISTEN** to those needs and then **EXPLAIN** what is happening and going to happen at each step of the procedure.

- When recording details provide a full description of what you see and hear. Avoid interpreting behaviour and putting a label on it. Full descriptions aid assessment, communication and care delivery. Describing someone as agitated, for example provides very little information from which to care for that person.

Remember:

AIE

Ask, listen and explain

AIE



Practice guide to communication with the person who has dementia

The person with dementia benefits from a more focussed approach to communication. All of these key skills will make communicating much easier for you and the person with dementia. During assessment the person with dementia can often give good information but simply needs more help to provide this.

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Click on the keys to learn more:

Remember:

A little time spent can mean
a lot of time saved



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

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Understand what is normal for that person

In order to identify the presence of dementia or delirium all members of the Emergency Department team need a rapid understanding of what is normal for that person. The main sources of this information is the person themselves, the family, informal and formal carers. Asking the right questions and listening for informal or formal reports of symptoms provides the keys to identification and appropriate care delivery.

Practice Point

- Does this person already have a diagnosis or a history of dementia or delirium?
- Is the person able to give a good history, or do you need a carer present?
- What are the normal behaviour, 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 which is different or unusual for the person which the carer or others have noticed?

Screening for cognitive impairment and delirium

Screening in emergency departments is concerned with minimising risks, reducing the number of moves within the hospital, avoiding unnecessary admission and delivering appropriate care.

Cognitive impairment

The person may present with a known diagnosis of dementia. There may be difficulties when the person has no diagnosis but the clinical picture suggests dementia. Screening cannot be carried out for dementia as the diagnosis is too complex. Therefore most screening tools are used to identify the presence of cognitive impairment. 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. So 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 by the G.P. and Mental Health Services. The contents of this resource can be also used to care for the person who has cognitive impairment.

You may already have a screening tool in use and if this is effective then it is not recommended you change it. The screening tools contained in this resource are suggestions for you to consider.

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Screening for Cognitive Impairment: The Four Item Abbreviated Mental Test (AMT4)

The four Item Abbreviated Mental test has recently been found to be as effective as the 10 point AMT screening for cognitive impairment (Schofield et al 2010).

AMT4

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

The AMT4 should only be used if the presence of delirium has been clearly ruled out by appropriate screening and physical assessment.

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. This could be carried out in the hospital or in the community if discharge home is seen to be safe and appropriate.

The Mini Mental State Examination (MMSE) is another widely used measure of cognitive function and may be preferred by clinicians in your area of care. It is desirable to have some training to use this method.

Remember:

When working with an older person who seems confused, including the person with dementia,
THINK DELIRIUM!



A definition of delirium:

- Delirium is a clinical syndrome which has disturbed consciousness, cognitive function or perception as its key symptoms. Delirium can be hyperactive or hypoactive.
- Hypoactive delirium causes a slowing down, reduction of consciousness and reduced speech or interaction.
- Hyperactive delirium causes the person to experience physical and psychological agitation, the need to move, speak quickly and have significantly reduced concentration

Symptoms of delirium:

- Disturbance of consciousness.
- Reduced awareness of the environment.
- Reduced ability to focus.
- Maintain or refocus attention.
- Memory deficits.
- Disorientation.
- Language difficulties.
- Perceptual difficulties **particularly vivid hallucination, illusions and delusions.**

Of course these screening tools are only intended to support your clinical assessment and must be used in conjunction with information from the person, the supporter and others.

An interesting new development is the 4AT tool , although still to be validated this may prove useful as an alternative to the current methods

Screening for delirium

The short Confusion Assessment Method (CAM) has been found to be valid in identifying delirium and requires the presence of Features 1 and 2 and either 3 or 4 as outlined.

- Feature 1. Acute onset and fluctuating course
- Feature 2. Inattention
- Feature 3. Disorganised thinking
- Feature 4. Altered level of consciousness

Section three:

Intervention



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Special Considerations

- Work in partnership with the patient and supporter
- Minimise pain and discomfort.
- Ensure food and fluids are offered.
- Reduce time spent in brightly lit or noisy environments
- Respond to calling out or cries for help in a calm and comforting manner
- Always seek permission to proceed with an intervention
- Respond appropriately to agitated, suspicious or aggressive behaviour
- Involve specialist staff if needed

Introduction

Before you begin this section take a moment to think again how being treated in the emergency department might affect the person with dementia. We all experience stress at some time and for the person who has dementia that stress can be overwhelming leading to distressed and perhaps behaviour which is challenging for staff.

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?

Communication Challenges

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 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 area of the brain are damaged and a variety of

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communication challenges are the result. These may include some of the following.

Click on the keys to learn more:

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

Mr. James McKillop
A person with dementia

Stress and the person with dementia

Stress is a very important and often underestimated aspect of the experience of dementia. Consider the scene that can face an older person with dementia being treated in the emergency department. The person has memory and other thinking problems; compounded by the noise and bustle of a busy emergency department and the added impact of pain, feeling unwell or perhaps injured.

