Dementia

Study Guide

***Myth*: Dementia is when a person just loses their memory**

One of the important things to recognise about dementia is that it is more than just difficulties with memory.

Dementia is an umbrella term used to describe a set of symptoms, including difficulties with memory, mood changes, behaviour, personality, recognition and perception, confusion and problems with communication and reasoning, and difficulty with everyday tasks. These symptoms occur when the brain is damaged by certain diseases.

***Myth*: getting older means you will get dementia.**

Dementia is the result of brain cells being damaged in an ongoing way. This happens as a result of a number of different diseases (sometimes referred to as 'types' of dementia). It is not an inevitable part of ageing. The most common types of dementia include:

Alzheimer's disease. Alzheimer's disease is the most common cause of dementia. Alzheimer's disease is thought to be caused by the abnormal build-up of proteins in and around brain cells. One of the proteins involved is called amyloid, deposits of which form plaques around brain cells. The other protein is called tau, deposits of which form tangles within brain cells. Although it's not known exactly what causes this process to begin, scientists now know that it begins many years before symptoms appear. Over time, different areas of the brain shrink. The first areas usually affected are responsible for memories.

Most people who develop Alzheimer's disease do so after the age of 65, but people under this age can also develop it. This is called early-onset Alzheimer's disease, a type of young-onset dementia. In the UK there are over 40,000 people under the age of 65 with dementia.

Young-onset dementia is more likely than late-onset dementia to be hereditary. In around 10% of all people with young onset dementia the condition seems to have been inherited from a parent. If dementia has been inherited, the diagnosis may have implications for birth relatives of the person such as their siblings (brothers and sisters) or children

Vascular dementia. Vascular dementia is the second most common type of dementia (after Alzheimer's disease). Symptoms occur when the brain is damaged because of problems with the supply of blood to the brain, to have a good healthy brain it needs a good healthy blood supply. This death of brain cells can cause problems with memory, thinking or reasoning. Together, these three elements are known as cognition. Vascular dementia - is linked to high blood pressure, high cholesterol and being overweight in mid-life. Someone can reduce their risk of developing these by having regular check-ups (over the age of 40), by not smoking, and by keeping physically active. It will also help to eat a healthy balanced diet and drink alcohol only in moderation.

Dementia with Lewy Bodies. Dementia with Lewy bodies (DLB) is a type of dementia that shares symptoms with both Alzheimer's disease and Parkinson's disease. It may account for 10-15 per cent of all cases of dementia. DLB can be diagnosed wrongly and is often mistaken for Alzheimer's disease. As with most types of dementia, the first symptoms of DLB may affect someone only slightly, but gradually they get worse and cause problems with daily living. Everyone is different, but a person with DLB will usually have some of the symptoms of Alzheimer's disease and some of the symptoms of Parkinson's disease.

Visual hallucinations (seeing things that are not there) occur frequently in people with DLB, often in the early stages of the condition. Visual hallucinations are often of people or animals and are detailed and convincing to the person with dementia. They can last several minutes and may be distressing. (Auditory hallucinations - hearing sounds that are not real, such as knocking - can happen but are less common. Up to two-thirds of people with DLB have movement difficulties when the condition is diagnosed. These symptoms are like those of Parkinson's disease and include slow and stiff (rigid) movement with a blank facial expression. The person's posture may be stooped, and their walk may be shuffling. They may also have difficulty with their balance, and their limbs may sometimes tremble. Movement problems are one reason why a person with DLB is particularly prone to falls.

Fronto-temporal Dementia. Fronto-temporal dementia (FTD) is one of the less common types of dementia. The term covers a wide range of different conditions. It is sometimes called Pick’s disease or frontal lobe dementia. The frontal lobes of the brain, found behind the forehead, deal with behaviour, problem-solving, planning and the control of emotions. An area of usually the left frontal lobe also controls speech. FTD is much less common than other forms of dementia, such as Alzheimer’s disease or vascular dementia. FTD is most often diagnosed between the ages of 45 and 65. However, it can also affect people younger or older than this, and it is probably under-recognised in older people. During the early stages, changes are seen in the person’s personality and behaviour.

A person with behavioural variant FTD may lose their inhibitions, behave in socially inappropriate ways and act in an impulsive or rash manner. This could include making tactless or inappropriate comments about someone’s appearance.

All types of dementia are progressive, which means symptoms will get worse over time. The rate the dementia progresses will depend on the individual person and what type of dementia they have. Each person is individual and will experience dementia in their own way. In the UK, there are around 850,000 people diagnosed with Dementia. The number of people with dementia in the UK is forecast to increase to over 1 million by 2025 and over 2 million by 2051.

