

# “Getting to Know Me”

Supporting people with dementia  
in general hospitals



## Booklet for Staff

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## Introduction

Dementia affects over 800,000 people in the UK. This figure continues to rise and is expected to be in excess of 1.7 million by 2051.<sup>1</sup> It is estimated that 25% of people in hospitals may have dementia.<sup>2</sup>

Being in hospital can be an unsettling and disorientating experience for anyone. For a person with dementia it may be much worse. There is growing evidence that when compared to patients without dementia, patients with dementia in hospital are more likely to:

- Experience poor nutrition and poor hydration
- Develop delirium
- Receive inadequate pain control
- Experience lengthier hospital stays
- Move from hospital into long term care

This booklet is designed to help you understand what dementia is, and offers straightforward and accessible advice on caring for people with dementia in the hospital environment.

<sup>1</sup> Alzheimer's Society (2012). *Dementia 2012: A national challenge*. London: Alzheimer's Society.

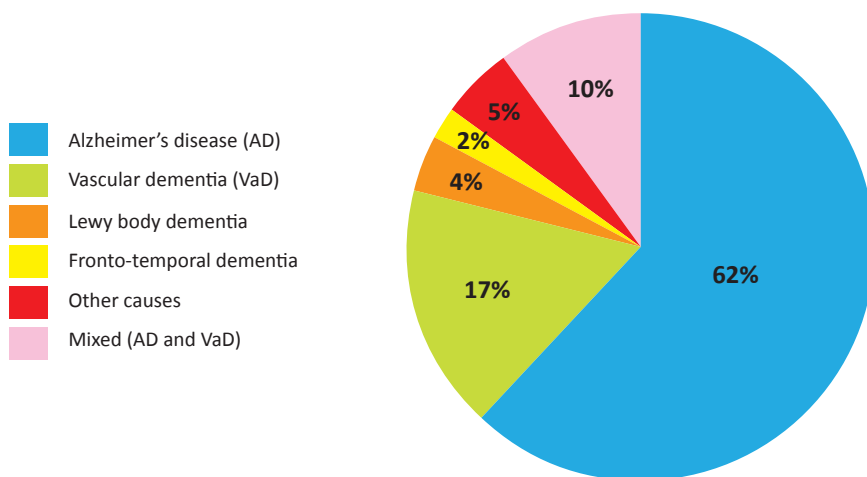
<sup>2</sup> Department of Health (2012). *Using the commissioning for quality and innovation (CQUIN) payment framework. Guidance on new national goals for 2012-13*. London: Department of Health.

## What is dementia?

### Dementia can be described as:

“...a syndrome (a group of related symptoms) that is associated with an ongoing decline of the brain and its abilities. These include thinking, language, memory, understanding and judgement; the consequences are that people will be less able to care for themselves.”<sup>3</sup>

Dementia can be caused by a number of different diseases:



Figures taken from Alzheimer's Society (2007) Report <sup>4</sup>

Dementia is an age-related condition. It occurs much more commonly in older people with one in five people over the age of 80 affected.<sup>4</sup> However, dementia also affects younger people, and there are over 16,000 people diagnosed with dementia under the age of 65 in the UK.<sup>5</sup>

<sup>3</sup> The NHS Confederation (2010). *Acute Awareness: Improving hospital care for people with dementia*. London: NHS Confederation.

<sup>4</sup> Alzheimer's Society (2007). *Dementia UK*. London: Alzheimer's Society.

<sup>5</sup> Alzheimer's Society (2012). *Dementia 2012: A national challenge*. London: Alzheimer's Society.

## What is Alzheimer's disease?

Alzheimer's disease is the most common cause of dementia. It is a progressive condition with gradual onset. There is a complex pathology in which neurones (brain cells) and the communication pathways of the brain are destroyed. Plaques and tangles develop in the structures of the brain, chemical messengers are affected, and areas of the brain decrease in size.