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The following are the main sources of stress for the person with dementia in the A&E. Click on the keys to learn more:



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.

Distress and the person with dementia

If stress is not reduced or managed for the person with dementia the result can be what is often termed challenging behaviour. This term can give the wrong impression however because it can be perceived as the person behaving in a way that is a direct challenge **to** staff rather than the person's behaviour being a challenge **for** staff. The term used here is one that perhaps provides a better picture of the experience of the person with dementia; distressed behaviour.

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. Given below are some approaches to distressed behaviour that may be of assistance to emergency department staff trying to provide care and treatment. 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.

Remember:

All distressed behaviour is a way with communicating with you



The following are a range of responses you may see in the distressed person with dementia. Click on the keys below and on the next page to learn more:

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 to respond to an aggressive reaction.

- Try and find out what is upsetting them
- Reduce the stress or demands made on them
- Explain what is happening frequently using their name and explain 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 supporter if available; they may know how to manage the situation.

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- Do not make sudden movements or use a sharp tone, remain calm and keep your voice low. .
- Give the person plenty of space and do not stand between them and any exits from the room,
- Leave them for a few minutes, if you can do this safely, to let them calm down.
- It is generally better not to give medication for this behaviour unless absolutely necessary as this can increase confusion and make the situation worse.
- If they grab or pull you, do not try to resist them, instead stay calm and ask them to release you.

Using medication to manage distress in the person with dementia?

These medicines are usually from the neuroleptic or anti-psychotic groups. Medication to manage distressed behaviour is normally used for people with dementia or delirium in the Emergency department for three reasons:

- It is the person's regular medication.
- To manage safety and risk, when the person is posing a risk to themselves or others.
- To reduce stress and distress when all other interventions have proved ineffective.

There is guidance which recommends appropriate use of medicines for these reasons, which can be found in the links below. Caution must always be employed in the use of neuroleptic or anti-psychotic medicines with people with suspected dementia and many older people due to the risk of serious side effects.

There is no medication that will work in every situation. It can be useful to consider pain relief before using other medicines to manage distressed behaviour. The most commonly used medications for managing distressed and disruptive behaviour in dementia are the typical antipsychotic or neuroleptic medications such as haloperidol. While there is some indication that this medication can have an effect in reducing distressed behaviour it has a number of unwanted effects that may suggest caution when considering this approach.

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 in

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the emergency department can be unbearable to the person with dementia.

Because of this it is important the presentation of the person with dementia 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 patients, supporters and staff in the journey through the emergency department.

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.

Just a thought

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.

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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?

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.



Section four:

Resolution



Section four: Resolution

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- If the person has to wait is there a plan to support them?
- Is there an effective discharge plan in place?
- Has time been spent explaining the next move to the patient and supporter?
- Have arrangements been made to forward relevant information to the next care agent?

Introduction

When the person with dementia has been satisfactorily treated, there are often issues about where they are to go and when they will be able to leave. This will vary from the person who came into the emergency department with a supporter from their own home, and are able to return home immediately after being treated, to more complex situations. This may result in the person having to be prepared for hospital admission or waiting for various time periods for supporters to arrive, or transport to be available, to take them back to their place of residence.

The person with dementia, who is seen, treated and discharged

The person may not have come into the department with information about any diagnosis of dementia but any concerns, assessments and information you have gathered must be passed on to the G. P. or staff of the ward or care home. It could be that you are the first professional to suspect that the person may have dementia. Passing on information about the person to wards, including if they have dementia, is vitally important. Some hospitals use flag systems. What happens in your emergency department?

Another way to do this is to have some simple indicator for dementia on the person's notes. One department uses a butterfly sticker. No matter what

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system is used it must be clearly understood by all those who are involved in the care of the person with dementia.

When the information is clearly passed to others, this ensures the person who has dementia is given the chance to have the same high quality care that you have provided in your department.

The person with dementia who has to wait:

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 be able to find their way around a busy emergency department.

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

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?

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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

A quiet environment in the emergency department

It would be ideal for the department 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.

Just a thought

- Is there an area in your department that is not used all the time?
- Do you have any area that is not constantly bypassed by people?

Walk around your department this time.

- Is there an area in your department that is not used all the time?
- Do you have any area that is not constantly bypassed by people?

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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 supporter 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.

Written communication

Finally, if the person needs to have written instructions or information before they leave. Below are examples of different type faces and sizes for notices, letters or information:

Practice point

Check these three examples for 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?

Caring for and treating the person with dementia in the emergency department can be a challenge, for the person, the supporter and the staff. The person with dementia and their supporter have very little control over those challenges and depend on the staff to make their journey as positive as possible. This resource contains some key information that could help staff facilitate that journey.

