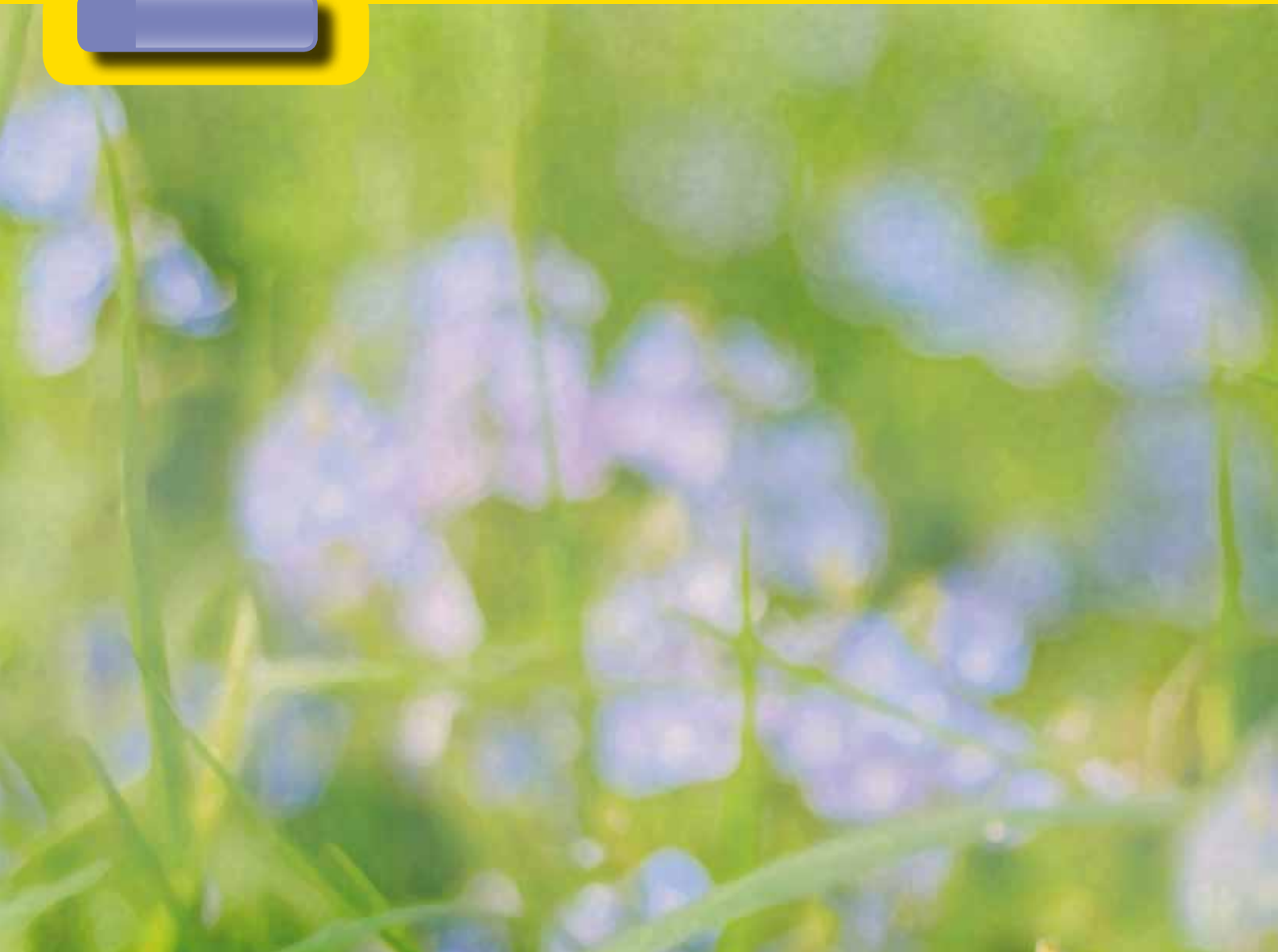


Acute Care Dementia Learning Resource





Section one:

Coming into the ward



Section one: Coming into the ward

Introduction

- There are approximately 82,000 people with dementia in Scotland (Statistics: Number of people with dementia in Scotland 2011, Alzheimer's Scotland)
- Up to one in four of all general hospital beds in the U.K. are occupied by a person over 65 years who has dementia (Alzheimer's Society, 2009).
- In a study by Sampson et al (2009) it was found that of those older people in acute wards only approximately half of those with dementia had been diagnosed before admission.

The person with dementia comes into an acute care environment for the same reasons other people do. Most of these reasons are not related to dementia but there is no doubt that this can increase the complexity of assessment, treatment, care and discharge of the person.

The hospital is a disorientating, and often frightening, place for the person with dementia, who is challenged by any change in their routine or environment. The stress of these changes, the unfamiliar environment and the constant challenge they face in understanding what is happening can overwhelm the person. This not only increases their risk of becoming distressed but can lead to deterioration in their health and well being. Prolonged stays in hospital and delays in discharge can also lead to a higher risk of the person moving

to institutional care on leaving the hospital setting. In order to change this series of events, it is vital for staff to have an insight and understanding into the needs of the person with dementia.

This section is concerned with helping you to lay the foundations to provide excellent care for person with dementia in hospital. What you do in the first few days of the person's stay can influence their whole experience and how quickly they return home. Understanding the person's life experience, values and expectations of care is essential to forming and maintaining relationships which aid excellent quality care. You have the opportunity in this section to understand the importance of knowing the person's story, applying this to care delivery and using it to support their return home. Your assessment is an opportunity to form relationships and collaborate both with the person and with their carer.

What about you?

Caring for the person with dementia in an acute ward environment can be a stressful experience at times. The busy environment of the ward, the fast turnover of patients and the complex presentation of the person with dementia can all contribute to care being a challenge for staff. A clearer understanding of how to approach care for the person with dementia, in this setting, may make the experience more satisfying for all concerned. Attached is a short survey that contains a series

Section one: Coming into the ward

of statements about dementia and you may find it useful to complete it now then return to it after you have finished working on this resource.

Just a thought

Sit somewhere safe on the ward, out of the way but near the main areas.
Close your eyes for two minutes and just become aware of the environment around you.

- What can you hear, see, smell, and feel.
- Can you manage to keep your eyes closed for this time?
- What did you notice most?
- Was the ward quiet or noisy?
- Did you feel safe and secure?
- What were the sounds you heard?

The sights, sounds, noise and smells of an acute ward can be overwhelming and frightening. In order to make this more manageable, the essence of caring for the person with dementia is knowledge of the impact of change and careful communication.

Communicate carefully

If it is an older person consider if they need dentures, glasses and hearing aids to enable them to communicate effectively as they may not be able to explain they need them. Communication skills are progressively affected as dementia develops in the person. In the early stages there may be 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.

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 dementia progresses the person may develop a range of more specific language problems. Some people experience expressive dysphasia, where they may understand

Section one: Coming into the ward

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.

As the person moves into the later stages of dementia you need to attend more carefully to communication with them. In this situation attempts to reason or disagreeing with the person 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 and it may be necessary to refer to speech and language therapy. A gentle tone means more than words here. You will again revisit communication and find more in depth guidance later in the resource.

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?usterm=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

Section one: Coming into the ward

Coping with change

The person with dementia is usually cared for at home or in their care setting by familiar people and coming into hospital will bring them into contact with a bewildering number and range of people. The caregiver at home may have established a routine with which the person with dementia has become familiar and it is important to make an effort to find out about this and try to keep at least some daily activities the same. You have the opportunity here to discover how being a carer for a person with dementia is different in so many ways, bringing its own challenges and joys.

Before reading further, view this film where the Duchess of Hamilton describes what it was like for her husband to receive general hospital care and some of the initiatives in place to support you to deliver good care.

http://www.youtube.com/watch?v=JEmD_5Jji_w

Practice Point

What you need to know from carers:

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

Knowing the person: the importance of 'My Story'

First take a few minutes to view this film where people with dementia describe their hopes, dreams and plans for the future.

<http://www.youtube.com/watch?v=WR74FEyc9KY&feature=related>

Professor Tom Kitwood introduced the concept of 'Personhood' in relation to people with dementia in the 1990s and his work remains as powerful today. The term personhood describes the very essence of humanity, of who we are. He asserted that the deterioration observed in people with dementia was not just about the illness, it was also strongly influenced by how people were treated by people and society.

One of the key concepts of his work was the person's 'Life Story' and the importance of biography. In order to understand the importance of 'knowing the person with dementia' consider these questions:

- Who among your family or friends knows you well?
- Would they know enough to help deliver your care if you were unable to express yourself?
- Would they dress you to a standard/style you would be happy with? Could they do your hair the right way? Could they shave/put your make up on in a way you would be happy with?

Section one: Coming into the ward

- Do they know all your food and drink likes and dislikes?
- Do they know your deepest fears and highest hopes?
- Do they know how you make decisions?
- Do they know what events in your life have influenced who you are now?
- Do they know that you like a good hug or hate to be touched?
- Do they know what worries you early in the morning and late at night?
- Do they know what makes you cry/scream/shout/laugh/grumble/moan?

It is very important that we involve those people who know the person with dementia well so they can help us with questions above.