There are many features of Alzheimer's disease and people are affected differently. Some of the changes a person may experience include:

- Memory loss – short term memory is usually affected first. Long term memory often remains intact initially, although this too may be affected over time
- Increasing difficulty with everyday skills
- Word finding difficulties
- Increasing difficulty understanding verbal or written communication
- Impaired reasoning
- Recognition problems – objects and people
- Disinhibited behaviour
- Difficulties with purposeful actions
- Changes in mood
- Visual-perceptual and spatial awareness difficulties



## What is vascular dementia?

Vascular dementia is the second most common cause of dementia, and often co-exists with Alzheimer's disease. Major or minor strokes restrict blood getting to areas of the brain (sometimes resulting in multi-infarct dementia if the damage is significant enough). When deprived of blood, brain cells in affected areas can die which can cause cognitive impairment.

Small vessel disease can also result in vascular dementia. This is when there is damage to the smaller vessels deeper in the brain structure.

The difficulties experienced with vascular dementia are similar to Alzheimer's disease, but the following differences may also be apparent:

- The onset is often sudden (except in small vessel disease where symptoms develop more gradually)
- There may be periods when symptoms do not progress, followed by an episode of acute confusion often associated with a new major or minor stroke. A series of strokes can result in a "step-like" progression of impairments
- There is an increased likelihood of problems with unpredictable behaviour or changeable mood
- Some abilities may remain largely intact depending on which areas of the brain are undamaged
- In small vessel disease, symptoms tend to develop more gradually, mobility can be affected, and the person can appear "slower" in thought and action

## What is dementia with Lewy bodies?

Dementia with Lewy bodies (DLB) accounts for approximately 4% of all cases of dementia (although some studies put this figure much higher). Lewy bodies are tiny spherical protein deposits found in nerve cells in the brain (they also occur in the brains of people with Parkinson's disease). The condition shares some of the symptoms of both Alzheimer's disease and Parkinson's disease. The following are features:

- Fluctuating episodes of lucidity and confusion
- Auditory and visual hallucinations
- Parkinsonian symptoms such as tremor, muscle stiffness, slowness, changes to voice tone and strength
- Risk of falls
- Disturbed nights with nightmares and hallucinations
- Memory performance is often not affected to the extent it is in Alzheimer's disease
- People with DLB may have a dangerous sensitivity to neuroleptic medication

## What is fronto-temporal dementia?

Fronto-temporal dementia (FTD) covers a range of related conditions that affect the frontal and temporal lobes of the brain. Although much rarer than the dementias previously described, it is one of the more common causes of dementia in people under 65.

Symptoms vary according to the specific type of FTD but can include:

- Changes to personality, including a lack of insight and ability to empathise with others
- Disinhibition. People with FTD may act spontaneously and in a way that other people might deem “inappropriate”
- Obsessive compulsive behaviours and repetitive behaviours
- Eating habits can change and it is not uncommon for people with FTD to develop a compulsive appetite for sweet foods
- Language can be affected in some forms of FTD

## Delirium

Delirium and depression are highly prevalent conditions in older people admitted into hospital. Patients who have dementia are at a particularly high risk of also developing delirium<sup>6</sup> and/or depression.

Delirium (or acute confusional state) is characterised by disturbed consciousness and cognitive function or perception. It often has a rapid onset and a fluctuating course. It may be caused by any acute physical illness (e.g. urine or chest infections) or drugs (e.g. opiates), and it is a serious medical condition.

It is imperative to rapidly identify and treat the underlying cause.

**Delirium is frequently a sign of acute – perhaps severe – illness.**

### Risk factors for delirium:

Age 65 years or older

Cognitive impairment (past or present) and/or dementia

Current hip fracture

Severe illness (a clinical condition that is deteriorating or is at risk of deterioration)<sup>7</sup>

<sup>6</sup> Royal College of Psychiatrists (2005). *Who Cares Wins: Improving the outcome for older people admitted to the general hospital*. London: Royal College of Psychiatrists.

<sup>7</sup> National Institute for Health and Care Excellence (2010). *CG103 Delirium: Diagnosis, prevention and management*. London: National Institute for Health and Care Excellence.

## National Institute for Health and Care Excellence guidelines on delirium <sup>8</sup>

Indicators of delirium: at presentation

Assess people for recent changes (within hours or days) or fluctuations in behaviour. These may be reported by the person at risk, or 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 co-operation with reasonable requests, withdrawal,\* alterations in communication, mood and/or attitude

If any of these behaviour changes are present, a healthcare professional who is trained and competent in diagnosing delirium should carry out a clinical assessment to confirm the diagnosis.