Appendices



Disorders that may cause dementia

The different disorders that may cause dementia can result in different structural and chemical changes in the brain. This can have an impact on the person's behaviour, responses and communication. Having some knowledge of these can improve the interventions offered to the person with dementia. Therefore, one of the keys to treating and caring for the person with dementia is to have some understanding of the syndrome of dementia as well as the person who experiences this condition.

The most common diseases that cause dementia will be described here, these are: Alzheimer's disease, vascular dementia, dementia with Lewy bodies and fronto-temporal dementia.

What happens to the brain in Alzheimer's disease?

There are two key neuropathological processes that are linked with Alzheimer's disease; these are called senile plaques and neurofibrillary tangles. Although these usually occur in the ageing brain, their presence is increased in Alzheimer's disease. Senile plaques are formed from abnormal deposits of β -amyloid protein, forming a round, hard area; these areas accumulate and spread progressively throughout the brain.

Neurofibrillary tangles are caused by an accumulation of the protein tau which creates abnormal paired filaments in the nerve cell. In

Alzheimer's disease these damaged nerve cells eventually die; it is estimated that this can occur to as much as 30% or more of the nerve cells in the brain of the person with Alzheimer's disease.

Cell death begins in the limbic system and the first symptoms appear in disturbances of memory and learning. Later in the course of the condition changes in behaviour occur. Typically Alzheimer's disease progresses from the temporal to the parietal then occipital regions in the cerebral cortex causing visual impairment, deterioration of language (aphasia), motor skills (apraxia) and perceptions (agnosia).

When the damage progresses to the pre-frontal area of the brain, this can lead to apathy, impaired insight and lack of judgement; followed by repetitive language and behaviour and inefficient problem solving. There are a number of neurochemical changes that occur in Alzheimer's disease, the most prominent is in the cholinergic system governing brain functions such as perception, learning, cognition and judgement. This may result in symptoms such as visual hallucinations. This deficit in the cholinergic system may also be found in the other types of dementia explained here.

What happens to the brain in vascular dementia?

This is the next most common cause of dementia there can be an overlap between Alzheimer's disease and vascular dementia. For the person who has both conditions there may be a mixture

of symptoms from both conditions. Vascular dementia is caused by degeneration of the arteries in the brain. The result is that the person's arteries narrow or develop ulceration of the surface. This is the cause of the multiple small infarcts that lead to the pockets of damage in the brain of the affected person. The site and number of these infarcts create clinical signs dependant on the areas of the brain affected. This can include an unsteady gait and frequent falls. Vascular dementia is often described as like going down steps with sudden periods of deterioration and then periods of relative stability.

What happens to the brain in dementia with Lewy bodies?

Lewy bodies are abnormal spherical bodies that are found in the nerve cell. They are associated with nerve cell loss and if these occur widely in the cerebral cortex they can result in a dementia. This type of dementia can be easily confused with delirium as it can have a fluctuating presentation, where attention and alertness can fluctuate rapidly. The person with Lewy body dementia can experience vivid and detailed visual hallucinations. Because there is some link to Parkinson's disease they may also exhibit some of the clinical signs of that disorder and share the same risk of sensitivity to the neuroleptic group of medicines. These medicines are commonly used to calm and manage agitation and disturbed behaviour in the person with dementia and they can have a devastating effect on the person who has dementia with Lewy bodies.

They increase agitation, the risk of hallucinations and can cause movement disorder.

What happens to the brain in fronto-temporal dementia?

Those people affected by fronto-temporal dementia can be a younger age group than other dementias, generally occurring in the middle years, and happens equally in males and females. This form of dementia is the result of nerve cell loss on the frontal and temporal lobes of the brain. The frontal lobes of the brain are associated with making decisions and controlling behaviour; the temporal lobes with emotion and language. The clinical signs shown by the person with fronto-temporal dementia can be very dramatic and they may not show any of the conventional memory impairment of dementia until the disorder is advanced. The person is likely to be disinhibited, impulsive and restless; can be tactless and lack any insight into their condition. They may have progressive difficulty speaking but may understand words spoken to them.

These four disorders are only a fraction of those that can result in dementia, however, other conditions are considerably rarer. No matter what causes the dementia the result is damage to various aspects of brain function. Some of the responses, behaviours and reactions of the person with dementia can be the result of that damage to particular areas and functions of the brain. Some knowledge of these effects can make the behaviour and responses of the person more understandable.

However, understanding the impact of local damage to the brain is a rather simple explanation of some of the responses and reactions of the person with dementia. These physiological changes are considerably complicated by the person's physical health, their environment, the people in that environment and the individual's personality and history.

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. Importantly, use the person's name when you address them. It is very helpful to remind the person who you are each time you return to them and at frequent intervals while you are caring for them. This ensures they do not become alarmed at this apparent stranger trying to carry out interventions with them. Using the person's name may help them understand that you know them and are not a stranger; this can be very reassuring. Frequently repeating who you are may feel rather artificial but it will remind the person that they are with a professional who is caring for them. Older people tend to be respectful of health professionals and this makes it very important that they are aware of who you are.

