

NOTMAD NOTBAD!

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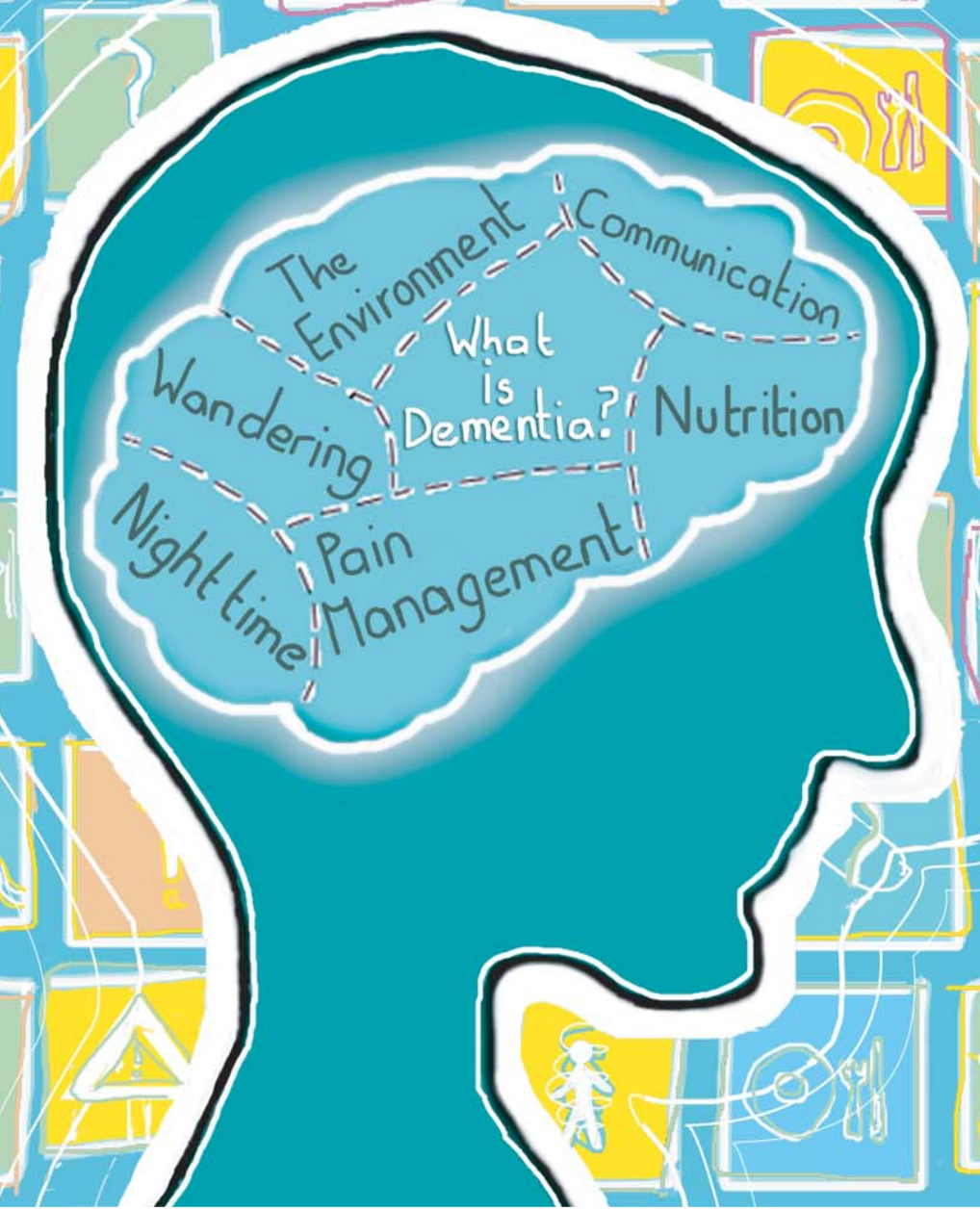
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A guide to dementia and behaviours that challenge for staff working in various care settings

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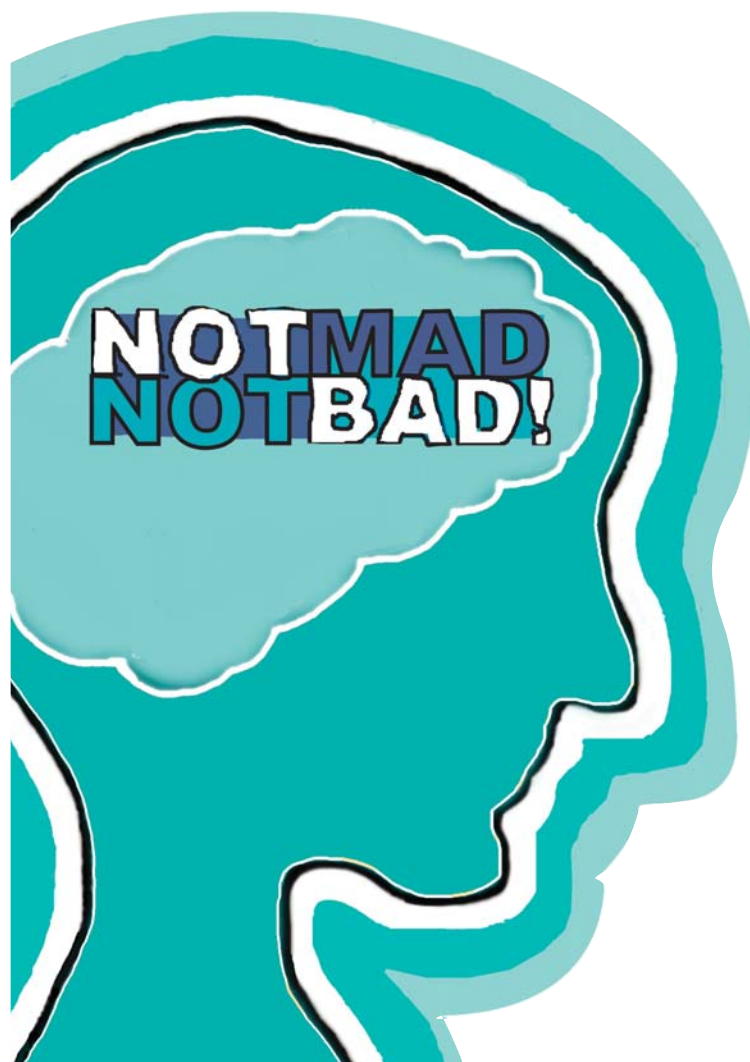
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Introduction

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This guide was created by a collaborative group of senior nurses undertaking the Accelerated Leadership Programme for Modern Matrons working in Older People's Services.