<sup>8</sup> National Institute for Health and Care Excellence (2010). *CG103 Delirium: Diagnosis, prevention and management*. London: National Institute for Health and Care Excellence.

## Warning about delirium

In hospitals delirium can be missed because:

a) Although patients experiencing delirium may be agitated and clearly confused (hyperactive delirium), this is not always the case. Patients with delirium may also be quiet, withdrawn or drowsy (hypoactive delirium) and they may be easily missed. Some patients may show signs of both (mixed delirium).

b) The patient may have a known diagnosis of dementia. Where this is the case, altered behaviour may be assumed to be “normal” for that person and “part of the dementia” rather than the manifestation of an underlying (and treatable) cause.

The guidelines for providing person centred care for people with dementia which appear in this booklet are also appropriate for providing care to people experiencing delirium.

**“ If only more people knew how easy it is to talk about dementia and how important it is to talk about it. It is by talking that we feel much more comfortable with our problem ”**

## Depression

Depression is a mood disorder and disturbs normal functioning. People can experience negative thoughts, low mood, forgetfulness and loss of interest. Depression can also be accompanied by physical symptoms such as fatigue, loss of appetite, difficulty sleeping, aches, pains, and sometimes delusions.

One in four older people have symptoms of depression that require treatment. Physical illness, hospital admission and dementia are all risk factors.<sup>9</sup>

If depression is suspected, consider a referral to the hospital liaison team and make an immediate referral if a person expresses thoughts of suicide or self-harm.

**20% - 25% of people with dementia also have symptoms of depression<sup>10</sup>**

### **Delirium and depression in people with dementia:**

- Do not assume that a person's behaviour and confusion is necessarily a direct consequence of their dementia
- Dementia can become a "label" and obscure the identification of depression or delirium and potentially serious underlying health concerns
- Relatives will often be the most important source of information and may be able to inform you what is - and what is not - "normal" behaviour for that person

<sup>9</sup> Royal College of General Practitioners (2011). *Factsheet: Management of depression in older people: why this is important to primary care*. London: Royal College of General Practitioners.

<sup>10</sup> Amore, M., Tagariello, P., Laterza, C., & Savoia, E.M. (2007). Subtypes of depression in dementia. *Archives of Gerontology and Geriatrics*, 44 (s1), 22-23.

## Seeing the person

Providing good quality care for people with dementia in hospital is about providing care for the whole person. The hints and tips in the pages that follow are about looking beyond the diagnosis and seeing the person.

*“Ask not what disease the person has, but rather what person the disease has”*

William Osler

**Good dementia care should be underpinned by the following principles:**

- **Stepping into the person’s world and asking:**

How might the person be perceiving their situation? Is their perception of reality likely to be any different from my own? What might they be thinking? Does the person know who I am or where they are? What might they be feeling – physically and emotionally?

- **Seeing and valuing the patient as a person:**

We must be vigilant to ensure that dignity and respect underpin all our interactions with people with dementia. We need to see the person beyond the diagnosis. Knowledge of the person, for example, their likes, dislikes, interests, cultural and spiritual needs can greatly inform the care we provide.

- **Focusing on feelings:**

Having dementia and being in a hospital environment will give rise to powerful emotions which might include fear, insecurity, abandonment, puzzlement, and frustration. Empathy is an essential pre-requisite in the care of people with dementia.



## Communication

People with dementia often experience increasing difficulties with communication. This can be related to a growing difficulty in both expressing and understanding language.

As a consequence, we need to pay greater attention to try to interpret a person's needs and feelings. When we wish to express something to a person with dementia we need to adapt our usual style of communication to compensate for their difficulties.

***“As we become more emotional and less cognitive, it's the way you talk to us, not what you say that we will remember ”<sup>11</sup>***

### Case example

Annie Winterton could no longer form words into sentences and she seemed to struggle to understand what was being said to her. Staff learned to communicate with her through actions. Rather than asking if she would like a cup of tea, the nurse would hold up an empty cup and mime taking a drink. This clearly worked for Annie, and it was evident from her facial expression whether she wanted a drink or not.