Since the work of Tom Kitwood became widely known in areas caring for people with dementia further studies have been carried out and further frameworks to support the care of people with dementia have been developed.

The link below takes you to a short template which can be completed by the person with dementia and their carer, called 'This is Me'
http://alzheimers.org.uk/site/scripts/download_info.php?fileID=849

It is hoped that this or something like it, is completed before the person has to have general hospital care and is with the person when they are admitted.

Remember:

Ask if the person has a life story to help you get to know them



What should you do with the information?

Knowing the person should give you a number of opportunities:

- It enables you to form relationships based upon understanding and empathy.
- It provides context and a deeper understanding to puzzling behaviours.
- It makes sure you are able to give people what they want and need, rather than just guessing.

Section one: Coming into the ward

- It can assist with 'risk enablement' which is based on the idea that the process of measuring risk involves balancing the positive benefits from taking risk against the negative effects of attempting to avoid risk altogether. The Department of Health Guidance 'Nothing Ventured, Nothing Gained' is a very helpful resource to follow and can be accessed at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121492

Below is a list of experiences which have occurred in practice, illustrating the relevance of knowing the person. Cover up the right hand side of the table and read the behaviours first. Imagine how you would react caring for this person, then read the snapshot life history.

Behaviour

Fred went around the ward at night switching all the lights off and would scold the night staff for being up.

Mary would search the ward for her children constantly and would gain great joy when a staff member brought a new born baby to the unit.

Caroline would get up at 4am; try to leave the unit stating she needed to go to work.

Lewis hit out at staff whenever he required assistance to go to the toilet. He became upset, angry, swore and tried to use his fists against staff.

Snapshot life story

Fred was a night security worker at a coal mine all his life and was just doing his job.

Mary had a large family, totalling 12 children, some of whom died as babies.

Again, Caroline was going to start milking the cows, something she had done all her married life.

Lewis was an adult survivor of repeated and prolonged childhood sexual abuse.

Section one: Coming into the ward

How do you feel now? Would you approach their care differently? This would perhaps challenge assumption you may have about a person with dementia but always remember every person is an individual with complex life histories.

In the past, life stories and profiles may have been completed and then filed away without influencing the care provided. This information can be used to foster positive collaborative relationships between you, the carer and the person with dementia.

Working in collaboration with carers

“People who care for people with dementia, suffer higher levels of stress and ill health themselves than the general public. While many people take great satisfaction from providing care for a loved one or friend, it can also be a significant personal challenge. If there is a lack of appropriate support and the challenge of offering care becomes too great for a person to sustain, then the consequence may be that a person with dementia may need to be admitted to care.”

The Scottish Government (2010)

Having a mental disorder such as dementia or delirium is a predictor of poor outcomes for older people using hospital services. The risks to older people with dementia can include one or more of the following:

- Increase in mortality
- Increase in bed days
- Increase in adverse drug reactions
- Earlier Admission to long term care
- Incidents of new incontinence which becomes permanent
- Poorer cognitive function
- Increased levels of dependence upon return home

What does it mean to be a carer?

Some people may be clear about their caring role, introduce themselves as a carer and have positive links to support them in their role. Other carers may have taken on the role without knowing what supports are available to them. Other carers may be working exceptionally hard in difficult circumstances but may not see themselves as carers or want to be called carers.

Many carers may not ‘fit’ with the expected spouse or adult child carer you may expect. Many people under 18 years old, partners in same sex

Section one: Coming into the ward

couples and families from ethnic minority groups are providing daily care and require support to fulfil their caring role. Providing support in these circumstances will require sensitivity and a focus upon the person as central to the issues at hand.

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

Remember when working with any person who has carers, you are working within a system and what you do say will ripple out and impact on all members of that system.



What do carers want?

By collecting carers' stories we have highlighted key themes and concerns to consider for collaborative working. These concerns can be broadly split into two areas:

1. Concerns about attitude, values and understanding of hospital team members.
2. Concerns about practical issues.

Capacity and consent

The person with dementia can make a choice, be it an oral answer, a nod or shake of the head, or perhaps moving a part of their body such as a finger. The trick is to get to know how they best communicate and go down that line.

James McKillop
A person with dementia



The ability of the individual with dementia to make decisions can vary enormously. Most 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 affected by physical illness, pain or delirium.

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

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

The Adults with Incapacity (Scotland) Act (2000) offers options to help the person with dementia, a learning disability or mental illness who lack capacity to make decisions. The Act sets out guidance and arrangements for giving medical treatment and granting intervention orders to allow decisions to be made for the person about specific issues. It also provides for the appointment of welfare and financial guardians who have authority to make decisions for the person who is not able to do so.

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

- Given freely and without coercion.

- Given by a person who is considered competent.
- Specific to the intervention or procedure.
- Informed, so that the person understands what is involved.
- Is continuous for the duration of the treatment or procedure.

The Mental Welfare Commission is an independent organisation set up to safeguard the welfare of any person with mental illness, learning disability or other mental disorders including dementia. They provide advice and excellent guidance on a range of legal and good practice issues. They also have powers to ensure care and treatment is in line with the law and good practice. They also promote the principles and monitor the use of the Mental Health (Care and Treatment) (Scotland) Act (2003). There are a wide range of resources on the website to support your knowledge of capacity and consent.

<http://www.mwcscot.org.uk>

For further reading about vulnerable adults including the person with dementia, please refer to: Respecting and Protecting Adults at Risk in Scotland: An Educational Resource. NHS Education Scotland (2011).

Section two:

recognising and
assessing care needs



Section two: Recognising and assessing care needs

Introduction

It is vital to identify key risks, such as delirium, undiagnosed dementia and depression quickly, allowing you to implement effective care. Front line identification of dementia, delirium and depression is vital to ensure that the older person receives appropriate care in both the short and long term. These three conditions of dementia, delirium and depression may have a confused and blurred presentation in an older person. The older adult in hospital may have one, two or all three of these

conditions and it is important to understand each one. Diagnosis of dementia or depression usually occurs following a specialist assessment either in a Memory Clinic, by a Liaison Mental Health Service or by a Consultant Psychiatrist or Geriatrician. In the acute care environment it is important to identify and treat any physical cause of delirium and identify the possible presence of a mental health need; deliver immediate care and refer on to appropriate services.

The 3 Ds, dementia, delirium and depression: a quick guide

Domain	Dementia	Delirium	Depression
History	Slow onset weeks/years	Sudden onset	Slow onset over weeks/ months
Awareness	Usually unaffected	Distracted, reduced or changes rapidly.	May have difficulty concentrating
Sleep pattern	Stable over time	Significant change from usual pattern	Difficulty getting to sleep or waking early.
Memory	Recent memory affected. Difficulty learning new material	Immediate and recent memory difficulties	Person may say memory is worse.
Thinking	Difficulty reasoning or understanding.	Disorganised, jumping from one subject to another	Slowed. Feelings of hopelessness.

Section two: Recognising and assessing care needs

Understanding what is usual for that person
In order to identify the presence of dementia, delirium or depression, all members of the team must gain a rapid understanding of what is usual for that person. Your main source of this information may be the person, the family and carers.

When recording details it is recommended that a full description is made of what you see and hear. Try to avoid interpreting behaviour. 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.

Practice Point : key questions

- Does this person already have a diagnosis or a history of dementia, delirium or depression?
- 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 usual 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 is concerned with minimising risks, reducing the number of moves within the hospital and delivering appropriate care.

Cognitive impairment

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, judgment 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 General Practitioner and Mental Health Services. The information in 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.

Section two: Recognising and assessing care needs

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?

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.

An alternative screening tool which is currently undergoing research and development is the 4AT. The 4AT merges components of the Short CAM, (Confusion Assessment Method) and the AMT4, both of which have been previously validated.

Remember:

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



Flag systems

Different hospitals may have methods or systems of making it clear to each staff member that a person has dementia or is at risk due to confusion or disorientation. If such a system is used, there should be a clear policy about how it is to be used and a mechanism which ensure everyone understands the system. This should be concerned with minimising risk, reducing the number of moves within the hospital, avoiding unnecessary admission and delivering appropriate care.

Just a thought

- Do you have a Mental Health Liaison Service or Dementia Nurse in your organisation?
- Who would you refer to if you suspected dementia or depression and at what point?
- Does everyone in your team know who to refer to for further assessment?
- What flagging system do you have in place?
- Do you have a clear understanding of when it should be used?

Section two: Recognising and assessing care needs

Dementia

Dementia is an overarching word for a group of illnesses whose origins are organic changes in the brain. The three most common types are Alzheimer's disease, vascular dementia and dementia with Lewy bodies.

Clinical features of dementia

- Short term memory loss, later in the illness long term memory is affected.
- Disorientation to time, place and person.
- Changes in ability to problem solve, plan ahead, make decisions and identify risks.
- Changes in ability to communicate: reduction in use of words, misplacing words, using words wrongly and changes in understanding verbal communication.
- A reduced ability to process and react well to stressors. Stress becomes a significant source of distress, agitation, anger or low mood for the person with dementia
- Changes in how they take care of themselves and their home, family and pets.
- Some people with dementia may experience vivid hallucinations or delusions. This means they may see things that are not there or have ideas which have not true. Common examples of these may be the older person seeing an animal or children which are not there or may develop a belief that their life partner is an imposter and may order them out of the house.
- Some people may engage in seemingly meaningless or undirected activity. Often the behaviour has significant meaning, but the person with dementia is unable to express this.