The title was chosen firstly to attract people's attention to it but also to highlight that people with a diagnosis of dementia and who present with challenging or difficult behaviour often act in a way that they would not have in the past.

More often than not people are unable to prevent developing dementia and it is a condition that can affect any person regardless of education, social class, culture or ethnic background. People with dementia haven't chosen to have it and often have had a valued and full life.

The aim is to guide nursing and care staff in the care of people with dementia and coping with the behaviours that patients can present with in care settings.

Throughout this guide we will use the term patient to refer to all people with dementia in all care settings.

What is dementia?

Dementia is an "umbrella term" which describes the various types of diseases that affect the brain in which a progressive decline occurs in memory, thinking abilities, personality and behaviour. There are over 50 causes of and types of dementia. Most types of dementia follow a similar pattern although it is important to point out that no two people with a dementia diagnosis are the same. However, some or all of the following signs and symptoms may be present:

- Short term memory loss.
- Disorientation.
- Loss of problem solving skill.
- Loss of independence.
- Loss of ability to care for own personal hygiene.
- Loss of control over bodily functions.

Most common forms of dementia

There are many different types of dementia; the following are the more common types of dementia that staff will encounter.

Alzheimer's Disease

Alzheimer's disease affects between 50-70% of all people with dementia. It is a degenerative brain disorder that occurs when nerve cells (neurones) in the outer layer of the brain (the cortex) die. The disease affects memory and mental functioning (e.g. thinking and speaking, etc.), but can also lead to other problems such as changes in mood and personality and disorientation in time and space.

Multi-infarct dementia, also known as vascular dementia

This is the second most common form of dementia, affecting around 25-30% of people with a dementia diagnosis. This form of dementia is caused by a series of small strokes that cut off the blood supply to certain areas of the brain causing brain cells to die. Any area of the brain can be affected causing difficulties with memory, speech, language and learning. Symptoms vary considerably from person to person and over time. Speech problems, mood swings, epileptic fits and partial or total paralysis of a limb are fairly common. The symptoms also vary over time in that after the initial deterioration due to the stroke, the patient's condition may seem to stabilise.

Lewy Bodies dementia

Accounts for around 15% of dementia diagnoses. Lewy bodies are tiny, round protein deposits found in nerve cells. Their presence in the brain disrupts the brain's normal functioning, disrupting the action of important chemical messengers.



Pick's Disease – also known as Frontal lobe dementia – Fronto-temporal degeneration

Frontal lobe dementias account for around 5% of all dementia diagnosis. This describes the area in the brain that is affected i.e. damage to the brain cells mainly in the frontal lobe of the brain. Pick's disease is one such form. As damage occurs in the part of the brain that controls planning and behaviour, this form of dementia is often marked by noticeable changes in the personality of the person. Rude, arrogant, dis-inhibited behaviours and failing to respect social rules are early symptoms of this type of dementia. There is a marked lack of initiative, speech is impaired and there is a failing memory for recent events. Spatial disorientation also occurs. Pick's Disease has an earlier age of onset and is very often confused with other mental health diagnoses.

Korsakoff's Syndrome

Korsakoff's syndrome is caused by excessive drinking and a lack of vitamin B12 (Thiamin), leading to neurological damage. Symptoms include very poor short-term memory. In some cases symptoms can be halted or reversed if the person stops drinking and starts to eat healthily.

Other causes of dementia

Creutzfeldt-Jakob Disease, Acquired Immune Deficiency Syndrome (AIDS), Stroke, Parkinson's disease, Huntington's disease.

Statistics and Information

- Dementia is normally associated with old age.
- The prevalence of dementia in people over 65 is approximately 5%, increasing to 20% of the population over 80 years of age (Age Concern 1998).
- The prevalence of dementia in people between the ages of 60 and 65 years of age is approximately 1% (Hofman et al 1991).
- The Department of Health estimates that there are 17,000 people under the age of 65 with a dementia diagnosis (DoH 2001).
- Other studies have shown the prevalence of dementia in the 30-64 years age group as 67.2 per 100,000 (0.07%) (Harvey 1998).
- The vast majority of people with a diagnosis of dementia, around 80%, live in their own home or with relatives or families and only around 10-20% of those with dementia currently come into contact with old age psychiatric services (Goldsmith 1996).

Patient Experience

A small group of patients with dementia were asked about how they would like to be treated and any other comments that would be beneficial for teaching staff about dementia. Their comments are;

- 'I don't want to be looked at or talked to as if you're something from normality'
- the group described wanting 'to be treated as a person, not patronised'
- 'I want them (staff) to have an understanding without having to mention it (dementia)'
- 'want to boost confidence, not knock it'
- 'the person doesn't want the problem broadcast'
- 'if staff are sympathetic then it helps the patient feel less ostracised'
- 'staff need to know how to deal with it but still need to treat people with respect'

The same group of patients were asked about how it feels to have dementia. Their comments included:

- 'it affects all areas of our lives – serious and incidental'
- 'I can't talk to anyone else, can't talk to people who haven't suffered from it'
- people described a 'sense of shame' about the diagnosis
- 'think you've got the plague' and that's also how other people may see you
- 'feel like a dope!'
- 'I've got it and I don't really care who knows I've got it'
- 'it isn't the pariah kind of condition I thought it was'

“The vast majority of people with a diagnosis of dementia, around 80%, live in their own home or with relatives or families (Gold Smith 1996).”