**“Bear in mind it takes my mind sometimes a second or two to understand what is being said, so it's important not to speak too quickly, to speak clearly and to leave a little space for me here and there ”**

<sup>11</sup> Bryden, C. (2005). *Dancing with Dementia*. London: Jessica Kingsley.

## Communication: hints and tips

- Concentrate on your non-verbal communication (your words might not make sense to the person but your tone of voice and body language probably will)
- Slow down speech (do not out-pace) and reduce the length of your sentences. Bite sized chunks of information may be more readily understood than lengthy sentences
- Approach the person from the front and speak “face-to-face” with good eye contact
- Keep speech clear and simple, avoiding both jargon and figurative phrases such as “it’s raining cats and dogs”
- Make use of objects/cues/pictures to support what you are saying. Even when the spoken word is not recognised, it may be that an image or object representing the word or phrase is understood
- Concentrate on the feeling/need behind what a person is saying. For example, if a person is asking for their mother, think why this might be. Are they feeling anxious or lost? Do they need comfort? Are they experiencing pain? Do they need to go to the toilet?
- Try to provide opportunities for reassuring human interaction. Stop and share a few moments when you can. Encourage flexible visiting where possible
- Talk through procedures clearly as you do them to try to reduce any fears
- Repeat information regularly, for example, say who you are and where the person is. Remember, short term memory is often affected in people with dementia, this can mean people may forget information in a matter of moments

## Coping in a strange environment

The hospital environment can be a strange and unfamiliar place.

People with dementia may have impaired memory, reasoning, spatial awareness and communication. This makes it more difficult for them to make sense of their surroundings and to feel safe, secure and orientated.

Put yourself in the shoes of a person with dementia. If you were in a strange and disturbing place and your short-term memory was so poor that you couldn't retain information:

- What or who might help you to feel more safe and secure?
- What would help you to find your way around?

### Case example

When Roger is in an unfamiliar situation or when he is unsure what is expected of him, he often becomes anxious. As a consequence he can become agitated and sometimes aggressive. On a recent occasion – prior to his current admission – Roger attended a clinic for a procedure under local anaesthetic. Roger's wife, Joan, was discouraged from entering the theatre with him. Midway into the procedure Roger became anxious and agitated, and the procedure had to be abandoned. Both he and Joan were left feeling very distressed by the experience. Joan feels this could have been avoided had she simply been permitted to be at his side to reassure him. Now when Roger is in hospital, Joan has requested to be with him during procedures (e.g. scans) whenever possible.

## Improving the physical environment: hints and tips

- Use prominent clocks, calendars and pictures on walls to help orientation
- Keep signage simple and uncluttered. Use images as well as words (for example, an image of a toilet on a toilet door)
- Consider drawing attention to toilets/bathrooms with colours that help define these areas
- Try to “soften” the appearance of bathrooms to create a domestic and unthreatening space
- Ensure adequate lighting but avoid glare
- Avoid reflective, highly polished floors that reflect glare
- Control noise as far as possible
- Create areas of interest/talking points such as interesting pictures on walls, some of which might have reminiscence value
- Create spaces for interesting activity where possible e.g. activity table/day room

**“ It was the simple things which gave me a problem, like: Where is the toilet? How do I get there? How do I get back? ”**

## Case example

Judith became tense and agitated when helped to mobilise along the hospital corridor and stammered “I can’t, I can’t, I can’t, it’s at sea, it’s all at sea”. She did not appear to be in any obvious discomfort and staff assumed her “awkward” behaviour was simply “due to her dementia”. A healthcare assistant tried to “see” the difficulty from Judith’s perspective. When viewing the corridor floor she noted how reflective and shiny it was compared with the matt surface of the floor in the ward bay area. She wondered whether the glare might look to Judith like the reflection on the surface of water. Indeed, it was subsequently noted that Judith could walk perfectly well on all surfaces that were not reflective. In perceiving the corridor to be flooded she was, in fact, behaving in a rational manner by refusing to walk any further!