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 in dementia. http://www.youtube.com/profile?feature=iv&annotation_id=annotation_758333&user=DementiaEd#p/u/4/hDtQLhv4s50

How to live well with dementia

Many people live well with dementia, either on their own, with families or carers. Many of you will know someone with dementia or someone who is caring for people with dementia.

The person with dementia has:

- A sense of control over their lives and environments.
- Elements of routine and predictability in their daily lives which provide security.
- Environments which they know well and have been adjusted to enable them to live well with dementia.
- Regular contact with those people with whom they have supportive relationships.
- Social contact with the communities and friends around them.
- A sense of reciprocity, not only am I being helped but I can also help others.
- The ability to drive, do paid or unpaid work, care for others, engage in educating others about dementia, continue their hobbies and fully live spiritual and sensual lives.

Section two: Recognising and assessing care needs

Admission to hospital can place one or all of those elements at risk, leading to a long term risk to the person's health and wellbeing, not just because they are ill or have had an accident, but because they are out of their familiar and supportive systems.

Overall studies have shown that having a mental disorder such as dementia, delirium or depression is a predictor of poor outcomes for older people using hospital services. The risks to older people with dementia can include one or more of the following:

- Increase in mortality.
- Increase in time on hospital.
- Increase in unwanted drug reactions.
- Earlier admission to residential care.
- Incontinence.
- Reduced cognitive function.
- Increase levels of dependence if they return home.

The person with Delirium

Remember:

When working with older people,

THINK DELIRIUM!



What is 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, sleepiness, 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.

Clinical features of delirium

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

Remember:

Delirium is a medical emergency



Section two: Recognising and assessing care needs

Risk factors for delirium

- Dementia, which can increase the risk of developing delirium fivefold.
- 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 intake
- Pain
- Renal Impairment

Delirium is precipitated by:

- Any acute illness
- Some medicines (especially analgesics, psychoactive drugs, those with anticholinergic side-effects).
- Surgery
- Trauma, especially hip fracture
- Withdrawal from drugs (eg. benzodiazepine) or alcohol
- Psychological stress (eg. brought on by hospital admission)
- Dehydration or malnourishment
- Uncontrolled pain

Identifying those at risk of developing delirium

The older person may have no disturbance of mental capabilities and functioning, but do have all the risk factors as described above. As part of a multi-disciplinary assessment it would be best practice to highlight this and put into place a care plan which minimises the risk of that person developing delirium. There are guidelines on interventions to prevent delirium in National Institute for Clinical Excellence (NICE) (2010) guideline which are accessible and easy to use.

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

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 two: Recognising and assessing care needs

Of course these screening tools are only intended to support your clinical assessment and must be used in conjunction with observation of the indicators of delirium, information from the person, their carer and others.

Co-morbidity

It is not uncommon for an older person to present with multiple physical and mental healthcare needs; including:

- Both forms of delirium, hypoactive during 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.
- Or a combination of all three.

Remember:

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 likely to be in severe distress.

Depression

Depression is a broad and heterogeneous diagnosis. Central to this is depressed mood and/or loss of pleasure in most activities.

“Depression is a significant health problem. It affects men and women of all ages and social backgrounds. Around one in five of the population of Scotland will experience depression at some point in their lives. Prevalence is higher in women than men. It can range in severity from a mild disturbance to a severe illness with a high risk of suicide. The impact of the disorder will also be experienced by family, friends and colleagues. In Scotland in 2006/07 there were around 500,000 general practitioner consultations with depression and other affective disorders. Over half of those with depression do not seek formal treatment.”
(SIGN 2010 page 1)

Incidence in general hospitals

The figures vary for the number of older people experiencing depression in general hospitals, in a literature review by the Royal College of Psychiatrists in 2005 it was asserted that the true prevalence of depression in older people in general hospitals is 30%. This is concerning as the same

Section two: Recognising and assessing care needs

report stated that prevalence in the community was 12%. So if you are an older person in hospital, you are over twice as likely to develop depression than if you were in the community.

Risk factors for depression in general hospitals

- Being physically ill.
- Chronic illness and disability.
- Being separated from normal sources of support.
- Unwanted effects of some medicines.
- Delayed discharge.
- Poorly managed sensory disability.
- Reduced physical activity and boredom.
- Lack of control about their care.
- Lack of control about their future care.

Clinical features of depression

- Persistent sadness or low mood.
- Marked loss of interests or pleasure.

If any of above is present, ask about associated symptoms:

- Disturbed sleep (decreased or increased compared to usual).
- Decreased or increased appetite and/or weight.
- Fatigue or loss of energy.
- Agitation or slowing of movements.
- Poor concentration or indecisiveness.
- Feelings of worthlessness or excessive or inappropriate guilt.
- Suicidal thoughts or acts.

Ask

- During the last month, have you often been bothered by feeling down, depressed or hopeless?
- During the last month, have you often been bothered by having little interest or pleasure in doing things?

Suicide and older people

Suicide in older people is a significant concern as people over 65 years are often more successful than any other age group at taking their own lives; this is particularly true for older men.

It is suggested this is due to three factors:

- Due to physical illness and frailty older people cannot withstand the physical trauma which may be associated with a suicide attempt.
- Older people are more likely to live alone therefore reducing opportunity for recognition of suicidal ideation and potential interruption or discovery whilst in the act.
- Older people show greater planning and determination, less impulsivity and increased use of lethal means.

As the strongest predictor for completed suicide is past attempts, any previous attempts must be taken seriously.

Many frontline staff may misread some clues to thoughts of suicide as 'what it is to be old' or part of the everyday 'wear and tear of life' and miss

Section two: Recognising and assessing care needs

opportunities to discuss the older person's needs and risks.

Section three:

The care experience



Section three: The care experience

Just like all of us, the person with dementia finds it difficult when others invade his or her personal space. When this happens to you, you have a choice; to move away from the other person or to tell them to move away from you. This choice is the same for the person with dementia in the acute ward. However when they move away from care or they communicate that they want you to move away from them, their choice is not always accepted.

Just a thought

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

How does this seem?

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

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

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

If the person with dementia is not able to understand the care that is offered, or does not agree to this, then as you move closer to them to provide personal care they may become distressed. Activities like washing, dressing, bathing, or re-positioning may cause the person to feel they are being harmed. Any attempt to continue will make this situation worse. This can be very challenging for staff trying to provide good care to the person. The situation can become even worse where more invasive procedures, such as catheterisation, cannulation or wound dressings, must be carried out. This can make care very challenging as these procedures and care tasks are vital to prevent the complications of infection, dehydration and malnutrition.

The person with dementia is very sensitive to non verbal behaviour and reactions. It is likely that the person will sense if the nurse is anxious, rushed or annoyed and will respond negatively. It is very important to be calm and relaxed in your approach, smile and use the person's name.

Section three: The care experience

Remember:

A little time spent can mean a lot of time saved



Face the person and speak clearly. The tone and volume of your voice is important. Many people who are older have hearing difficulties. 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.

James McKillop
A person with dementia

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.

Remember:

Sensory overstimulation can increase agitation and confusion



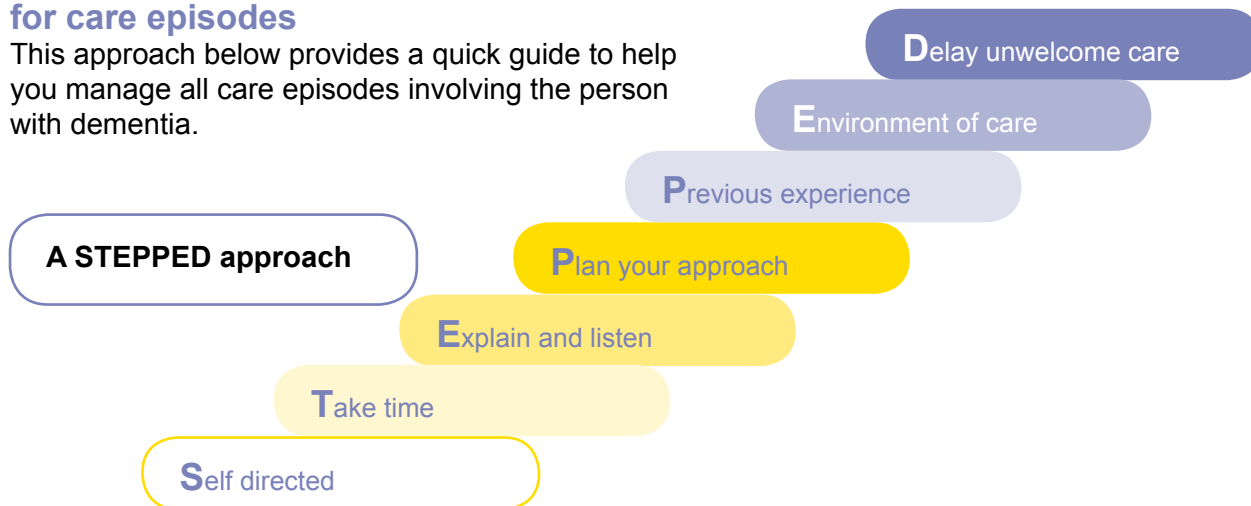
The hospital environment and the person with dementia.