Conditions confused with Dementia

It is important to rule out other physical and mental health conditions that often present similar symptoms to dementia. The following are a few examples.

Depression

London has the highest rates of depression for elderly people in Europe (Rees 2002). Approximately 15% of people over 65 will experience mild depression and around 3% will experience severe depression.

Similarities to dementia

Lack of self care, and the person complaining of poor short term memory.

Differences to dementia

Dementia has a slow development whereas depression can have a sudden onset. Also, the person with depression may appear more disorientated in the morning and show improvement as the day progresses.

Paraphrenia

Paraphrenia is a rare condition often caused as a result of problems with hearing or eyesight or if the person is socially isolated. The delusional or paranoid ideas experienced by the patient are similar to symptoms seen in schizophrenia.

Similarities to dementia

Misinterpretation of events actions and statements, self neglect.

Differences to dementia

Components of behaviour unimpaired, no missing out of steps in tasks, even if reasoning seems bizarre. Responds to treatment.

Anxiety and panic attacks

The person feels agitated and worried about what are often trivial day-to-day issues, to a degree that interferes with their life. They may constantly feel butterflies in their stomach, palpitations, sickness or headaches. Sleep problems are also common and there may be endless worries about their health.

Similarities to dementia

Inability to carry out day to day tasks because of agitation, catastrophic reaction - total failure to cope.

Differences to dementia

Insight into impaired functioning; when stressors are minimised, ability is as normal.

Alcohol related problems

In the age group over sixty-five years of age, between 2% and 15% of men and women drink over recommended limits (Alcohol Concern 2002). These figures are part of an upward trend over the past decade. This late-onset drinking is often associated with problems prevalent in old age (e.g. bereavement, isolation, and mental illness).

Older people are more vulnerable to the physical and psychological effects of alcohol, particularly when mixed with prescribed drugs (Alcohol Concern).

Similarities to dementia

Disorientation, recent memory loss, poor co-ordination.

Differences to dementia

Problems reduced when sober.

Acute confusional state (also known as) delirium

The development of an acute confusional state/delirium characteristically takes place over hours or days and is usually accompanied by signs of physical ill health such as infection or drug toxicity.

Causes can be attributed to one or more of the following:

- Medication side effects or incorrectly administered medication
- Poor diet with reduced fluid intake.
- Endocrine disturbances such as diabetes or thyrotoxicosis.
- Cerebral hypoxia caused by anaemia, pneumonia or transient ischaemic attacks, chest or urinary tract infections.
- Faecal impaction.
- Renal failure.
- Heart disease.
- Hypothermia.
- Trauma i.e. following a fracture or surgery
- Sensory deprivation due to poor sight, poor hearing and social isolation.
- Night time or early morning waking, leading to excess fatigue.
- Environmental changes.
- Grief reaction to bereavement.

Similarities to dementia

Disorientation, poor concentration, self-neglect.

Differences to dementia

Occurs rapidly, worse at night; disappears after underlying cause treated; clouding of consciousness.

Note: A patient with a diagnosis of dementia may also develop an acute confusional state, presenting with a sudden worsening in memory and functioning; the cause may be treatable and should be investigated.

Assumptions and Attitudes towards Dementia

All patients receiving care in any setting want to be treated with respect and dignity and this is the same for people with dementia.

A person with a diagnosis of dementia who is experiencing memory problems is liable to feel vulnerable and in need of support. Staff should do everything they can to help the person with dementia preserve their sense of identity and their feelings of self worth.

Staff working with people with dementia must remember that:

- The person with dementia is an individual with his or her own unique and different life experiences and background. Each will have his or her own likes and dislikes and beliefs and values.
- Symptoms of dementia may present in a similar way; however, each person's experience of dementia will be different and also the way the dementia progresses will be different.
- Staff need to understand the disease and how it will impact on the person.
- Dementia is not a condition to be ashamed of, but requires understanding and patience from staff providing support and care.

A person with dementia might behave in ways that others find annoying, irritating or upsetting. It is important to remember that this is often not deliberate or intentional. Difficult behaviour could be the patient's attempt to communicate with others.

Behaviours that Challenge

People with a dementia can behave in ways that are challenging for staff working with them as the behaviour can be described as dangerous, aggressive or disinhibited.

When working with people with dementia it is important to look beyond the behaviour and try to establish why the person is behaving in such a way.

Often, the behaviour is the only way the patient can communicate, or is a reflection of how they interpret events happening around them or to them due to problems with perception or memory. When a person with dementia is moved to a new environment such as a busy ward or nursing home this can be very unsettling and confusing for the person.

Reasons for challenging behaviour

It is important that staff try to understand the underlying reason for the behaviour instead of just thinking that it is a normal part of dementia. Some behaviours that you may see are:

- Aggression (physical/verbal).
- Wandering.
- Disinhibited behaviour.
- Repetitive questioning.
- Suspicion.
- Pacing.
- Lethargy.

These behaviours are usually associated with the changes that are taking place in the brain, although there may be other factors involved. It is important to always remember that behaviour will vary from person to person. The progression of the disease can cause depression, anxiety, paranoia and hallucinations, which often lead to stressful and challenging behaviour. Before assuming that all difficult behaviour is caused solely by the dementia, caregivers must consider and eliminate other possible causes. Some common examples include:

Physical Illness

Consider any illness or infection the person with dementia may have. For example, a urinary tract infection, ulcer, chest infection, arthritis, or angina and any associated pain or discomfort may cause agitated behaviour or a reduced level of functioning.

REMEMBER it may not always be easy to diagnose the physical problem. For example, toothache may be present with no obvious signs or swelling of the gums.

Medication

Some medications can cause confusion, agitation or other side effects. Sedative medications are often used for people who present with challenging behaviour or to help the person sleep. These must be used very carefully as they could bring unwanted side effects. Problems can include bladder disturbance including incontinence or urinary retention, and the sedating effects can contribute to a higher risk of falls and also impact on the other activities of daily living.