**“ It was frightening, I felt...  
out of control ”**

**“ It is often not knowing what is going on,  
and what is expected of me as a patient ”**

## Discovering ways to meaningfully occupy people with dementia

Like everyone else, people with dementia have a need to be active, occupied and purposeful.

All too often in hospital there is very little to occupy people and focus attention. For a person with dementia this lack of occupation may lead to them behaving in ways that cause difficulties for themselves and others. Alternatively, it can also lead to a person withdrawing into themselves and losing all motivation.

### Case example

Mr Rhodes had lost the ability to communicate verbally, and he appeared anxious when his family were not around. His brother had completed his “Getting to Know Me” card and this contained lots of useful information that helped staff gain a fuller picture of Mr Rhodes. It was then apparent that he was a person with a rich and interesting past, he had been an art historian and had taught evening classes. Art books and magazines were brought into hospital and these became well used by Mr Rhodes who drew particular satisfaction from looking at them in an “educative” role in the company of another.

**“ If [the staff] were aware...that my wife was a former ladies fencing champion, she liked hiking and she used to play the piano, they could talk to her about that ”**

## Meaningful activities: hints and tips

- Use of the “Getting to Know Me” card or a similar initiative such as the Alzheimer’s Society/ Royal College of Nursing (RCN) “This is Me” leaflet <sup>12</sup> (both pictured), can help staff to “see” the person beyond their dementia and aid the generation of ideas for interactions and purposeful activity.

The card is designed to be viewed by the bedside. It is not a medical document and it does not have to be completed. If it is completed, please be mindful not to include information that you (or the person you are completing it on behalf of) would not want to be shared with others.

We hope the information you can share about yourself will help us to get to know you. It will give us ideas on how to talk to you, how to help you pass the time and how to help you feel at ease.

**Information for relatives and friends:**

- We really value the information you are able to share with us that will help us improve our care.
- If you have any questions/concerns about how this card will be used, including those about confidentiality, please speak to a member of staff.
- Please don't hesitate to speak to a member of staff if you have any further information, ideas or tips on how we can best meet the needs of your relative/friend.
- If you would like to be most involved in the care of your relative/friend while they are in hospital, please let a member of staff know.
- If you have any questions about sources of support/information/advice for either yourself or for your relative/friend, please ask a member of staff.

Equipped by Greater Manchester Health, Lancashire and Cheshire NHS Trust  
And developed by our specialist partners  
Greater Manchester West NHS

Royal College of Nursing  
Alzheimer's Society

# This is me

This leaflet will help you support me in an unfamiliar place

Please place a photograph of yourself in the space provided.

My name: \_\_\_\_\_

- Encourage families to visit and to bring in anything that may help to keep the person occupied
- Be creative! Books, photographs, bags with items to rummage through may all help
- Provide opportunities for exercise and walks whenever possible
- Think of creative ways to help a person to feel useful, purposeful and valued

<sup>12</sup> Available for download at: [http://www.alzheimers.org.uk/site/scripts/download\\_info.php?downloadID=399](http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=399)

## Promoting eating and drinking

A person with dementia may look like they are perfectly able to eat and drink without assistance, but they may in fact need help.

Physical discomfort, loss of appetite, and sensory impairment can prevent anyone from eating well in hospital. In addition to these problems, a person with dementia may have specific problems such as:

- Difficulty initiating an action (for example, picking up a fork or spoon to eat)
- Difficulty recognising food, drinks or cutlery for what they are (agnosia)
- Difficulty with spatial awareness, making picking up the food or using utensils more difficult
- Problems with memory – remembering to eat and drink
- Experiencing anxiety and other emotions that may affect appetite. This may be exacerbated by the distractions (noise, appearance, smells) of the ward environment



## Promoting eating and drinking: hints and tips

- Try appropriate prompting
- Consider the presentation of the food – does it look appetising? Are foods in containers or packaging that the person may need help with?
- Consider whether the person may have visuo-perceptual problems. Can they see the food clearly? Do they recognise it as food and realise it is for them to eat?
- Can the eating environment be made quieter and stress free? Too much noise and distraction do not encourage eating
- Some people with dementia prefer to eat little and often, rather than at set mealtimes
- Be aware of personal preferences and special dietary needs

### Case example

Enid, Reginald and Margaret all had some difficulties eating their main meals. The ward decided to create a “dining club”. A dining area was created at lunchtimes in the small day room. A table would be appropriately set for four people and at lunchtime a member of staff would sit to have a meal with Enid, Reginald and Margaret. In the quiet and calm, away from the distractions of the busy ward, and with appropriate prompts and cues, meals were regularly enjoyed.