Keep the noise down

Reduce distractions around you where you can; such as activity and noise. 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 cooperate 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; then give them the same time to answer. 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 more comfortable with you. It is important to remember that the person with dementia, no matter how severely impaired, 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.

Use the correct words

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

It is vital that you are specific in your language; using full names rather than pronouns and giving clear instructions. For example rather than saying 'sit there' you could try saying 'sit in this blue chair'. Humour can be a very useful way both of communicating and defusing tense situations, however it must be used very carefully as it can misfire particularly where the person with dementia has been unable to process the subtle or complex message involved. A smile is almost always effective in smoothing the communication pathway.

Delirium is a medical emergency for many older people, particularly in the presence of the following risk factors:

Risk factors for Delirium:

- Dementia, which can increase the risk of developing delirium five-fold.
- Sepsis
- Dehydration
- Sensory Impairment
- Constipation
- Hypoxia
- Severe physical illness
- Urine/chest/ear infection
- Incontinence of urine and faeces
- Older age
- Fracture/ surgery, particularly hip fracture
- Frailty
- Polypharmacy (four, or more, prescribed medications)
- Excess alcohol
- Pain
- Renal Impairment

Delirium is frequently precipitated by:

- Immobility.
- Catheterisation.
- Some medicines (especially analgesics, psychoactive drugs, those with anticholinergic side-effects).
- Severe and or multiple illness.
- Intoxication (alcohol, drugs, medicines).
- Physical restraint.
- Malnutrition.
- Dehydration.

Some consequences for the person of untreated or undertreated delirium

- Increased risk of developing dementia.
- Increased time in hospital.
- Increased rates of admission to long term care.
- Death due to falls.
- Death due to malnutrition and dehydration.

Identifying those at risk of developing delirium

You may have older people whom you are working with who have no disturbance of mental capabilities and functioning but do have all the risk factors as described above. So do always consider delirium prevention in the older person.

Appendices: key seven

There are guidelines on Interventions to prevent Delirium in the National Institute for Clinical Excellence (NICE) (2010) guideline 103 page 6 which are accessible and easy to use.

<http://guidance.nice.org.uk/CG103/QuickRefGuide/pdf/English>

Co-morbidity Issues

It is not uncommon for an older person to present with multiple physical healthcare needs; the same can be said for mental health care needs. It is known the people can present with:

- 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)

Remember:

For immediate care, the principles remain the same; identify and treat the delirium first



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.

[Click here to view a guide to Dementia and Delirium](#)

More information

The Let's Respect website contains more useful information about delirium including podcasts.
<http://www.nmhdu.org.uk/nmhdu/en/our-work/mhep/later-life/lets-respect/lets-respect-podcasts/lets-respect-delirium/>

Appendices: key seven

Areas of identification	Dementia	Delirium
History	Slow onset over months and years.	Recent sudden onset.
Course	Progresses slowly, symptoms generally stable on a day to day basis.	Disturbance in presentation develops over a short period of time and fluctuates over the course of the day.
Awareness, alertness, attention.	Usually unaffected.	May be significantly worse in the evening and at night.
Sleep/wake cycle	Each person may have their own sleep wake cycle which will be generally stable.	Reduced awareness, changing alertness, very alert or not alert, short attention span, easily distracted, lots of apparent undirected activity.
Psychomotor presentation	Generally unaffected, unless in the presence of Lewy body Dementia or Parkinson disease	Sleep may be significantly disturbed from the person's normal pattern, with no obvious pattern in the short term.
Perception	Possible experience of hallucinations and delusions.	Hyperactive-speeded up or agitated or Hypoactive-slowed down.
Physical function	Slow progressive changes in physical function, co-ordination,	May see/hear/feel things vividly that are not there. May appear frightened or distressed by these experiences. May appear paranoid
Memory	Short and immediate memory reduced. Difficulty in learning new information.	Sudden loss or change in normal physical functioning such as sudden incontinence, falls or clumsiness.
Thinking	Reduced problem solving abilities, reasoning and ability to understand abstract concepts.	Reduced immediate and short term memory.
Speech	Ability to name things, find words or engage in long conversations difficult.	Disorganised, leaping from one subject to another.
Causes	Dementia is an overarching word for a group of illnesses whose origins are based in organic changes in the brain. Alzheimer's disease, Vascular Dementia, Lewy Body Dementia	Significantly different to reported normal for that person, very loud, upset, angry or quiet, slow, difficult to understand.

Appendices: key eight

(Adapted from Inouye et al., 1990)

Patient's Name: _____ Date: _____

Instructions: Assess the following factors.

Acute Onset

1. Is there evidence of an acute change in mental status from the patient's baseline?
___ YES ___ NO ___ UNCERTAIN ___ NOT APPLICABLE

Inattention

(The questions listed under this topic are repeated for each topic where applicable.)