Physical discomfort

Physical discomfort from any external cause, such as being too hot, too cold, or needing to go to the toilet is an important consideration. Ensure that the patient's clothing fits comfortably. Seating may be uncomfortable, or at night, bedding may be inappropriate for the individual.

Dehydration (lack of fluids)

Sometimes a person with dementia may forget to drink or fail to ask, so drinks must be offered. Insufficient fluid may cause many different problems including dizziness, headaches, dry skin, infection, cramp, constipation, urinary problems and increased confusion.

Constipation

Can be extremely uncomfortable and lead to agitated behaviour. Constipation can also cause an acute confusional state.

Environmental Considerations

Too much stimulation in the environment, e.g. TV, radio or other loud conversation, may upset or frustrate a person with dementia. If an aggressive or challenging incident has occurred consider what was happening prior to it – maybe there was too much noise? Crowds, large gatherings and fast-moving people can create agitation. Too little stimulation on the other hand can cause boredom and frustration.

Routine is important to a person with dementia. Problems may occur because a routine has been altered. It is important to remember that some flexibility in the routine may be necessary to cope with the changing moods of the person.

Emotional Concerns

Staff need to be aware of the changes that have occurred recently for the patient, for example having to go to hospital in an emergency, moving into a care home etc. Be aware of any recent loss this includes bereavement, loss of function or loss of role etc. Also the patient may have some insight and awareness of their dementia and will need support to come to terms with the diagnosis.

Cultural and Spiritual considerations

Staff need to be aware of the patient's cultural, spiritual and religious needs and ensure that these are respected and supported.

Life/Social History

As part of the patient's assessment staff need to establish and have an awareness of their life/social history. This may provide an explanation of some the behaviours the patient presents.

Understanding the reason behind problem behaviours

Identify and deal with the most pressing problem first, i.e. the one that occurs most often or causes the person with dementia and the carer most stress.

Is it really a problem?

- For whom is it a problem? Can you accept this behaviour rather than try to alter it.

Identify the possible cause(s)

- Identify what might trigger a particular behaviour at a specific time and place, e.g. what was happening beforehand and who was involved. Patterns may emerge which will show why challenging behaviours have occurred. It may be helpful to keep a written record, for example up to a month, to help you identify causes.
- Are you using an approach that is likely to reduce behavioural problems? Work at the patient's pace i.e. give them time to carry out tasks, provide distraction, avoid infantilisation (treating the person as if they are a child), give straightforward choices, communicate clearly and simply with a calm voice and gentle touch.

Look at possible options

- Think of as many options as possible. Talk to others about the situation – they may have suggestions. Develop and implement a plan that all those involved agree with.

What worked?

- If the challenging behaviour is occurring less frequently, the plan is working. Remember, problem solving is a process of trial and error, there are no simple solutions. What works for one person will not necessarily work for another and what worked once may not work every time.
- It may not always be possible to solve the problem completely. Reducing the frequency or severity of challenging behaviours (increasing the length of time between them) may be as much as can be achieved.

Behaviours that challenge

Understanding the reason behind problem behaviours checklist

This checklist is a guide only and is not an exhaustive list – please photocopy

Patient's Name	Hospital Number
Does the patient have a formal diagnosis of dementia i.e. from a psychiatrist?	
What type of dementia does the patient have?	
When was the patient diagnosed?	
Give brief details of the behaviour.	
How often and for how long does the behaviour occur?	
When does the behaviour occur, Time, place, what was the patient doing and other factors to consider.	
How is the behaviour managed?	
What happens after the behaviour? Is the patient moved to another area?	
Do staff intervene, give medication	
PHYSICAL CONSIDERATIONS CHECKLIST	
Is the patient constipated?	
Last bowel action?	
Blood glucose checked?	
Any physical illness or infection?	
Does the patient appear to be in any pain or has complained of being in pain?	
Has regular or PRN (when required) medication been reviewed (include date).	
Is the patient eating and drinking adequate amounts.	
Date completed	Completed by
Print Name	Designation

Managing behaviour

Managing behaviour

Aggressive behaviour

Some patients with dementia may at some time present with aggressive behaviour. This can be either verbal or physical aggression; the reported rates vary between 20-30% of patients (1999 Alzheimer's Disease International). Care givers and staff refer to aggressive behaviour as a major concern when dealing with a person with dementia (Snyder & Burns 1995).

Triggers for aggression

There are several reasons for such behaviour. It is important to remember that every person with dementia will react to situations in different ways. Aggressive behaviour such as shouting or hitting out, may be due to changes within the brain. Other factors such as the environment either being too noisy, too hot or overcrowded may cause the individual to become agitated or aggressive. Other triggers need to be considered for example, too many demands being put on the individual, fear or frustration.

Preventing aggressive behaviour

By using the behavioural checklist staff may be able to establish the cause of the aggressive behaviour.

- Do not place too many demands on the individual; if they are carrying out tasks ensure that they are not rushed.
- Offer help in a tactful way, guide and prompt the individual, ensure tasks are broken down into easy to manage tasks.
- Be aware of how the environment may be making the person feel, ask yourself is it too hot, cold, noisy or crowded?
- Focus on the patient's abilities. Recognise achievements when carrying out any activity and do not criticise or continually point out errors.
- Be aware of your tone of voice and the words

used when talking to the patient. Remember they may misinterpret what is being said.

- Be aware of warning signs such as the person becoming frustrated, anxious or frightened.

Coping with aggressive behaviour

- Try and remain calm and be aware of how your feelings may be interpreted by the person with dementia.
- Avoid being drawn into an argument or attempting to correct the individual.
- Ensure that the patient has enough space and don't crowd in or make the individual feel trapped.
- Ensure the safety of other patients and only use any form of restraint if absolutely necessary and if competent to do so.
- Distract the individual with another activity or an offer of a drink etc.
- Always remember to never take aggression personally. The patient does not mean to be aggressive and doesn't specifically want to harm you. Very often it is because you are the person who is there.
- Discuss with team members concerns and feelings you may have especially if you have been subject to an aggressive incident. Also discuss ways of approaching the patient with your colleagues to ensure a consistent approach.