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

Section three: The care experience

Take a STEPPED approach: guidance for care episodes

This approach below provides a quick guide to help you manage all care episodes involving the person with dementia.



Click on the keys for more detail:

Section three: The care experience

The right time has its place. Many people take medication for all sorts of conditions and these may still be in their system in the morning or some hours later. Do your homework and find out when the person is at their best, say morning, noon or afternoon.

James McKillop
A person with dementia

The STEPPED approach contains principles that can be applied to all care episodes. The following information will add some specific guidance about some of the fundamental aspects of care the person with dementia may experience in hospital.

How to help the person with dementia eat and drink

Not only is eating and drinking vital to health, it is also important as a social activity to maintain well-being. The person with dementia in hospital may face special challenges when maintaining a good food and fluid intake. They also face the same issues as any older adult in hospital, such as the effects of illness, infection, delirium, medication, oral and dental problems and constipation. In addition because of their memory and other cognitive problems they may not remember to eat or drink, they may believe they have finished their meal or they may not clearly see, or recognise, the food in front of them. Co-ordination may be an issue and they may have lost the ability to manage the processes involved in eating and drinking. The result may be a greater risk of malnutrition,

dehydration and delirium; a reduction in fluid intake may also cause urinary tract infections resulting in incontinence. A prompt referral to dietetics should also be considered here.

How to help the person with dementia go to the toilet

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

- Know where you are now
- Know that you are looking for the toilet
- Know how to get to the toilet
- Recognise it when you get there
- Know how to remove the appropriate clothing etc.

Quite a challenge

Of course there may be those who manage very well and those who may benefit greatly from a referral to occupational therapy for further

Section three: The care experience

assessment to maximise their abilities. Others may require more intensive help.

The person with dementia can experience difficulty in recognising what an object is for or telling objects apart. For example they may not recognise the difference between a toilet and a bin and may use the bin to urinate in. If they have age related changes in vision or an eye disorder this can make this lack of recognition worse.

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.



How to help the person with dementia wash and bathe

Washing and bathing can become a source of great distress for the person with dementia, it can also be physically and emotionally challenging. There are a number of reasons for this including some of the following:

- Pain as a result of illness and musculoskeletal conditions.
- Weakness caused by frailty and ill health.
- Anxiety and misunderstanding because of memory impairment, loss of understanding or recognition of the bathroom or previous negative bathing experiences.
- Fear of falling, especially when being moved around in lifting equipment and hoists.
- Noisy, cold or unfamiliar environments. The bathroom in a hospital is not domestic in size or appearance.
- Being naked in front of a stranger. The person with dementia may not understand that you are there to care for them.

It is not always necessary to provide an immersion bath for the person with dementia. While they are in hospital it may be better to seek other means of maintaining hygiene. Showers are used more frequently in hospital if the person can manage these; however they are also subject to many of the same problems noted above.

Section three: The care experience

The long term impact of a negative bathing experience can have serious implications for the person with dementia and their carers.

The Bath



Emily was admitted to the ward from a care home with chest and urinary tract infections. She had dementia and, of course, delirium. It was some weeks before she was able to return to the care home.

After her return her key worker tried to get her to have a bath, something she had enjoyed before her admission to hospital. Emily cried and pulled away, refusing to go near the bath.

While she was in hospital, she had been bathed by two nurses using a hoist. The nurses were very kind and reassuring but Emily had never needed lifting equipment before. The whole experience had been very distressing for her.

The person with dementia may forget incidents as Emily forgot the bath in the hospital. However, the emotions those incidents generate may remain with them for a long time. Emily saw the bath and felt afraid.

For Emily the pleasure of bathing was lost and she could not explain why.

When the person is in a severe or advanced stage of dementia, care tasks such as washing, bathing or changing their clothes can be very difficult to manage. The person may continually grasp at people and objects in the environment. This hand grasp is often a reflex action and the patient cannot help himself or herself. If you try to prise their hand off they will simply try to grip harder, often causing pain and injury.

Try this

Using a very light touch of your finger or a piece of cotton wool, gently stroke the back of the hand from side to side or the outside of the arm. Continue until the person's grasp loosens. Have a face cloth handy to place in their hand or they may simply grab something else. This will allow you to proceed safely with the care the person needs.

How to help, when the person has to have a catheter or cannula

The use of invasive procedures should be avoided if possible, and discontinued as soon as is practical. However, it is recognised that these may be essential to the person's treatment. Catheters and cannulae can cause local irritation and appropriate hygiene, observation and pain management measures should be in place. There are a few other approaches that may help.

- Explain clearly what these tubes are, some people with dementia can still understand and

Section three: The care experience

with frequent information may well stop trying to disturb them.

- The tubing may be covered with cloths as the person may then forget about them.
- Family and carers can be invaluable if they can distract the person from the presence of these tubes or remind them that are essential to their care.
- Camouflage tubes that are obvious to the person may help. These are secondary, unattached tubes in brighter colours. These can be taped over light bandages and can help reduce the tugging and self removal of the hidden cannulae and catheters.

What if there are specific procedures that seem to agitate the person with dementia?

Where there are particular activities that seem to cause distress it is essential that these are examined to try and resolve the problems.

Questions to ask

- Does this procedure need to be done?
- Is the procedure painful?
- How many staff are there when it is carried out?
- Is it being carried out at a time of day when the ward is noisy and busy?
- Where is it being carried out?
- Would it be appropriate for family or other carers to be present during the procedure?
- What activity or procedure was the person with dementia doing before this procedure?

Surgical intervention and the person with dementia

Surgery presents considerable stress and increased risk of delirium and other complications for the person with dementia.

- The combination of cognitive and sensory impairments can jeopardise the impact of preoperative education and preparation.
- The person may be taking multiple medications that can interact with medicines given in the perioperative period.
- The presence of dementia can slow the recovery from surgical procedures.
- The management of pain is a continuing issue for the person who cannot communicate clearly. A randomized controlled trial by Morrison and Sui (2000) found that 76% of people with dementia did not receive regular post operative pain relief following surgery related to hip fracture.
- The experience of undergoing anaesthesia can have an enormous impact on the person in both the short and long term. It can not only cause postoperative delirium but may also result in longer term impairment. (Ballard, Clack and Green, 2007).

Section three: The care experience

Practice points for perioperative care

This should include:

- The family member or carer who knows the person well
- Risk assessment for the use of anaesthesia
- Multidisciplinary assessment for the presence of preoperative delirium
- Preoperative nutritional assessment, particularly for hydration
- Preoperative identification for the presence of chronic pain
- postoperatively, pain control should include dementia specific tools, such as the Abbey pain scale
- The carer should be allowed to remain with the person, whenever possible
- The person should return to a familiar environment and people as soon as practical

but die from some other identifiable condition, for example cancer.

- People who die as a result of a combination of dementia and another illness.
- People who reach end of life and die of the complications of dementia, as in end-stage dementia.

(Cox and Cook, 2002)

Palliative and end of life care for the person with dementia

For the person with dementia the disease trajectory may vary considerably and is often dependent on the type of dementia the person has. The National Audit Office (2007) highlighted that the dementia progression falls into three stages: early, middle and late. The person with dementia may die at any of these stages; they go on to suggest that the people with dementia that die are linked to three groups:

- People who reach the end of life with dementia

Section four:

Meeting the needs of the person who is distressed



Section four: Meeting the needs of the person who is distressed

Introduction

Meet Jim, Jeannie and Penny

I am in a very strange place today. There is a lot of noise and many people walking about very fast. I don't know why I am here, I should be at home, my mum will be looking for me and wondering where I am. I think I better go. Everyone is very busy; I'll just slip out and not bother them.

That woman is trying to take off my clothes!! Who is she? I only came in here to get my wee brother and take him home. The police should know about this place. Well she won't be stripping me. I think she must be mad. I'll give her a good slap; that will stop her!

I have lived in this house all my life and I can't believe all these people that I don't know are sitting in my bedroom. Who are they? I have shouted and shouted at them but they won't leave.
HELP!! HELP!!

Remember:

All distressed behaviour is a way of communicating with you



Distressed behaviour

Distressed behaviour may be the only way the person with dementia can still communicate with you. However this behaviour can sometimes be strange and unusual and is often called challenging behaviour, not because the person is challenging you, but because their behaviour can make you feel challenged. Such behaviour can be difficult for staff to manage; it is often caused by multiple problems faced by the person with dementia. Some of the common causes of distressed behaviour are:

Section four: Meeting the needs of the person who is distressed

- Having a physical illness
- Experiencing pain
- Experiencing the effects of medication, including unwanted effects
- Being dehydrated
- Being constipated
- Needing to go to the toilet
- Being too hot or too cold
- Having itchy or sore skin
- Wearing clothing that rubs, or is too tight.
- Sitting or lying in an uncomfortable position
- Experiencing too much stimuli from light, noise and activity
- Having changes in their routine
- Missing their family or pets
- Withdrawing from alcohol or tobacco

Of course these reasons can apply to any patient in hospital but when the person has communication and comprehension difficulties these can become a source of real distress. Most distressed behaviour occurs some rather than all of the time and the person may behave in a number of different challenging ways. It is important to assess the situation accurately.