- 2A. Did the patient have difficulty focusing attention (for example, being easily distractible or having difficulty keeping track of what was being said)?

_____ Not present at any time during interview
_____ Present at some time during interview, but in mild form
_____ Present at some time during interview, in marked form
_____ Uncertain

- 2B. *(If present or abnormal)* Did this behavior fluctuate during the interview (that is, tend to come and go or increase and decrease in severity)?

___ YES ___ NO ___ UNCERTAIN ___ NOT APPLICABLE

- 2C. *(If present or abnormal)* Please describe this behavior.

Disorganized Thinking

3. Was the patient's thinking disorganized or incoherent, such as rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable, switching from subject to subject?

___ YES ___ NO ___ UNCERTAIN ___ NOT APPLICABLE

Altered Level of Consciousness

4. Overall, how would you rate this patient's level of consciousness?

_____ Alert (*normal*)
_____ Vigilant (*hyperalert, overly sensitive to environmental stimuli, startled very easily*)
_____ Lethargic (*drowsy, easily aroused*)
_____ Stupor (*difficult to arouse*)
_____ Coma (*unarousable*)
_____ Uncertain

Appendices: key nine



(Label)
Patient name:
Date of birth:
Patient number:

.....

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

Date: _____ Time: _____
Tester: _____

CIRCLE

[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

[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

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).

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.

Speaks in what seems to be nonsense

Listen for any specific words or phrases they keep repeating and try and 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.

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.

The use of validating or listening to feelings rather than words can be very helpful where the person is distressed and becoming agitated. If the person for example wants to go and find her mother, it should be remembered that most people would consider that our mother would be a safe person, someone who could protect you and make things better. An understanding of the feelings behind the words the person is using can guide staff to respond differently.

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. The repetition may not be within the person's control and it may be more helpful to use distraction instead

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. The use of photographs or other images can be invaluable here and these can also be used for other patients who may have difficulty expressing their needs.

Tiredness

Tiredness and fatigue is 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, light, 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 and novelty in their 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; supporters 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

Finally and most importantly in the Emergency Department setting all of the demands on the person with dementia are made worse by their current physical health care 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.

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 stage 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.

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 the stages of the disorder 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 patient 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 in words about their pain 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 carers or their behaviours may only be interpreted in the light of their dementia. Some communication problems also lead to problems in their ability to self-report their needs.

Clinical history is always extremely important but sometimes accessing this is difficult. Information may be missing or incorrect, there may be supporters attending with them who do not know them well and the person with dementia may simply be unable to provide any reliable history.

Where these are available, collateral reports from family and friends especially about the person's usual behaviour when experiencing pain are helpful, as are the current carer's reports.

Observation of the person is a primary element of assessment however this can be confounded by the behaviours exhibited by the responses and behaviours in the later stages of the disorder in a strange environment such as agitation, aggression and shouting. These behaviours can be easily mistaken for those that may result from the person's mental state and as a result may be treated using neuroleptics medicines, such as haloperidol.

Care in assessment is crucial to the appropriate treatment and management of pain. There are a number of assessment tools available to assess pain in the non-verbal person with dementia and one of these is the Abbey Pain Scale.

[Click here to view the Abbey Pain Scale](#)

This is an observational rating scale and can be a very useful addition to the assessment processes used for detection of pain.

There is limited research available about the detection and management of pain for the person with dementia in the general hospital. One of the best known is a randomized controlled trial by Morrison and Sui (2000) who found that 76% of people with dementia did not receive regular post operative pain relief following surgery related to hip fracture. Furthermore, they only received one third of the pain relief offered to the cognitively

intact older adults in comparable conditions who were able to express their pain experience. These findings reinforce how challenging the pain experience can be for the person with dementia.

Appendices: key twenty

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:

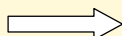
Name and designation of person completing the scale:

Date: **Time:**

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

- Q1. Vocalisation**
eg: whimpering, groaning, crying **Q1**
Absent 0 Mild 1 Moderate 2 Severe 3
- Q2. Facial expression**
eg: looking tense, frowning grimacing, looking frightened **Q2**
Absent 0 Mild 1 Moderate 2 Severe 3
- Q3. Change in body language**
eg: fidgeting, rocking, guarding part of body, withdrawn **Q3**
Absent 0 Mild 1 Moderate 2 Severe 3
- Q4. Behavioural Change**
eg: increased confusion, refusing to eat, alteration in usual patterns **Q4**
Absent 0 Mild 1 Moderate 2 Severe 3
- Q5. Physiological change**
eg: temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor **Q5**
Absent 0 Mild 1 Moderate 2 Severe 3
- Q6. Physical changes**
eg: skin tears, pressure areas, arthritis, contractures, previous injuries. **Q6**
Absent 0 Mild 1 Moderate 2 Severe 3

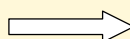
Add scores for 1 – 6 and record here



Total Pain Score

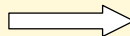
Now tick the box that matches the

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
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Dementia Care Australia Pty Ltd
Website: www.dementiacareaustralia.com

Agitated behaviour

This response is an indicator that all is not well with the person who has dementia. Where the person has a decline of their communication skills then agitated behaviour can be their 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 the behaviour is sought.