“ Always remember to never take aggression personally. ”

Wandering

Patients with dementia can wander for many different reasons:

- They may have always been active person and this is normal behaviour for them.
- Disorientation.
- Boredom.
- Fear and anxiety, for example, unfamiliar surroundings, noise, smells etc.

How can you help?

- Observation; look for triggers, examine the patient history.
- Discuss with carers, is this a normal pattern of behaviour? Does the patient need routine?

Management

Allan (1994) suggested there are several different types of wandering.

- **Social wandering:** be visible, place the patient near the staff and offer frequent personal contact. Enable access to T.V. radio or group activities as appropriate.
- **Self-absorbed wandering:** provide opportunities for patient to be alone, position patient away from others who may initiate unwanted contact. Provide music via headphones, provide magazines and newspapers.
- **Goal directed wandering:** Try and establish what the patient wants to do. Try and help the patient to feel they are doing something meaningful or useful. Initiate conversation about the activity.
- **Emotional wandering:** Staff should acknowledge the patient's expression of emotion, offer comfort. Provide familiar photographs, clothing, music etc.
- **Environment-related wandering:** Minimise triggers such as noise and bright lights, offer flexible routines to suit the person. Ensure the patient is familiar with their environment for example reminding them where the toilet or their bedroom is.
- **Continuous wandering:** For staff this could be the most difficult to manage, look for clues and increase the safety of the environment. Be creative and imaginative, each patient will be different, care will need to be individualised.

Wandering is challenging and requires carers to be sensitive in the approach to individual patient care. Observation and thoughtful intervention can reduce wandering.

Staff and carers in all settings need support in managing patients who wander.

Other Key Factors

Communication

Patients with dementia can have declining communicative abilities that cause physical and emotional barriers that diminish their quality of life.

- Receptive aphasia - where the person has difficulty interpreting the spoken word. Detailed information can become a jumble of sounds, but understanding of non-verbal communication may be reasonable.
- Expressive aphasia - where a person may understand what you say but be unable to find the words to reply.
- Apraxia - where a person is unable to follow a command to carry out a purposeful movement.
- Caregivers need to recognise that many of the so called "problem behaviours" are as a result of an attempt at communication, often related to feelings, needs and wishes.

Communication Techniques

Remember to allow for:

- Sensory losses, such as diminished vision and hearing.
- Effects of medication, such as drowsiness and confusion.
- Physical condition, for example pain, hunger, tiredness, etc.
- Emotional condition, such as anxiety, fear, boredom, anger.
- Environmental conditions, such as noise, discomfort, strange surroundings.

When communicating remember to

- Use the person's name correctly.
- Position yourself so they can see you and make eye contact.
- Be aware of your body language. Avoid tense expressions and agitated movements. Use gentle touch when appropriate and acceptable.

- Use body language to back up what you are communicating e.g. smiles, nods, and gestures.
- Speak clearly, calmly and slowly. Avoid loud or abrupt speech.
- Avoid the use of jargon but instead use phrases/expressions that are familiar to the person.
- Keep sentences short and concise. If asking questions do so one at a time.
- If a person does not understand what you are saying do not keep repeating the same words but rephrase what you are trying to communicate.
- Never talk in a patronising tone or treat the person as if they are a child.
- Genuinely listen to the person allowing them time to communicate. Observe carefully for any underlying meaning/messages especially if the words are unclear or incorrect.
- Pay attention to the person's non-verbal language including tone of voice and body language.
- Encourage the use of gestures if the person has difficulty communicating verbally.
- When attempting to understand what a person is trying to communicate use clues to try and guess what they might be communicating and check these clues with them.
- If the person has apraxia, you may need to use techniques such as distraction by talking about something other than the task at hand. Use touch and guidance with your body movements to help the person respond appropriately. For example, slightly moving a walking frame will often start a person walking, whereas with a direct request to walk they may freeze.
- Communicating effectively with patients with dementia requires caregivers to draw on a range of skills. Acting upon the knowledge that people have many different ways of understanding and expressing themselves is the key to successful communications.

The Environment

A sensitively planned environment is very important to improve the well being of a person with dementia. If they are in an unfamiliar and unsupportive environment their confusion may increase and their ability to retain information will deteriorate. A cognitively impaired physically active person will be more orientated in an environment with adequate sign posting and cues. A simple structure and layout can reduce wandering.

Colours

Some patients with dementia have difficulty distinguishing between yellow and blue. In fact, colour coding with contrasting pastel colours has been shown to encourage independence and a feeling of control through easy identification of places and rooms for normal routines e.g. using the toilet, bathing, meals and relaxation (Bell 1992). Patients may experience difficulty walking from room to room if there are significant contrasts in the colours of the floor coverings.

Surroundings

Unfamiliar surroundings can reinforce perceptions that they are being kept away from loved ones, so place personal items like dressing gown and pictures by the bed. Try not to move their bed space around in the home or hospital. It should be noted that placing the person too far from staff may cause feelings of insecurity, and placing them too near can lead to over stimulation. Environmental noise and bright lights can induce extreme stress and agitated behaviour such as agitation, so it is important to try to assess each person individually to see what suits them best.

Toilet

Given the increased incidence of urinary frequency and reduced mobility in older age, it is important that toilets can be easily identified. Low intensity lighting at night, visual cues such as signs with

pictures and words can assist the patient to find the toilet. Contrasting colours can make the toilet or sink visible against walls and flooring.

Mirrors

Coming across a mirror could suddenly distract the patient. Removing or covering mirrors may assist in managing any agitated behaviour, for some patients with dementia may not recognise their own reflection.

Lighting

A diffuser over fluorescent lighting can make over-bright lights softer and less clinical. The environment will then appear cosy and relaxed.

Therapeutic environment

It is the responsibility of staff to provide a healing and supportive environment. Simple measures can be implemented to help the person feel safe and secure, such as allowing them to walk without restrictions. While it can be difficult to make an area risk free, ensuring that there is a clear area for people to walk freely will mean that they can feel that they have personal space and control.