Ask the following questions first:

- Is it really a problem?
- Can the behaviour be tolerated rather than changed?

If the behaviour is resulting in an unacceptable risk

to the person with dementia or others then it must be assessed and treated.

Identify the cause

It is important to record triggers that may have caused the behaviour. These should be described, including exactly what happened and what intervention seemed to help. A very useful way to do this is to use the ABC approach. This approach looks at antecedents (A) or triggers for the behaviour, the resulting behaviour (B) and the consequences (C). Including this information in the form of a chart and recording it for just a few days can often uncover some of the reasons for distressed behaviour.

What works?

When recording information about distressed behaviour it is vital to note anything that seems to change the person's responses or behaviour. You may find that it is not possible to completely eliminate distress and while challenging behaviour does not stop it may become less frequent. This reduction may be enough to make the behaviour more tolerable and reduce risks for the person and others.

Section four: Meeting the needs of the person who is distressed

Specific behaviours that may challenge

There are some specific behaviours that can be the result of distress and below is some guidance about how to intervene that may be useful. **Click on the keys 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, using their name frequently 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 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.

Section four: Meeting the needs of the person who is distressed

- 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.

Pain and dementia

Pain is one of the commonest causes of distressed and challenging behaviour in the person with dementia



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.

What about using medication to manage distress in the person with dementia?

Medicines may be used for people in hospital who have distressed behaviour associated with dementia or delirium 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.

The most commonly used medications for managing distressed and challenging behaviour in dementia are the typical antipsychotic (neuroleptic) medications, such as haloperidol. While there is some indication that this medication can have an effect in reducing distressed behaviour it has a number of unwanted effects that may suggest caution when considering this approach. In particular there can be serious unwanted effects where this group of medicines are given to the person with dementia with Lewy bodies. These medicines can make the person's symptoms worse. If the person is unable to understand or consent to the use of these medicines it is vital to use the guidance and powers contained in the Adults with Incapacity (Scotland) Act (2000) in order to protect

Section four: Meeting the needs of the person who is distressed

the person's rights.

There is guidance which recommends appropriate use of medicines for these reasons, which can be found in the links below.

NICE guideline for Delirium, page 15 NICE (2010)
<http://www.nice.org.uk/nicemedia/live/13060/49909/49909.pdf>

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

Remember:
Distressed behaviour?
Think pain first.



Using medication to manage distress in the person with dementia.

Remember:

When using medication to manage distress:

Start at the lowest possible dose

Increase the dose slowly

Use for the shortest possible time



Section five:

Leaving the ward /
transitions



Section five: Leaving the ward / transitions

Introduction

Transitions are part of the hospital experience and they can be difficult to avoid. However, for the person with dementia, the experience of moving or changing routines can be devastating. Where there is more than one move, either within the ward, or from one ward to another, the multiple changes can result in distress and disorientation. The person may then behave in ways that can seem challenging in an effort to express their distress and anxiety.

Getting the transitions right

- The move should be carried out with the interests of the person with dementia considered first.
- The number of moves both within and outside the ward should be kept to a minimum.
- Moves should take place during the day, late morning is best.
- Family and carers should be informed before the move, they may wish to help.
- One member of staff should be the named person to ensure all the people involved are kept fully informed.
- If the person is going to a new care setting there should be a person nominated in the setting and their details should be given to family, carers and any other professional involved.
- The involvement of an independent advocate should be considered for the person with dementia who has no carer.

The combination of physical illness, change and dementia can result in the person becoming more disabled and they may no longer be able to function as they did before admission. This may result in a decision that they are no longer able to return home and instead are discharged to a care home. Where the person with dementia has come to hospital from their own home, the aim of discharge planning should be to return there. Only in rare and unavoidable circumstances should residential care be substituted. There are a range of support services and increasingly there are new technologies that can be put in place to support the person to return home. Where there are older person's mental health liaison services available it is important to involve them as soon as it is practical. The person with dementia may take time to recover but returning to a familiar environment will be more effective than exposure to an entirely new setting.

You will remember the link to the Department of Health guidance 'Nothing Ventured Nothing Gained' on risk enablement earlier in the resource and application of this guidance in discharge planning will again be essential http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121492

Discharge planning

For people with dementia discharge planning should commence on admission to the acute unit. This process involves the multidisciplinary team, the person with dementia and their family/

Section five: Leaving the ward / transitions

carer. Appropriate referrals should be made to key disciplines such as occupational therapy and physiotherapy. The key aims of the discharge planning include;

- To improve the preparation and coordination of care and services.
- To identify any potential problems or obstacles to discharge and plan solutions.

(Katikireddi and Cloud, 2008)

Discharge planning is a critical component in the care of a person with dementia, and this can be simple and straight forward or very complex (Department of Health, 2003). The Scottish Government (2010) highlighted in the National Dementia Strategy,

“We will work to improve the response to dementia in general hospital settings, including through alternatives to admission and better planning for discharge.”

(Scottish Government, 2010, p 42)

People with dementia can receive support from a range of sources health, local authority, private and voluntary services. The Scottish Executive (2005) published Better Outcomes for Older People: Framework for Joint Services, and section 6, is dedicated to joint services for people with dementia and their carers. The key features of joint services include provision of:

- the ability to live as normal a life as possible whether in their own home or a care home;
- successful re-adjustment to living in their own home when a person with dementia returns from a period of institutional care;
- the best possible quality of life for the person with dementia within the limitations of their disability;
- the ability of the carer to be able to continue caring for the person with dementia in their own home for as long as practical;
- the maintenance of a caring relationship between the person with dementia and his or her carer;
- fulfillment and satisfaction by the carer in being able to carry out that role.

(The Scottish Executive, 2005)

To support high quality care delivery for people with dementia, NHS Quality Improvement Scotland (2007) published Standards for Integrated Care Pathways for Mental Health. See this at: http://www.nhshealthquality.org/nhsqis/files/mentalhealth_standardsforICP_DEC07.pdf

This document contains generic care standards

Section five: Leaving the ward / transitions

and specific standards for dementia care. There are ongoing consultations on the development of Scotland wide dementia care standards that will be available for more information access the Mental Welfare Commission website: http://www.mwscot.org.uk/mwc_home/home.asp

The identification of the professional that will be co-ordinating the care after discharge is critical. At the simplest level the person may be discharged to the care of the General Practitioner and family/ carer. However, in complex cases the person may be referred to a hospital discharge team to liaise with community and primary care services. The person may require ongoing assessment and care management in the community. In some cases this will mean that the individual may already have a care manager that can support the discharge (Scottish Executive, 2006). In such cases this person will work with you to support and augment their client's discharge.

A final thought: what a journey!

You have arrived at the airport to go on a trip. 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.

Suddenly a member of staff who speaks your language appears and you see a good friend arrive who has brought a big bag with sandwiches and coffee. They have come to stay with you until you get home. **What a relief!!!!**

You may wish to re-visit the Approaches to Dementia Questionnaire you completed earlier. Have any of your responses changed? If so, why do you think this could be?

Appendices



Section one: key two

Professor Mike Nolan and his team have carried out extensive developmental work on a more inclusive approach to supporting people with dementia, their formal and informal carers. They place the person with dementia in a 'relationship centred' approach where everyone concerned is supported to have a sense of the following:

- Security
- Continuity
- Belonging
- Purpose
- Achievement
- Significance

To read a seminal article on this work, please follow the link below:

http://www.ssiacymru.org.uk/media/pdf/9/n/Beyond_Person_Centred_Care.pdf

These influential innovators in dementia care assert the need to 'know' the person with dementia. When asserting the need for a sense of continuity, Nolan et al (2004) describes the, "Recognition and value of personal biography; skilful use of knowledge of the past to help contextualise present and future. Seamless, consistent care delivered within an established relationship by known people." Page 50

Section one: key three

Attitudes towards older people with mental health problems

A number of studies have shown that there is a direct link between having a positive attitude towards people with dementia and job satisfaction for care staff.

Essentially, having a positive attitude to working with people with dementia is good for your own working life. In addition, a range of studies have demonstrated that it is not only older people with mental health needs who are stigmatised by society. Those staff who work with them are also stigmatised by association. Simple steps can be taken to reduce stigma and develop a positive person-centered attitude to working with older people, these are:

- Regular personal and professional development in line with the Knowledge and Skills Framework.
- Having an understanding of your approach to older people and reviewing your attitudes and beliefs on a regular basis.
- Being supportive of your colleagues who work with older people.
- Refusing to enter into stigmatising talk about older people or people with mental health needs, (especially when hidden in humour).

Think about your clinical area, who do you work with, who people with dementia respond positively to, (each clinical area has one). Who is the person who can reduce distress, find it straightforward to

assist people to eat and are fondly thought of by carers? What is it they do? What is different about that person? Talk to them about their approach? Can they describe to you what works? Is it OK for you to watch them work? Is it you?