In particular agitation can result from delirium caused by infection, polypharmacy, injury or pain. Where an older person with dementia is showing agitated behaviours then it is vital to exclude physical causes. The person with dementia in the Emergency Department presenting with agitation is likely to be experiencing a physical cause for this behaviour rather than this being caused by their dementia.

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

Agitation and aggression behaviours are not the same. Agitated behaviour tends to be pacing,

restlessness, lifting and moving items and undressing inappropriately. Verbal behaviours can include repetitive questioning and constant requests for attention.

Agitated behaviour can have serious consequences for the person with dementia as they can pose a risk both to themselves and others in the environment. At the very least the person can cause disruption and delay to their care and treatment.

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. Try not to be insensitive when you respond, don't say things like, "I've already told you that" as this can increase the person's feelings of anxiety. Try helping them to find the answer for themselves. For example if they keep asking where they are, try prompting them to look at your uniform and badge and reminding them in words and by cues that they are in hospital.

If they are too distressed for this then try and distract them or encourage their supporter to do so. Distraction can be a very effective way of managing a number of distressed behaviours in dementia. The general idea is to talk about something that is not related to what is distressing the person. It is important to use short and simple sentences and to stay calm. Use events happening around them or something in another part of the department. The main aim of distraction is to try and re focus the person on to something that is less distressing or anxiety provoking.

If you find yourself becoming irritated by their repetition it can help to leave them with someone else for a short time until you feel more responsive. The person can also become stressed by future

events such as going to x-ray departments. In this case it is often better to tell them about this just before it happens so they don't get anxious and worried.

Repetitive phrases or movements

Some people repeat the same phrase or movement time after time. This is called perseveration. This can be caused by physical discomfort and is made worse when the person is in pain or unwell. It can also be exacerbated by the demands of noisy, busy environments. Treating the person's physical condition and reducing the demands of the environment may help. There are times you can do little about this.

Repetitive behaviour such as moving the chairs around or trying to empty bins or trolleys can be caused both by anxiety or boredom. Having something safe for the person to occupy themselves with may help here.

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. They may perceive the examination couch as a bed and be trying to get into bed to sleep.

Sexually inappropriate behaviour such as inappropriate touching or touching their genitals should be gently discouraged and some assessment of the person providing care should be made. Perhaps a male staff member would be more appropriately perceived by a male patient. It is also helpful for the member of staff to repeat frequently who they are and what the person with dementia is doing in the department.

When the person with dementia has to wait for a period in the Emergency Department they may become restless and begin to pace around. They may simply be hungry, thirsty, need the toilet or are in pain and be unable to express this. They may simply feel unwell. The noise and busyness around them may be upsetting them. If you have tried to deal with all of these then it may be helpful to try and find a quieter area for them if possible and let them move around safely.

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. It is therefore useless to argue with these beliefs. Of course it is also important to check the truth of any assertions the person may make but if these are clearly untrue then it is equally important to support the person with dementia who is likely to be very distressed by these beliefs. 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. Distracting them rather than discussing their beliefs and reassuring the person that you are there to help may ease the situation.

Misperceptions and hallucinations

Visual hallucinations are often associated with more severe 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.

The person may see hear or feel things that are not there. This can be a misperception of something in the environment or an effect of the damage to their brain. Misperceptions are common, particularly when the person has visual or hearing impairment and is unwell or injured in addition to their dementia. The Emergency Department environment is full of strange equipment and sounds for the person with dementia and can easily be misunderstood by them. It is important to assess the environment first 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. This may be enough to resolve the problem.

However, sometimes the person with dementia does experience hallucinations due to the changes occurring in the brain. Visual hallucinations occur most often in those people who have Lewy body dementia. This will usually be accompanied by

slowed, stiff movements, frequent falls and a variation over the day in the ability of the person to do things for themselves.

Auditory hallucinations are when people hear noises or voices that are not there, this can cause the person not only to talk when no one is there but they can become disruptive and shout at the object or person. This is less likely to be troublesome if there is a real person there to distract them and talk to them.

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. It can seem that a very minor incident can set off a catastrophic reaction. However if the situation is seen through the eyes of the person with dementia, the reaction can become understandable. Aggression can involve kicking, hitting, throwing objects, swearing and screaming. It must be borne in mind, however, that for the older person with dementia who finds themselves in a strange environment with people they do not know who are physically touching and treating them, the aggression they exhibit may well be an understandable response.