Temperature

Staff must be aware that persons with dementia could have reduced sensory awareness and reduced problem solving skills. To help overcome these problems, find out whether they are hot or cold or uncomfortable, and help them add or remove a jumper or adjust temperature, seating or bedding accordingly.

If the environment can be made as therapeutic as possible, staff may find that their patients could present with less challenging behaviour.

Night Time

People with advanced dementia sometimes become more confused and agitated during late afternoon, evening and nighttime. It is often referred to as the 'Sundowning' phenomenon. The cause is not known but seems to result from brain diseases whether acute or chronic. Some theories link it to the condition Seasonal Adjustment Disorder (SAD), a mild type of depression that occurs during winter related to lack of day light. Others link it to low energy levels and lack of ability to concentrate as the day progresses, particularly affecting people who have Alzheimer's.

It is more likely to occur when the person's routine is altered suddenly, or the environment changes and unfamiliar faces are present.

To try and manage the situation the following steps could be taken:

- Find out as much as possible about the person's lifestyle and their normal evening and bedtime routine.
- Ensure adequate lighting as confusion can increase if the environment appears dim.
- Allow the person to wander in a safe area, as restraint will lead to further agitation and upset.
- Talk to the person in a calm and reassuring manner, walking with them if necessary.
- Limit the intake of stimulants e.g. coffee, tea, cola etc.
- Offer a warm bath.
- Keep noise to a minimum.
- Provide activity and stimulation during the daytime.
- Assess for pain.
- Offer food or a milky drink.
- Offer the toilet.
- As a last resort discuss the possible use of medication with a Doctor.

People with dementia can easily become scared but are unable to seek reassurance because of communication and thought processes impairment. They should always be approached in a calm and reassuring manner.

Pain Management

Depending on the level of cognitive impairment, patients with dementia may not always receive adequate treatment for pain. This could be because of the difficulty of assessing pain in people with severe dementia if they are unable to communicate their experience to their carers. Pain can therefore be under-treated or, in some cases, untreated. It must be remembered that it is equally difficult to assess the effectiveness of pain control once pain relief has been given. The following signs and symptoms may be expressed and can be used to assist in assessing pain and pain control. (Closs 2002)

- Increased agitation, fidgeting or repetitive movements.
- Tense muscles, body bracing.
- Increased calling out or repetitive verbalizations.
- Decreased cognition and functional ability.
- Changes in sleep pattern.
- Falling.
- Increased pulse, blood pressure, sweating and pallor.
- Emotional signs for example; withdrawing or crying.
- A general change in the patient's normal behaviour.

Staff should consider referral to the pain specialist services and the use of a pain assessment tool.

Nutrition

It is important to make sure individuals with dementia get enough food and drink.

Weight loss can be common and is often linked to factors such as a lack of recognition of hunger and thirst, increased physical activity, and poor nutrition. This weight loss should not be considered inevitable. There are several ways it can be reduced, particularly when combined with an awareness of how dementia can impact an individual's pattern of eating;

- Food preferences often change. They may become unusual, for example mixing foods that don't physically go together, or eating non-food items. Individuals with dementia may develop a very sweet tooth.
- Our sense of smell diminishes as we age, and this can be further impaired in dementia.
- Age and dementia can also affect vision. Persons with dementia may have difficulty recognising contrasting colours or shades. They are better able to discriminate in the red/yellow areas of the colour spectrum. Discrimination can be helped by colour contrast between food, plate and tablecloth. However, certain patterns e.g. flowered tablecloths, can confuse.

When providing food, you need to remember to:

- Consider cultural and religious needs.
- Consider dietary requirements e.g. diabetic.
- Establish the person's prior food preferences.
- Still continue to offer choices e.g. if they want gravy.
- Provide assistance with eating as individually required.

Individuals may tend to walk about rather than sit still so serve food promptly and consider the use of finger foods and frequent small snacks.

Ensure the individual can reach their food and prompt them as necessary so that they know to eat and drink.

Dementia patients may eat in a messy way, have difficulty using cutlery or even use their fingers. If appropriate, use equipment such as plate guards and special cups. Caregivers need to be more flexible, as our aim should be to improve dietary intake; table manners are secondary.

Caregivers need to remember to ensure the condition of the individual's teeth or dentures and gums is conducive to eating.

The mealtime environment can critically impact intake. It is important to have appropriate lighting, temperature, noise level and table layout. Individuals need to be seated comfortably. Their mealtime companions should be selected as the most compatible to encourage eating.

Some individuals with dementia may need assistance with feeding; this experience can be enhanced by caregivers showing respect and undivided attention towards individual. Staff need to be aware how their actions i.e. talking to colleagues and assisting several people at one time may impact on the individual's dietary intake. However staff must encourage them to be as independent as possible.

Time of day can impact intake. People with dementia often eat better earlier in the day (e.g. breakfast time) when they are less tired and tolerance and cognitive ability are at a peak.

Consent

Obtaining Consent for Treatment

Treatment is any intervention taken by a team member, such as: taking observations, feeding, administering medication, and delivering personal care.

Consent must be obtained before administering treatment. It may be indicated orally, in writing or non-verbally (e.g. by holding out an arm so blood pressure can be measured).

The basic concept of human rights, and also the law, presumes a person has capacity to make a decision unless demonstrated otherwise.

- We often fail to consider consent until it is withheld.
- When an individual lacks the mental capacity to give consent for himself or herself, no one else can give consent on their behalf..
- Treatment may be given to those who lack capacity if it is considered to be in their "best interests."

Consent and Dementia

- Capacity relates to a person's ability to make the decision, not to the actual decision. All adults have the right to make a decision even if others consider it to be irrational.
- A person with dementia may lack capacity to make a complex decision but be able to make other more straightforward decisions.
- Capacity is "decision specific"; it varies from time to time and decision to decision.

A person lacks capacity if he/she cannot understand information about the treatment and its consequences long enough to make a decision, and/or is unable to use and weigh this information in the decision-making process. Staff should consider whether the treatment being refused can be as effectively achieved in a manner less restrictive of the person's freedom of choice.