You will probably find that the person is compassionate, caring and kind in everything they do. They will have excellent communication skills and are calm and positive in their approach with everyone.

There have been a number of programmes where general hospital staff have had the opportunity for increased education around working with people with dementia. Below are quotes from the programme for Dementia Champions from NHS Dumfries & Galloway:

“Staff find it really stressful managing patients with dementia; they feel insecure because they don’t know what to do.”

“I listen more, take time with patients and carers and always ensure a good history is taken.”

“I am not scared to work with a person with dementia, I can discuss things with their relatives- I am better informed.”

“For me my way of thinking about patients with dementia has changed. It has changed my attitude and changed the way I speak to people with dementia. I have a lot more understanding and so much more patience.”

Section one: key three

These members of the multi-disciplinary team have discovered the benefit of education, reflection and trying a different approach when working with people with dementia.

They report building on 'quick wins' and creative ways of managing care when they have attempted a person-centred approach. Because it has worked for everyone, they have continued to work in this way. Good practice and positive feedback has led to a sense of accomplishment and pride in their work.

Section one: key four

Concerns about attitudes, values and understanding

- Understand what dementia is.
- Be aware of dementia but do not let it overshadow or distract you from discovering what is wrong with the person.
- Value me as a carer; understand that many carers are expert in working with their people.
- Remembers all experiences of caring are different, ask me to find out what mine is.
- Be aware carers may have needs due to age, frailty and experience of the stressors of caring.
- Understand that loss of control can be devastating for me and my person, help us retain control.
- If you don't understand, ask and listen to what we tell you.
- Understand your agenda may not match ours, our agenda will be about preventing problems and supporting someone who may be frightened, yours may be about speed, prioritising and effective use of resources.

Ask us what our role is. Don't assume what our normal caring role is, we may advocate strongly for our person but they may not want us to help them to the toilet.

- Help us to tell you our history in a private and dignified manner.
- Help us to agree upon treatment plans or options together, give us time to take in recommendations and consider them.
- Be aware of local services and make sure you are able to support alternatives to admission to hospital.

Remember:

Loss of control can be devastating, help us regain control



Concerns about practical matters

- Call us and help us to get to our person's side quickly.
- Support all staff to know when someone identifies themselves as a carer, that we can be a partner in care.
- Do not send us away, let us help with things we normally do at home.

Section one: key four

- Try to give us one identified team to work with throughout our stay.
- Check on us regularly so I don't have to leave my person to come and find you.
- Respond to the person's requests for help, the toilet, food, water as you would with anyone else.
- Let us go with our person to other hospital departments, not as a replacement escort but as someone who is there just for our person.
- Help us contact others if we need to, can we use your phone, the payphone or have a break to use our mobile?
- Give us regular breaks if we have been in the department a while.
- Helps us to find tea, coffee and something to eat.
- Make sure we are comfortable.
- Please document well and pass on all information we tell you so we don't have to repeat ourselves over and over again.
- If I give you a profile or history of the person, please keep it safe and use it to communicate their care needs to others.

Remember:
Helping us will help you



Sources of help for carers

Alzheimer Scotland web pages
<http://www.alzscot.org/>

24 hour Dementia Helpline
Freephone 0808 808 3000

Government Information for Carers
<http://www.direct.gov.uk/en/CaringForSomeone/index.htm>

Adults with Incapacity (Scotland Act 2000) - A Short Guide <http://www.scotland.gov.uk/Resource/Doc/217194/0058194.pdf>

Section two: key four

Indicators of delirium

At presentation, assess the person at risk for recent changes or fluctuations in behaviour. These may be reported by the person at risk, a carer or relative. Be particularly vigilant for behaviour indicating hypoactive delirium (marked*). These behaviour changes may affect:

- Cognitive function: for example, worsened concentration*, slow responses*, confusion.
- Perception: for example, visual or auditory hallucinations.
- Physical function: for example, reduced mobility*, reduced movement*, restlessness, agitation, changes in appetite*, sleep disturbance.
- Social behaviour: for example, lack of cooperation with reasonable requests, withdrawal*, or alterations in communication, mood and/or attitude.

If any of these behaviour changes are present, a healthcare professional, trained in diagnosing delirium should carry out a clinical assessment to confirm the diagnosis.
(NICE 2010)

The keys to care:

- Ask if the carer can be available to support the person and give essential history and current situation.
- Carry out the assessment in a single quiet, calm, area.
- Discover what is 'usual' for the person.
- Minimise assessment procedures, can the team do them together or identify one person to carry out the assessments.
- Ask what the person needs, listen to their needs and then explain what is happening and going to happen at each step of the procedure.
- Revisit the person with regular updates even if you have nothing new to tell them. Proactive discussions and ask, listen, explain, ask, listen, explain will minimise any small risks developing into larger ones.
- Be confident, competent, swift and reassuring when carrying out physical procedures, employing the ask, listen, explain throughout.
- Always respond to shouts, cries or requests for help, the person may need help for a long time before they ask for it.
- Consider discomfort and pain as an ongoing concern for each person, assess for pain at each interaction and respond accordingly.
- Ensure the persons fundamental needs are addressed such as hunger, thirst, warmth, cold, use of the toilet.
- Ensure the person's carer is with them at all times and give the carer support to do this, tea,

Section two: key four

coffee, regular breaks, time and opportunity to call other people. If the person has no carer, try to have someone with them for the majority of the time.

- Listen to the person and the carer across the range of their concerns, what may not be relevant now, may be later.
- Try to ensure that one person works with the person, including escorts to other departments, during their time in the hospital.
- Try not to move the person to different areas in the department.
- Try to minimise noise, bright lighting and fast paced activity directly in the vicinity of the person.

Section two: key five

You or some of your colleagues may have been on a SafeTALK or ASIST course in the last two years. These courses were made available as part of the national strategy to reduce the number of suicides across Scotland. If you have not attended one of these courses then contact your local Choose Life Office to find local courses in your area.

<http://www.chooselife.net/home/Home.asp>

These courses are designed to support all staff and members of the public to become ready, willing and able caregivers when they meet someone with thoughts of suicide.

Indication of thoughts of suicide in older people

- The person says they feel hopeless, have or see no future, say there is no point to things; they won't be around. The person may say they want to die or want to kill themselves; all direct statements about wanting to die MUST be taken seriously.
- They may hide medicines, talk about putting their affairs into order, give things away.
- Any sudden change where loss of control or choice is a factor, such as coming into hospital, diagnosis of a serious illness or moving to a residential environment.
- Depression, anxiety, agitation, guilt, isolation, changes in sleep and eating patterns.

Interventions in the hospital environment

If you suspect depression or thoughts of suicide may be indicated in the person's presentation, then refer for a mental health assessment, either to a psychiatrist, Liaison Psychiatry or Liaison Mental Health Nurse Team. If you are not the doctor in charge of the person's care then ensure they know your concerns.

If you feel thoughts of suicide are present or have been described by the older person,

- LISTEN to their concerns.
- Do not dissuade, argue or minimise these thoughts
- Do not show shock, alarm or judgement.
- Refer urgently for a mental health assessment.
- Reassure them you will do all you can for help.
- Inform all those involved in their care.
- Ask them to keep talking to yourself and other members of the team while waiting for the mental health assessment to take place.

Review all medicines, do any of them have depression as a side effect? If so consider alternatives.

Review their physical healthcare needs:

- Do they have poorly controlled pain?
- Do they have distressing side effects of medicines?

Section two: key five

- Do they have uncertainty about their physical healthcare needs/diagnosis?
- Is there an opportunity to engage them in education about their physical illness and discuss a range of treatments?
- Do they have a physical healthcare need which may cause shame such as incontinence, a stoma, high dependence upon staff for personal care.
- Do they have a healthcare need which has caused loss? Loss of function, loss of a limb, loss of their home or independence?
- Do they have a poorly managed hearing or vision disability? Can you get these reviewed and managed appropriately?
- How are older people viewed in your unit/ward/team? Can you be sure the older person feels valued, useful and that someone is being their voice?

Support and encourage social supports, can you offer flexible visiting times to family and carers, can you facilitate regular and frequent visiting by family? Can the person phone their family or carers when they wish?

Source material and further reading

An informal and accessible leaflet which sets out the competent care needed to prevent or detect depression in older people.

http://www.healthcareimprovementscotland.org/previous_resources/best_practice_statement/working_with_older_people.aspx

NHSQIS Best Practice Guidelines on Working with older people towards prevention and early detection of depression.

http://www.nhshealthquality.org/nhsqis/files/OLDPEOPLEPREVDEP_BPS_JAN04.pdf

Literature review on Suicide and Older People
www.nmhdu.org.uk/silo/files/older-people-and-suicide.doc

Section three: key one

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 strange person 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. Repeating who you are frequently may feel rather artificial but it will remind the person that they are with a professional who is caring for them.

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.

Remember:

A little time spent can mean a lot of time saved.



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

Section three: key one

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 where the person with dementia has been unable to process the subtle or complex message involved in what you say. A smile is almost always as effective in smoothing the communication pathway.