Using medication to manage behaviour in the person with dementia

The report Counting the Cost by the Alzheimer's Society (2009), contains a survey of nurses working in general hospitals. 77% of these nurses reported that antipsychotic medication was used for people with dementia in hospitals. A government report by Professor Sube Bannarjee in 2009 states that approximately 180,000 people with dementia were prescribed neuroleptic or antipsychotic drugs every year but only 36,000 showed any benefit. Unwanted events following these medicines being prescribed included 1,800 deaths a year and 1,620 cerebrovascular events will result. He suggest that while there are some people with dementia who benefit from these medicines that their positive effect is limited and they carry considerable risk for this vulnerable population. The non-pharmacological approach described in this resource is suggested as an alternative whenever possible.

There is a useful discussion on the use of haloperidol for dementia in a Cochrane systematic review at:
<http://www2.cochrane.org/reviews/en/ab002852.html>

The atypical antipsychotic or neuroleptic medicines such as Olanzapine and Risperidone are not currently recommended due to risk of serious unwanted effects especially stroke.

Further guidance on the pharmacological management of behaviour in dementia can be found in SIGN guideline 86 at:
<http://www.sign.ac.uk/guidelines/fulltext/86/index.html>

Improving the environment for the person with dementia

Most acute hospital settings are not supportive environments for the person with dementia, however, modifying these environments can be challenging. While we cannot change the person with dementia, we can change our environments and develop strategies to accommodate them. 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.

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 some degree by staff and can often be managed during the working day.

Remember:

Sensory overstimulation can increase agitation and confusion



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.

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. That lighting should also be direct and come from an overhead source to minimise shadows being cast over the visual area.

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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 top left has the light directly on the statue almost obliterating the features. The light from behind on the bottom left photograph casts shadows over half the image making the features hard to make out clearly.



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.



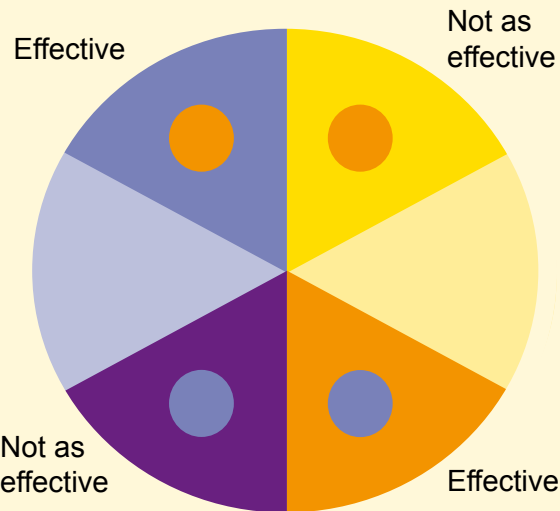
Colour and contrast

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

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likely to be preserved.

The person with dementia has sometimes additional deficits in visiospatial ability; this can cause further misperceptions. 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.



Effective



Not as effective



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.



This key point is useful in a number of ways such as:

- Cover trolleys and equipment with drapes to minimise contrasts of trolley surface and equipment, the area is less likely to be attractive to touch.
- Cover clear intravenous tubing with light bandages and loop and tape coloured tubing in an obvious place on the top. The person will pull at the coloured tubing giving time to reassure them before they cause themselves injury by pulling out lines.

These principles extend to the use of signs, where the use of strong colours and high contrast is very important to the older person with dementia.

Commercial signs are freely available and are suitable for both those with visual and cognitive impairment. For maximum impact these should include a photographic image and written words large enough to read. These should also be at an appropriate height for the person to see. Signs are often placed too high in care settings and older people in particular may not be able to raise their head high enough to see them. This is also a particular challenge for those people being transported in a wheelchair; where vision is even more limited. The person with dementia is even more disadvantaged as they are unlikely to seek out such cues unless they are obvious or they are directed by others.

Going to the toilet

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 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. 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.



Written communication

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

References and Further Reading



References and Further Reading

Alzheimer Scotland (2007) *Making decisions about future treatment: information sheet*. Edinburgh: Alzheimer Scotland Action on Dementia [online] Available: <http://www.alzscot.org/downloads/makingdecisions.pdf>

Alzheimer Scotland (2008) *Antipsychotics drugs and dementia: briefing paper*. <http://www.alzscot.org/pages/policy/antipsychoticdrugsbriefing.htm>

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

Alzheimer Society (2011) *Statistics: Number of people with dementia in Scotland 2011, Edinburgh: Alzheimer Scotland*.

Ballard, C., Clack, H and Green, D.(2007) *Postoperative cognitive decline, dementia and anaesthesia*. British Journal of Hospital Medicine Vol. 68(11), pp. 576 – 577.

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

Cox, S. and Cook, A. (2002) *Caring for people with dementia at the end of life*. In Hockley, J and Clark, D. (eds) *Palliative Care for Older People in Care Homes*. Buckingham: Open University Press.