If a person is unable to give consent treatment may be given if it is in their best interest, but when doing this staff must remember to not make the decision too hastily but with full consideration. This includes remembering to:

- Confirm that the person had been permitted to participate as much as possible in the decision-making process e.g. using suitable communication techniques.
- Consider the person's past and present wishes, which will involve obtaining information from

relatives, friends and carers that includes information about their religious, cultural and non-medical views.

It is crucial to consider communication techniques used when seeking consent as communication problems are often linked to a lack of co-operation and misunderstandings.

Try to seek consent in a conducive setting e.g. familiar surroundings. Also when possible at a time that is better for the individual e.g. earlier in the day when less tired.

Documentation Related to Consent

Must clearly record relevant details including:

- What happened and who was involved in the decision making process.
- Information about best techniques/approaches to use to achieve a more therapeutic interaction with the patient.

Consequences of Giving Treatment in the Absence of Consent

A civil law action may be brought against the person administering treatment (and possibly against the employer as well) on grounds of 'trespass to person' or negligence in addition to criminal charges for battery.

Disguising medication in food

- Only in exceptional circumstances and never as a way to avoid consent or as a first course of action.
- Must be sure that an appropriate medicinal preparation is used; many medicines are not designed to be crushed, dissolved etc. as this could result in unpredictable pharmacological outcomes and in some cases serious physical consequences.
- Staff should never make a decision to do this in isolation but consult with the rest of the multidisciplinary team.

Always document clearly when this practice is adopted

Medication

Wandering, aggression, inability to sleep and other challenging behaviours should not be managed through medications as the first option. Other solutions should be investigated. Over prescribing of medications may result in other side effects such as increased falls, more challenging behaviour etc.

The National Service Framework for Older People has targeted Primary Care Trusts and in particular GP's to review patient's medication on a regular basis. Patients on four or more medications should be reviewed six monthly and an annual review for people on less medication. This should encourage active monitoring of medications to ensure they continue to produce the desired effect and help prevent adverse reactions.

“Wandering, aggression, inability to sleep and other challenging behaviours should not be managed through medications as the first option.”

Abuse

“A single or repeated act or lack of appropriate action occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person.” (1995 Action on Elder Abuse, London).

Unfortunately, abuse of older persons does occur. They are a vulnerable group and within the group those with dementia are at even higher risk of abuse.

Staff must be concerned about recognising the signs of possible abuse and be aware of their responsibilities if it is suspected.

It must be remembered that abuse can occur in both formal and informal care settings.

Types of Abuse

Physical Abuse

Any physical contact which results in discomfort, pain or injury. Includes inappropriate administration of medication.

Verbal Abuse

Any remark made about a patient which may be reasonably perceived to be demeaning, disrespectful, humiliating, intimidating or offensive in ways which cause distress.

Emotional Abuse

Verbal or non-verbal behaviour which is not only disrespectful of a patient but could also be emotionally or psychologically damaging.

Sexual Abuse

Coercing, forcing or attempting to make the patient take part in a sexual act

Discriminatory Abuse

Abuse based on age, sex, race, disability etc.

Financial / Material Abuse

Theft or misuse of money, valuables, property or resources.

Information Abuse

Failure to adhere to relevant data protection guidance and lack of information

Institutional Abuse

Failure to recognise individuality and rights as a citizen

Care Omission /Neglect

Refusal or failure to identify and/or meet the essential care needs of an individual.

Signs of Possible Abuse

- Frequent visits to the GP and/or Accident & Emergency Department.
- Frequent unexplained injuries or complaints of pain without obvious injury.
- Burns or bruises suggesting the use of instruments, cigarettes, etc.

- Evidence of over-medication: poisoning, stupor.
- Passive, withdrawn and emotionless behaviour.
- Lack of reaction to pain.
- Sexually transmitted diseases or injury to the genital area.
- Difficulty in sitting or walking.
- Fear of being alone with care givers.
- Obvious malnutrition.
- Lack of personal cleanliness.
- Habitually dressed in torn or dirty clothes.
- Deprivation of aids to mobility and perception e.g. frame, glasses, hearing aid.
- Obvious fatigue and listlessness.
- Begs for food or water.
- In need of medical or dental care.
- Evidence of physical restraint (marks from tying).
- Bedsores and skin lesions.
- Deprivation of personal effects, money, possessions.

If staff are aware of abuse and do not report it they are not fulfilling their “duty of care” to do “whatever is reasonable” to promote the welfare of their patient. At all times when abuse is suspected or known staff must follow their local policy and act accordingly.

Staff will not be penalised at any time for their good faith actions to protect patients.

All allegations from a patient that indicate possible abuse must be followed up and investigated. If it transpires that the patient is repeatedly making groundless allegations, the facts must be recorded in the care plan so that they are available for other staff to see. Failure to do so may result in wasted time and unnecessary stress and suspicion of innocent staff members. If you encounter such a situation, you should first make sure that there are no other indications of abuse before overlooking the allegation.

Teaching and discussion scenarios

Guidelines for the facilitator

If using this pack for training or teaching purposes, before the session ask staff to read the relevant section and think about patients that they have come in contact with who have presented with similar challenges.

Present the vignette to staff and ask them to consider possible solutions to the scenario.

Following each vignette are some additional pointers to facilitate further discussion.

Please note this is not an exhaustive list of strategies for solving the issues described and each situation needs to be assessed individually.

Remember there is not always a clear solution to every problem.

Communication

Mrs B keeps banging on the table with her fist and humming loudly.

How do you manage this behaviour?

FACILITATORS NOTES

- Is the patient bored and frustrated?
- Has an assessment been carried out to identify any triggers?
- Does distraction help e.g. enrol patient in an activity such as laying the table, tidying linen cupboard etc.

Issues for discussion

- Don't be negative and tell patient off and say she must be quiet.
- Try to find out from the patient if anything is wrong, explore her feelings.
- Be genuinely interested.
- Listen patiently and encourage the patient to talk about her feelings.