Section three: key two

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.

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 opposite are good examples of different light sources. The picture on the top left has the light directly on the subject 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.



Section three: key two



The person with dementia has sometimes additional deficits in their visiospatial ability; this can cause further misperceptions in relation to highly reflective surfaces. These surfaces can appear to be three dimensional, 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 likely to be preserved. This can be useful if you wish the person to clearly find some areas in the department such as toilets.

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 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.

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

Section three: key two

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 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.

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.

Section three: key three

Self directed

The person with dementia should be encouraged to do as much of their own care as possible, it will always be less stressful for the person with dementia to try and complete simple tasks for themselves. Stepping back a little and providing simple one stage instructions can help the person feel calmer and in control of the situation.

Section three: key four

Take time

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 and movement can help. 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. Your movements should be deliberate with no sudden reactions. Role model calm behaviour and the person may respond in the same way.

Section three: key five

Explain and listen

We may believe that we have explained clearly what we are going to do with the person. However, it is important to listen carefully to ensure the person has understood what you have said. If the person with dementia has no memory of the explanation you have given, and someone approaches who touches them in an unexpected way, then a negative response is understandable. Wear your name badge in a prominent position and remind the person who you are regularly, this reinforces the clinical aspect of the care process.

Section three: key six

Plan your approach

The person with dementia is always very sensitive to non verbal behaviour and reactions; they will sense if the member of staff is anxious, rushed or annoyed and respond negatively. It is very important to be calm and relaxed in your approach, smile and use the person's name. Follow the good practice principles in your communication with them. Keep external stimulus to a minimum if you can. Chose a quieter time of day to carry out care and have as few staff involved as possible. If it is safe, only one staff member should carry out care. If more than one person needs to be involved then only one person should make the initial approach and the other staff can then come in to help. It is really important to be organised and have everything you need ready. If you have to leave the person and return they may have forgotten you have been there and you have to start again or they may believe that you have already carried out the care and refuse to be washed or shaved again! Noise reduction can be the key to care here. Careful planning of care around peak periods of ward activity may well reduce the demand on the person and improve the care experience.

Section three: key seven

Previous experience

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

Section three: key eight

Environment of care

The older person may have hearing and visual difficulties and will benefit from a reduction of noise and an increase in light. Low noise levels reduce agitation and ensure that the person with dementia can hear you and is not distracted by other noises and voices in the environment. Care may go wrong when there is a good deal of activity in the ward. This can include shift changes, meal times, medical rounds, receiving times and visiting hours. As we age we need more light to see well, up to three or four times more than a younger person. Lighting should be bright and shadows should be minimised. It is important for the person to be able to see your face clearly and also see what you are doing. Clutter in their immediate environment should be at a minimum.

Lighting is very important for people as they get older. Try and ensure that your back is not facing a bright window, otherwise your face will be in darkness. People like to see people's emotions as their lips move, to read what is said.

James McKillop
A person with dementia

Section three: key nine

Delay unwelcome care

Most care episodes can be delayed for a short period without any risk. If the person is resisting care and is becoming upset and distressed, then stop and move away from them, after making sure they are safe. Leave the person for five to ten minutes and then try again using a different approach or a different member of staff. Continuing to try and provide care for the distressed person with dementia will not only create problems for the current care episode but may also affect how they respond in the future. The person with dementia may not always be able to remember specific actions or incidents but they often retain the emotions that were generated and can react badly when placed in similar situations.

Section three: key ten

What if the person with dementia is not eating or drinking?

There are a number of interventions to try when the person with dementia is not managing to eat or drink. Of course the most important action is to speak to the family or carer and find out what they know about the person's likes and dislikes and any help they require.

Noisy environment.	The competing stimuli in the environment may distract the person from their meal.
The table is free from clutter.	This means there is less visual distraction and the person with dementia can focus on their food.
There is a clear contrast between the food, the plate and the table.	Vision is affected both by ageing and the effects of dementia. Good contrast can help the person see the plate and the food.
Prompt the person at each stage if this is needed.	Memory problems may mean the person forgets to lift the food to their mouth, chew or swallow.
When the person does not recognise food gently touch their lips with the spoon or cup.	Sometimes the person with dementia experiences agnosia, or difficulty recognising familiar things when they look at them. The sensation of food or drink in their mouth helps them recognise what these are.
The person holds food in their mouth.	Keep the person's head tilted forward and gently stroke the chin, repeating the word "swallow". You should also make obvious swallowing movements yourself, close enough so that the person can see you

Section three: key eleven

The person bites the spoon and is unable to release it.

Do not use plastic utensils that could break.
Do not put your fingers in the patient's mouth.
Place the spoon on the middle of the tongue, touching the gums or teeth can cause a bite reflex.
Pulling at a straw or spoon to remove it can also cause a bite reflex.
Gently stroke the jaw and cheek muscles to help release the bite reflex.

The person does not seem to want to eat and does not try and take food from the spoon.

Do not try and move the patient's head towards the spoon. The person is likely to have an involuntary reaction or reflex and will pull away. Instead gently stroke the cheek closest to you. This will stimulate a reflex response that will cause the patient to turn towards the spoon.

The person does not want to open his or her mouth to take food.

Again stroke the cheek to encourage the reflex. Gently spread a little food on the patient's top lip, this may stimulate the person to suck or lick this and they will open their mouth to accept the spoon.

Of course the person who is at this stage of dementia may require an referral to dietetics and speech and language to ensure their swallowing reflex is intact.

Section three: key twelve

- The words bath or shower may trigger unhappy memories of experiences for the person and using terms such as „having a wash“ may help them to understand the purpose of the care you are trying to provide.
- The person should have pain relieving medication, if needed, in good time before washing.
- The bathroom area should be warm and quiet.
- The bathroom should be private and as few staff as possible should be present.
- All the equipment needed should be available.
- Make sure the person can see and reach the handrails.
- When showering start washing from the person’s feet and move up, uncovering the person as little as possible at any time.
- If the person is uncomfortable being naked then leave a light towel over them. It can be used as a giant wash cloth and need only be removed when replaced by a dry towel.

Section three: key thirteen

Palliative and end of life care

Palliative care is not only about the end of life care of a person, a palliative care approach should be available to a person with dementia at any stage, from the point of diagnosis to the end of life (NICE, 2006). Palliative care is about ensuring that people do not suffer as a result the symptoms of their illness; not just at the end of the illness but throughout the journey. The Scottish Government (2008) highlighted that palliative and end of life care must be of a high quality. The main qualities of palliative care will be;

- Patient centred
- Safe
- Effective
- Efficient
- Equitable
- Timely

The key principle for palliative and end of life care within dementia include;

- Palliative approach in dementia is from diagnosis to death
- People with dementia should die with dignity
- People with dementia should be able to die in a place of their choice
- Focus is around quality of life issues at the end of life
- Carers should be supported during their loved one's illness and into bereavement.

(NICE, 2006)

The assessment and review of person with dementia's palliative care needs is critical. There are tools that have been successful in primary care including the palliative care register and prognostic indicators in primary care which were introduced by the Gold Standards Framework. Additionally, the use of an integrated care pathway; such as the Liverpool Care Pathway for the Dying Patient (LCP) in the last days of life has proved useful. The pocket guide is available at: <http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/>

The Scottish Government (2008) reinforced that these types of tools ought to be implemented within all care settings. There are specific issues around end of life with a person with dementia including;

- **Advanced decision making:** People with dementia may have prepared an advance statement. There are two types of advance statements. A general advance statement lodged with the family or the patients representative; the second is only for treatments if you became mentally unwell and need to receive compulsory treatment under the Mental Health (Care and Treatment) (Scotland) Act 2003. For more detailed information on Advance Statements access the Alzheimer Scotland link: <http://www.alzscot.org/downloads/makingdecisions.pdf>
- **Pain Management:** The Liverpool Care Pathway can support the management of pain at the end of life. Additionally, there is useful

Section three: key thirteen

information available in on the Social Care Institute for Excellence website: <http://www.scie.org.uk/publications/dementia/endoflife/pain.asp>

- **Withdrawal or withholding nutrition:** This is a particular difficult aspect of care. NICE (2006) offers guidance that artificial nutritional and hydrating support should be considered if there is dysphagia, and it is considered to be transient. Current best evidence suggests that support should not be considered necessary for people with dementia with end-stage dementia when the dysphagia or the disinclination to eat is a manifestation of disease severity (NICE, 2006). The General Medical Council (2010) have prepared extensive guidance on this topic: http://www.gmc-uk.org/static/documents/content/End_of_life.pdf
- **Treatment of fever:** During the end stages of dementia when people are reaching the end of life solely as a result of dementia; the most common cause of death is aspiration pneumonia (Keene, Hope, Fairburn et al, 2001). This would mean that you should expect to manage the person's pyrexia, pain and dyspnoea at this stage. The Liverpool Care Pathway will help support you in this: http://www.mcpcil.org.uk/liverpool_care_pathway

Section four: key two

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 acute ward, presenting with agitation is likely to be experiencing a physical cause for this behaviour rather than it 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 include pacing, restlessness, lifting and moving items and undressing inappropriately. Verbal behaviours can include repetitive questioning and constant requests for attention.