Downs, M. and Bowers, B. (2008) *Excellence in Dementia Care: Research into Practice*. Maidenhead: Open University Press.

General Medical Council (2010) *Treatment and Care Towards the End of Life: Good Practice in Decision Making*. London: GMC [online] Available: http://www.gmc-uk.org/static/documents/content/End_of_life.pdf

Gold Standards Framework Scotland website <http://www.gsfs.scot.nhs.uk/>

Katikireddi, S.V. and Cloud, G, C. (2008) *Planning a patient's discharge from hospital*. British Medical Journal, Vol. 33, p 2694.

Keene, A. Hope, T. Fairburn, C. Jacoby, R. (2001) *Death and Dementia*. *International Journal of Geriatric Psychiatry*. Vol. 16 (10). pp. 969-974.

Liverpool Care Pathway for the Dying Patient (LCP) website http://www.mcpcil.org.uk/liverpool_care_pathway

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.

National Audit Office (2007) *Improving Services and Support for People with Dementia*. London: The Stationary Office [online]. Available: <http://www.nao.org.uk/idoc.ashx?docId=64f3ffb3-16ce-4191-8556926f58adaa7b%26version=-1>

References and Further Reading

National Institute for Health and Clinical Excellence (2006) *Dementia: supporting people with dementia and their carers*. London: NICE [online] Available: <http://www.nice.org.uk/nicemedia/pdf/CG42PublicInfo.pdf>

National Institute for Health and Clinical Excellence (2010) *Delirium: Diagnosis, prevention and management* Guideline 103. London: NICE.

National Institute for Health and Clinical Excellence (2010) *End of life care for people with dementia: Commissioning guide, Implementing NICE guidance*. London: NICE [online] Available: <http://www.nice.org.uk/media/8E6/C4/CommissioningGuideEoLDementia.pdf>

NHS Quality Improvement Scotland (2007) *Standards for Integrated Care Pathways for Mental Health*. Edinburgh: NHS Quality Improvement Scotland [online] Available: http://www.nhshealthquality.org/nhsqis/files/mentalhealth_standardsforICP_DEC07.pdf

Royal College of Psychiatrists, (RCP) (2005) *Who Cares Wins: Improving the outcomes for older people admitted to the general hospital*. London: RCP.

Sampson, E.L., Blanchard, M.R., Jones, L., Tookman, A. and King, M. (2009) *Dementia in the acute hospital: prospective cohort study of prevalence and mortality*. British Journal of Psychiatry. Vol.195 pp. 61-66.

Scottish Intercollegiate Guidelines Network/ NHSQIS (2006) *Management of Patients with Dementia*. Edinburgh: SIGN/NHSQIS.

Scottish Intercollegiate Guidelines Network/ NHSQIS (2010) *Non-pharmaceutical management of depression in adults*. [online] Available: <http://sign.ac.uk/pdf/sign114.pdf>

Schofield, I., Stott, D, J., 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.

Social Care Institute for Excellence (2010) *Pain in advanced dementia* [online]. Available: <http://www.scie.org.uk/publications/dementia/endoflife/pain.asp>

Scottish Executive (2000) *The Adults with Incapacity (Scotland) Act*. Edinburgh: The Scottish Executive [online]. Available: <http://www.scotland.gov.uk/Topics/Justice/law/awi>

Scottish Executive (2003) *Mental Health (Care and Treatment) (Scotland) Act*. Edinburgh: The Scottish Executive [online]. Available: <http://www.legislation.gov.uk/asp/2003/13/contents>

Scottish Executive (2005) *Better Outcomes for Older People: Framework for Joint Services*. Edinburgh: The Scottish Executive [online]. Available: <http://www.scotland.gov.uk/Publications/2005/05/13101338/14143>

References and Further Reading

Scottish Executive (2006) *National Training Framework for Care Management: Manager's Guide*. Edinburgh: Scottish Executive [online]. Available: <http://www.scotland.gov.uk/Publications/2006/05/17100620/0>

Scottish Government (2008) *Living and Dying Well: a national action plan for palliative and end of life care in Scotland*. Edinburgh: The Scottish Government [online] Available: <http://www.scotland.gov.uk/Resource/Doc/239823/0066155.pdf>

Scottish Government (2010) *Scotland's National Dementia Strategy*. Edinburgh: The Scottish Government [online]. Available: <http://www.scotland.gov.uk/Resource/Doc/324377/0104420.pdf>

Further reading

Adams, T and Manthorpe, J (2003) *Dementia Care*. London: Arnold

Adams, T. (ed) (2008) *Dementia Care Nursing*. Hampshire: Palgrave McMillan.

Downs, M and Bowers, B. (eds) (2008) *Excellence in Dementia Care: Research into Practice*. England: Open University Press.

University of Stirling (2009) *Caring for People with Dementia in Acute Care Settings: A resource pack for staff*.