Mrs A is constantly asking for her mother and wanting to go home to her.

FACILITATORS NOTES

- Show genuine interest and concern.
- Encourage her to talk about her mother.
- Establish that she misses the security and affection her mother gave her.
- Allow her to express these feelings knowing someone has understood.
- Although this is not a solution to Mrs A's problem it will help her better cope with her feelings as she will feel less isolated. It might also help staff build up closer relationship with a patient.

Issues for discussion

- Do not respond to patient that her mother has died or dismiss her anxiety and distress with careless comments. Acknowledge the feeling behind the words.
- Validation was a term developed by Naomi Field, which gives more detail on how staff can use this type of empathic response.

Consent

Mrs T has dementia and cardiac problems. Each day she will take her morning medications in her room but at lunchtime when she is in the dining room she makes a fuss and refuses to take her medications when they are offered.

How do you manage this behaviour?

FACILITATORS NOTES

- Patients can be labelled as un-cooperative
- Staff need to establish reasons why she might not want to take the medicine at that time. Perhaps linked to all the noise and distraction in the dining room or that she prefers to take her medication privately in her room.
- Explore all other options including giving medication at another time, other location etc.
- Discuss issues of disguising medication in food.

All avenues should be explored before considering whether the medication should be disguised. This method of administering medications should only be considered as a last resort and should not happen on a regular basis. All team members and appropriate family members need to be aware of the decision and that the plan is clearly documented and reviewed on a regular basis.

Verbal

Whenever Mr A is assisted with personal hygiene, necessary as he is doubly incontinent and has dementia, he becomes verbally abusive (which can be of a racial nature) towards staff who are helping him, particularly if they are male.

How do you manage this behaviour?

FACILITATORS NOTES

Issues for discussion

- Be sensitive to the patient's needs, however consider what is in the best interest of the patient.
- Communication- remain calm, tactfully explain to the patient clearly and simply what you wish to do, at all times maintaining the patient's dignity.
- Staff need to have a clear plan how to manage this behaviour.
- It may be appropriate to give the patient some time and come back to them.
- Be aware of staff allocation.
- Support staff following any type of verbal or physical aggression.
- Always remember it is very often the dementia and not the person that makes them behave like this.
- Be aware of the social history and talk to staff and family members how this behaviour has been managed in the past.
- Document what has worked or not worked.

Nutrition

Mr R would regularly refuse food stating it was not fit for animals when in fact it was of an acceptable quality and enjoyed by many others. Sometimes he would also tip the food around his room or hide it in various places in the room including under his bed.

How do you manage this behaviour?

FACILITATORS NOTES

Issues for discussion

- Social History, particularly related to favourite foods etc.
- How food is presented and where meals are served. Is the dining area noisy or busy.
- Staff may need to be creative when considering nutritional intake, for example meals at different times, snacks, finger food.
- Ensure the patient is involved in menu choice regardless of the fact they may have short-term memory problems. Offer a visible choice of meals so that patient can see what is being offered.
- Ensure that the patient's dentures fit correctly, or that they are not in any pain or discomfort from tooth or gum ache.

Night Time

Mr C wakes at 04:00hrs every morning, gets up and wanders around the ward/home.

How would you manage this situation?

FACILITATORS NOTES

Discuss the following

- Social history.
- Pattern of behaviour.
- Medication.
- Risk factors.
- Whose problem is this? (staff, other patients or the patient).

Issues for discussion

- Imposing values and rules to fit in with ward routine.
- Is this normal behaviour? Was he a postman, farmer, milkman, shift worker?
- Has he always woken early?
- Provide a safe environment for the patient to continue with his activity.
- If the patient is causing a disruption and disturbing other patients or putting anyone at risk staff would have to intervene to maintain the safety of all concerned.
- If behaviour is disruptive for other patients this will need to be managed.
- Manage the environment.
- Is the patient asleep throughout the day.
- Are there enough appropriate activities that the patient can get involved in during the day.

Pain

Imagine you had an acute back pain and were in a foreign country unable to speak the language or make others understand your discomfort.

How would you behave?

FACILITATORS NOTES

Although this vignette is not about a particular patient, the exercise encourages staff to consider how it may feel for a patient with cognitive problems who is unable to communicate effectively.

Issues for discussion

Ask staff to relate their feelings to how the patient may behave who cannot communicate effectively. Identify how they would assess the patient's pain.

- Verbal and non verbal communication
- Patient observation
- Signs and symptoms of pain
- Pain may cause challenging behaviour i.e. pacing, rocking, increase calling out etc

Wandering

Talk about your experience of patients wandering.

FACILITATORS NOTES

- How have you managed this?
- Who has the wandering been a problem for?
- Is the patient at risk?
- How do you manage the environment?
- Are there any triggers to the wandering behaviour?

Issues for discussion

- Is the patient's wandering interfering with others?
- Is the patient in pain?
- Is the patient bored?
- Have you orientated the patient to the environment?
- Does the patient have their own belongings?
- Does the patient need some form of distraction – TV, radio, magazines, something to do?
- Manage the environment – lighting, noise, signage for toilets/bathrooms etc.
- Observe the patient and assess what is happening before intervening.
- Do not simply bring the patient back to where the wandering started and expect them to stop.

“...studies have shown the prevalence of dementia in the 30-64 years age group as 67.2 per 100,000 (0.07%) (Harvey 1998)”

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This guide was created by the following group of senior nurses undertaking the Accelerated Leadership Programme for Modern Matrons working in Older People's Services.

Chris O'Connor

Lead Nurse Older People's Services, (Merton and Wandsworth) South West London and St. George's Mental Health NHS Trust

Kim Parish

Head of Nursing Rehabilitation and Older People's Services Wandsworth PCT

Moira Isenman

Care Manager Heathland Court BUPA Care Homes

Shaaron Cartella

Home Manager The Westminster Queens Court

Sue Hadland

Clinical Nurse Manager for Older People Sutton and Merton PCT

Zeenat Den

Lead Nurse/Matron Geriatric Medicine St. George's Healthcare NHS Trust