## Relatives and friends: offering support and valuing their expertise

Relatives and friends can be a vital source of information and practical support in caring for a person with dementia during their stay in hospital. They will often possess important information on the person's needs, their likes and their dislikes. Furthermore, the physical presence of family and friends may bring the familiarity and security that a person with dementia in hospital will often need.

Relatives and friends may also have needs of their own: caring for a person with dementia can give rise to emotional, physical and financial stresses. It is important that communication with families is effective and that there are adequate resources for the provision of quality information and advice.

**“Once you are in the system everything is fine, but it is knowing how to get into the system. My wife and I have been very fortunate, in that we have had some excellent carers and excellent help from other organisations; it has helped me, it has helped her, but until you find out where those organisations are and how to get in touch with them you might just as well bash your head against a brick wall”**

## Involving and supporting relatives and friends: hints and tips

- Relatives may be able to suggest what actions/responses are likely to make a person more distressed. They may also know what could help a person feel more secure if they are already in a distressed state
- Relatives might be able to provide insight and explanations for behaviours that you find puzzling
- Make sure valuable information is recorded and shared across the care team
- Encourage use of the “Getting to Know Me” card (shown on page 19). This will provide a valuable resource to staff, and it is a concrete way of enabling relatives to contribute to the person’s care and wellbeing
- Family members should be made to feel that they can be actively involved in the person’s care to the extent that they wish
- Information on dementia and services outside of the hospital should always be available

### Case example

Clifford is reluctant to drink fluids despite the best attempts of nursing staff. When a relative is asked if they have any ideas, they point out that Clifford is an avid tea drinker but he only drinks it at home from a particular mug. This is brought in and Clifford’s tea consumption returns to normal!

## Providing pain relief

There is evidence to suggest that people with dementia are likely to experience less pain relief in hospital than people who do not have dementia. This becomes a greater problem the more severe a person's cognitive impairment is, hence, the more confused and disorientated a person is, the less likely they are to receive effective pain control.<sup>13</sup>

Behaviour such as shouting, aggression, agitation and pacing/walking may be triggered by pain. Too often, neuroleptic medication is prescribed for people with these behaviours rather than pain relief.

### Hints and tips:

- Regularly ask patients with dementia if they are in discomfort
- Use appropriate pain assessment scales, particularly if verbal communication skills are reduced
- Observe for behavioural, physiological and body language changes to guide assessment of pain
- Consider requesting “by the clock” medication for some patients rather than “as required”<sup>14</sup>

### Case example

Mr Mamoon shouted out repeatedly, but his words could not be identified by staff, interpreters or his family. A chart to monitor his behaviour was commenced but revealed no pattern. Unable to identify what was troubling Mr Mamoon, regular analgesia was prescribed. Mr Mamoon's shouting became significantly less frequent and less pronounced. The nursing and medical team were able to assume that his behaviour was likely to be related to pain, they could then focus attention on identifying its specific origin.

<sup>13</sup> Scherder, E., Osterman, J., & Swaab, B. (2005) Recent developments in pain in dementia. *British Medical Journal*, 330, 561-464.

<sup>14</sup> Cunningham, C. (2006). Managing pain in patients with dementia in hospital. *Nursing Standard*, 20 (46), 54-58.

## Behaviours and what they may mean

A person's behaviour may at times be challenging for staff and other patients. A person with dementia may, for example, shout persistently and repetitively, try to walk off the ward, or interfere with other patients' belongings or equipment.

It is important to acknowledge that all behaviour has meaning and that behaviour usually communicates a need or a feeling.