Agitated behaviour can have serious consequences for the person with dementia as 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.

Section four: key three

Wandering

There are two types of behaviour that may be termed wandering. One of these is wandering away, where the person leaves the ward because they want to go home or get away from the ward setting. The second is related to persistent walking around the ward and not knowing where they are. These may improve as the person becomes more familiar with the ward and any delirium is treated successfully. However, the behaviour may be more persistent and will require full assessment using the ABC approach to identify any triggers in their environment. It may be that their room is near the exit and they see people leaving all the time. The fundamental needs of the person have to be met and treated such as the need to go to the toilet, hunger, thirst, pain, feeling too cold or too hot.

The environment around them may be too noisy or too quiet. The older person with dementia may be at considerable risk when wandering in a hospital setting and some more specific measures may be required. Their room should not be near exits but easily observed by staff. A coloured sign could be used on their door to alert staff that the person may be at risk of wandering. Coloured wrist bands may serve a similar purpose. Involve the family if you can, especially at peak activity periods in the ward when the person may not be missed so quickly.

Section four: key four

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

If they are too distressed for this 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 ward. This is particularly effective if you know something of the person's life history, for example their hobbies or previous occupation. 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 become anxious and worried.

Section four: key five

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. 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.

Section four: key six

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.

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 ward.

When the person with dementia has to stay for long periods in the ward, 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.

Section four: key seven

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 their struggle 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.

Section four: key eight

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 ward 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, as these can often be misinterpreted as real objects or people.

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 a particular type of dementia, called 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.

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

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.

Section four: key ten

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 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 parts of 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 no one who knows 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 their behaviours and responses in a strange environment such as agitation, aggression and

Section four: key eleven

shouting. These behaviours can be easily mistaken for those that may result from the person's mental state.

When the person can no longer communicate verbally 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. 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.

Section four: key twelve

Antipsychotic medication

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 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. He suggests 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>

Reading on unwanted effects of antipsychotics:
<http://www.alzscot.org/pages/policy/antipsychoticdrugsbriefing.htm>

Please remember this section links to all the other sections in the learning resource and try to invest time to read this alongside the other sections.

Sometimes immediate care including verbal and non-verbal de-escalation techniques are not effective in relieving stress and distress, it is at this point you may have to consider restraint to promote and protect the safety of all staff and the person involved. Your clinical area will have standard procedures and appropriate training and it is good preparation for you to know the procedures and attend the training prior to an incident occurring. Below is a link to guidance from the Mental Welfare Commission, although intended for use in residential settings the guidance is useful to reflect upon in general hospital settings too:
http://www.mwcscot.org.uk/web/FILES/Publications/Rights_Risks_web.pdf

Section five: key one

A comprehensive multi-disciplinary assessment of the person with dementia is very important. While the documentation and discharge checklist will vary considerably across the country, this core information and these questions should be included:

- **The person's attitudes and wishes:** What does the person with dementia want and hope for? Does this person require the support of an Advocacy Service or other legal support and protection mechanism? For further guidance there is useful information on the Alzheimer Scotland website: <http://www.alzscot.org/pages/about/rightsandlegalprotectionpolicy.htm>
- **Family input concerning attitudes and wishes:** What does the family or any other informal carers want and hope for? What do they believe their future role and involvement in care will be? What support do they need? Do they know where and how to get the right support? There is helpful information on the Alzheimer Scotland website: <http://www.alzscot.org/pages/info/caring.htm>
- **Current level/ type of care:** What degree of care is being delivered at present? Will this level still be required on discharge? Might you need to consider more? How will this be arranged, monitored and reviewed?
- **Current accommodation:** Has the home environment been assessed? How suitable is this environment? What modifications and adaptations are required? Of course it is good practice to involve the occupational therapist and make appropriate referral.
- **Personal care needs:** What level of support is required? How and by whom will this aspect of care be delivered? If supported by informal carers, family or friend do they understand what is required and are they prepared with the knowledge and skills to ensure they can do this safely and effectively? If formal care is part of the care package considered; how will this be monitored and reviewed?
- **Mobility:** Has a home assessment been completed? Are the modifications and equipment to aid safe mobility in place?
- **Food provision and preparation:** Who will be ensuring that shopping and provisions are available? Who will be preparing meals and assisting with feeding if the person is no longer able to do this?
- **Medication organisation and compliance:** Who will be ordering and collecting prescribed medication? Who will be supporting and assisting with administration of prescribed medication? Have you involved the person's principle carers in medication education?
- **Finances:** How is care being paid for? Who will be supported to manage their finances?

Section five: key one

Has the person with dementia had their income maximised? Information on Money and Legal issues is available on the Alzheimer Scotland website: <http://www.alzscot.org/pages/info/moneyandlegalissues.htm>

- **Sleep habits:** Does the person have an altered sleep pattern? Have you discussed with relevant parties how will this be managed at home?
- **Wandering or getting lost:** What are the risks of this? What plans are in place to manage this safely?
- **Weekly structure and social outlets:** How will this person with dementia and their family or carers access social interaction opportunities? Is any extra support required to meet both the person and their carer's needs?
- **Vulnerability and risk of exploitation:** Have you considered the risks and vulnerability of the person when they are returned home? If you do recognise a risk, what have you done about it?

(Adapted from Downs and Bowers, 2008, p307)

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Attitudes to Dementia Questionnaire

© Tracey Lintern 1996
University of Wales, Bangor

Please indicate to what extent you agree or disagree with each of the following statements:

1. It is important to have a very strict routine when working with dementia sufferers.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Strongly Disagree
- Disagree

2. People with dementia are very much like children.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Strongly Disagree
- Disagree

3. There is no hope for people with dementia.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Strongly Disagree
- Disagree

4. People with dementia are unable to make decisions for themselves.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Strongly Disagree
- Disagree

5. It is important for people with dementia to have stimulating and enjoyable activities to occupy their time.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Strongly Disagree
- Disagree

6. Dementia sufferers are sick and need to be looked after.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Strongly Disagree
- Disagree

7. It is important for people with dementia to be given as much choice as possible in their daily lives.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Strongly Disagree
- Disagree

8. Nothing can be done for people with dementia, except for keeping them clean and comfortable.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Strongly Disagree
- Disagree

9. People with dementia are more likely to be contented when treated with understanding and reassurance.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Strongly Disagree
- Disagree

10. Once dementia develops in a person, it is inevitable that they will go down hill.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Strongly Disagree
- Disagree

11. People with dementia need to feel respected, just like anybody else.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Strongly Disagree
- Disagree

12. Good dementia care involves caring for a person's psychological needs as well as their physical needs.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Strongly Disagree
- Disagree

13. It is important not to become too attached to residents.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Strongly Disagree
- Disagree

14. It doesn't matter what you say to people with dementia because they forget anyway.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Strongly Disagree
- Disagree

15. People with dementia often have good reasons for behaving as they do.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Strongly Disagree
- Disagree

16. Spending time with people with dementia can be very enjoyable.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Strongly Disagree
- Disagree

17. It is important to respond to people with dementia with empathy and understanding.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Strongly Disagree
- Disagree

18. There are a lot of things that people with dementia can do.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Strongly Disagree
- Disagree

19. People with dementia are just ordinary people who need special understanding to fulfil their needs.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Strongly Disagree
- Disagree

3Ds

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

3Ds

Domains	Dementia	Delirium	Depression
Memory	Short and immediate memory reduced. Difficulty learning new information.	Reduced immediate and short term memory.	Some short term memory deficits may be present due to poor concentration. Person may report their memory is deteriorating.
Thinking	Reduced problem solving abilities, reasoning and ability to understand abstract concepts.	Disorganised, leaping from one subject to another.	Feelings of helplessness, worthlessness, guilt and hopelessness. Thinking may be slowed or at times people report being unable to think.
Speech	Decreased ability to name things, find words or engage in long conversations.	Significantly different to what is usual for that person, very loud, upset, angry or quiet, slow, difficult to understand.	May be slowed or absent. Expression may be quiet and with short sentences, single words only.
Causes	Dementia is an overarching word for a group of illnesses whose origins are based in organic changes in the brain. Alzheimers disease, vascular dementia, Lewy Body Dementia	Infection, dehydration, medicine toxicity, renal failure, head injury, sepsis, hyponatraemia, hyperglycaemia, malnutrition.	May have a negative view of the world, themselves and people around them, in extreme depression hallucinations and delusion may occur.



(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).

Confusion Assessment Method

(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

ABC Chart

Date/place/time	Antecedents	Behaviour	Consequences	Signature

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:

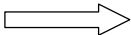
Date: **Time:**

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

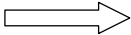
- Q1. Vocalisation**
eg: whimpering, groaning, crying **Q1**
Absent 0 Mild 1 Moderate 2 Severe 3
- Q2. Facial expression**
eg: looking tense, frowning grimacing, looking frightened **Q2**
Absent 0 Mild 1 Moderate 2 Severe 3
- Q3. Change in body language**
eg: fidgeting, rocking, guarding part of body, 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
--------------------------------	-----------------------------	----------------------------------	-----------------------------

Finally, tick the box which matches the type of pain 

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

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