Medication for people with dementia

There is currently no cure for dementia, but some drug treatments have been developed that can help to improve the symptoms of Alzheimer’s Disease. The drugs may slow down the progression of symptoms, delaying deterioration in some people. Under the NICE Guideline (NG97, published date: June 2018), the following are the recommended for pharmacological management: **Donepezil, Galantamine, Rivastigmine, and Memantine.**

A person with dementia may experience difficulties such as a feeling restlessness, feeling angry or delusions and / or hallucinations. It is very important to try to understand the reasons for these feelings and behaviours and to offer nonpharmacological interventions before resorting to anti-psychotics. Anti-psychotic medication should be avoided unless it is necessary. If these difficulties are not responsive to person centred approaches and are causing severe distress to the person with dementia or posing significant risk to the person, refer to a health professional who can evaluate and prescribe the need for medication. Examples of anti-psychotic medications are **Haloperidol**, **Olanzapine**, **Quetiapine** and **Risperidone**.

The person with dementia must be monitored regularly for side-effects as these can have a negative impact on their quality of life. Where side effects are causing harm to the person, the medication should be reviewed urgently. For people with Lewy Body dementia, it is recognised that antipsychotics may be particularly dangerous.

Caring for people with dementia when they come into hospital.

People with dementia are not usually admitted to acute care for their dementia, it is usually because they have a co-existing physical illness, therefore it is recognised that acute services must respond to the growing numbers of people with this condition and their more complex needs.

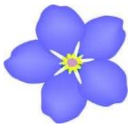
Going into hospital offers an opportunity for a person with dementia to receive the care they need in crisis situations and for their acute illness to be treated. However, when individuals are ill and in pain, or have experienced an accident or fall, noisy environments; fast pace of work, new and unfamiliar faces, intense questioning and moving through different hospital wards can often be very traumatic and confusing for them.

There are several things we can do to improve the experience of people living with dementia and their carers whilst they are in hospital.

1. Getting to know the person

During a busy workday, it may be hard to find the time to get to know a person with dementia. However, finding this time is important as a means of preventing situations that could lead to aggressive behaviour. Hospital staff need to know what might trigger stress or anxiety in a person with dementia and how they would prefer to receive care.

FHFT use the ***'THIS IS ME'*** tool to know the person with dementia much better. The '***THIS IS ME'*** document can be filled out with the person living with dementia, if possible, or by someone who knows them well, including family, friends, and hospital staff. It enables health and social care professionals to see the person as an individual and deliver person-centred care that is tailored specifically to the person's needs. It can therefore help to reduce distress for the person with dementia and their carer. It can also help to prevent issues with communication, or more serious conditions such as malnutrition and dehydration.



FHFT also adopted the '***FORGET-ME-NOT'*** flower, using the flower icon to identify and support patients with a diagnosis of dementia. This flower icon can be found on patients' note, drug chart, beside patient's name on the white board above their bed and on the ward and admission booklet that they have a diagnosis of dementia. These can also be found in the hospital's patient electronic system to flag up to the hospital staff that there is someone under their care that might need extra attention or care.

It is essential to know as much as possible about the person living with dementia. The more we know about our patients, the more effectively we can care for them.

> **"When you've met one person with dementia, you've met one person with dementia"**
> Tom Kitwood

2. Providing Person Centred care

People with dementia are easily overwhelmed by care that is provided too quickly or without emotional connection and explanation. When they are overwhelmed (for example, by overstimulation), they are often fearful and frustrated. Because dementia affects impulse control, they may express their frustration by grabbing a care's arm or lashing out.

Person-centred care is a socio-psychological care approach that recognizes each person's unique identity, preferences, and needs. Person-centred care prioritizes individual well-being through meaningful occupation and improving the quality of relationships between care and the person with dementia. Although persons with dementia experience deteriorating cognitive and functional abilities, their need for human interaction and participation in purposeful pursuits remains.

To practice person centred care, it is necessary to focus on these needs by using responses and approaches that help to uphold the person's dignity, engage in purposeful activity, and provide comfort. If a person with dementia is drawing from memories from the past the person might say such things as 'Where is my mother?' 'I need to go home to get the tea'.

When this happens consider if it is possible to orientate the person to reality**.** Can the person be reassured about where they are in the *'here and now'*? If 'Yes', then provide reassurance and prompts/cues to help the person keep in touch with this information i.e.: *visual cues such as pictures/symbols/written words on notices/cards.*
If, however the person is distressed when confronted with the facts of the situation and this distress is difficult for the person to manage then it might be helpful at these times to consider several different approaches such as **Validating the person's feelings**. For example, *'Are you feeling lost without your mum?', 'You seem very sad not finding your mother', 'You seem to really miss your mum'.*
Explore memories that the person is *experiencing 'What was your mother like?', 'Can you tell me about your mother?* Provide reassurance and comfort *'It seems very upsetting for you to be still looking for your mother, I'm sure things are ok'. 'I can see you are upset and worried, but it will be all right'. 'I know you are worried, but things are taken care of'.*

You don't have to disagree or argue with the person – instead, focus less on the factual content of what is being said and more on how the person is feeling.