Behaviour may indicate many things, here are just a few possibilities:

- Underlying illness (delirium)
- Pain or discomfort
- Feeling afraid
- Feeling lost
- Being overwhelmed by too much noise or activity on the ward
- Boredom - not having enough meaningful activity to feel occupied
- Trying to express a need – hunger, thirst, the need for the toilet
- Side-effects of medication
- Trying to find someone or something familiar
- An action connected with a person's past (for example, a former doctor may be inclined to attend to his/her patients!)

### **WARNING**

- a) A neuroleptic when used to control behaviour will not meet any of the underlying needs described above.
- b) Patients with dementia who are quiet and withdrawn are at risk of receiving less care and staff interaction than those whose behaviours are more obviously demanding.

## Responding to behaviours that challenge: hints and tips

- As a team, utilise all your knowledge of the person to consider what might be the cause of their behaviour. Pool your ideas and begin to eliminate those that are least likely
- Consider using a behaviour monitoring chart to observe for patterns that may be clues to triggers for behaviours
- Talk to relatives, they are likely to know the person best
- Always consider delirium/underlying physical illness
- Try to put yourself in the person's shoes to consider their perspective. Remember their view of reality may be different from your own
- Be aware that the trigger for the behaviour may be the unlikeliest of causes (for example, a person who does not recognise their own reflection in a mirror when alone in a bathroom may result in them becoming frightened and agitated)
- Be aware that aggressive behaviour is often a resistance to the actions of others that are mistakenly perceived as threats
- If a person is aggressive, avoid invading their personal space if possible
- Where possible give a person the space and the opportunity to calm down
- Seek support from other staff but avoid crowding the person
- Use a calm and even tone of voice
- Maintain your own safety and that of others

## Case example

Millie created problems for ward staff by continually needing to be on the move. Nurses would regularly escort Millie back to her bedside, much to her annoyance and frustration. Following a discussion with her husband, Tom, it was decided to give Millie more opportunities for “purposeful walking”. Tom was encouraged to walk Millie to the cafe and WRVS shop whenever he (or any other relative) visited. Staff also began to regularly ask Millie if she would like to help them when they went off the ward for a specific purpose, for example, to collect medicines from pharmacy. This practice seemed to give Millie a renewed sense of purpose, and staff began to experience fewer challenging episodes with Millie on the ward.

**“ I can look at a flannel and think: Yeah, okay, what is that? So it is the simple things that I need help with ”**

## Sources of help and support

### **Age UK**

Comprehensive advice and information on health, welfare, leisure etc.  
Telephone 0800 169 6565  
[www.ageuk.org.uk](http://www.ageuk.org.uk)

### **Alzheimer's Society**

National dementia helpline, and a website with free factsheets and online discussion forum:  
Helpline 0300 222 1122  
[www.alzheimers.org.uk](http://www.alzheimers.org.uk)

### **ATDementia**

Information and advice on technologies that can support independence.  
[www.atdementia.org.uk](http://www.atdementia.org.uk)

### **Dementia UK**

A national charity, committed to improving quality of life for all people affected by dementia. Helpline provided by Admiral Nurses: 0845 257 9406 [direct@dementiauk.org](mailto:direct@dementiauk.org)  
[www.dementiauk.org](http://www.dementiauk.org)

### **The King's Fund**

Resources to enable hospitals to improve the physical care environment for people with dementia.  
[www.kingsfund.org.uk/projects/enhancing-healing-environment](http://www.kingsfund.org.uk/projects/enhancing-healing-environment)

### **The Lewy Body Society**

A charity with a specific focus on information on dementia with Lewy bodies.  
[www.lewybody.org.uk](http://www.lewybody.org.uk)

### **The Frontotemporal Dementia Support Group**

Information and advice particularly directed at “carers who are coping with behavioural changes in a partner, family member or friend as a result of frontotemporal dementia.”  
[www.ftdsg.org](http://www.ftdsg.org)



The quotations in this booklet that appear in blue text are reproduced with the kind permission of Ann Johnson, Mike Howorth and Brian Briggs. Brian cared for his wife who had dementia; Ann and Mike both have a diagnosis of Alzheimer's disease. Ann, Mike and Brian were involved in the development and production of the "Getting to Know Me" training materials.







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