3. Influence on ward environment

Hospital environment plays a key part in how someone feels. Several factors about the environment may have a negative effect on a person with dementia including the level of noise, lighting, heating, lack of signs and changes in their routine. A person with dementia may become distressed when in company or when left alone for long periods. Lack of 'comfort cues' which are objects, pictures, pieces of furniture, photographs which help to link to past comfortable memories can also impact on the person's wellbeing.

When thinking about having a positive environment for a person it is essential to consider a variety of factors:

- What is the person's past wishes and preferences regarding spending time in company?
- What is the person's present response to being with others?

- Are individual comfort cues available for the person such as favourite pieces of furniture/blankets?
- What objects are available to touch/hold that might be engaging /comforting
- What is the background noise and how is the person responding to this?
- Are there opportunities for the person to move around should they wish?
- Are there clear signs to direct the person to the toilet?
- Is there the opportunity for the person to access food and/or drinks?

There have been several studies which suggest the person with dementia can be helped using colour in the environment. This had led to the Trust's initiative on red trays and coloured cups. The 'red cups scheme' is used to encourage the person with dementia to drink by supplying a red cups and tumbler. Other ideas include use of coloured toilet seats or large signage on the doorways of toilets.

Mealtimes in a busy hospital environment is another factor to consider and can be stressful for a person with dementia. FHFT has a red tray and yellow tray policy. Red trays are used for patients who require full assistance with nutrition and yellow trays are for those who require minimal assistance. In conjunction with yellow and red tray policy, protected mealtime is in placed to support the nutritional needs.

Evidence based research from Australia (Gohar, 2009) considered the application of colour and colour contrast in the home environment of the elderly and visually impaired individuals. The conclusion was that the use of colour and colour contrasts specifically was found to be effective, not only for improving vision and clarity of the environment, but also in promoting better orientation, memory enhancement, a sense of safety and independence.

4. Impact of positive Communication

People with dementia struggle to communicate, and this affects how others communicate with them. In approaching and supporting the person it becomes important to use the opportunity to uphold and promote a person's wellbeing.

Connecting with the person at any opportunity and when engaging in any care tasks. This can be achieved by making eye contact or talking with/to the person. If the person feels ignored or handled insensitively it could result in the person feeling as though they do not exist as a person but rather as a 'task' to be done to. This could lead to ill being.

Talking to the person in a way that is appropriate for their age and status. This can be achieved by addressing the person by the name they prefer to be called and avoiding talking to the person in the way you might talk to a child. When a person is having difficulties with everyday tasks it is important to remember that the person is not a child and language/ tone of voice need to reflect this to promote the person's sense of identity and dignity. For example, 'You are a good boy' when said to a 75-year-old man with dementia who has washed and dressed could lead to him feeling belittled or ridiculed.

Talking calmly and with empathy when a person with dementia is having difficulties. This can be achieved by allowing for a relaxed pace with both speech and actions when communicating with the person and allowing a person to express how they are feeling which will help to validate feelings.

If a person is shouted at or blamed when struggling with tasks this will lead to ill being.

Some important points to remember when communicating with a person living with dementia:

- Always stand where they can see you clearly and ensure they can hear you, make sure hearing aids are working and glasses are clean.
- Be aware of your body language. Standing with our arms crossed or our hands in our pockets when talking with a patient living with dementia may be perceived as anger.
- Always tell the patient your name, why you are there and what you are going to do.
- Be prepared to repeat things as often as necessary.
- Always explain what is happening and why – it may seem obvious to you, but it may not to the person with dementia. Using language that is familiar to the person and giving one piece of information at a time may support the patient's understanding of the situation.
- If a patient tells you they are worried, be kind and listen to their concerns. Avoid patronising the person.
- Include the person in conversation. Don't talk over their head or assume they don't understand what is being said.
- Do not scald, contradict, or argue with a person living with dementia.

Remember, all behaviour is a form of communication. Whether this behaviour is perceived as 'good' or 'bad', it is an expression of an individual's feelings and needs. Try to look for the meaning behind their words and behaviours. For example, if a patient appears restless and is fidgeting with their clothing, they may want to use the toilet.

5. Responding to emotional distress, expressions of anger, and excessive walking

When a person with dementia is showing signs of agitation such as hitting out at others or walking around continuously it is important to consider this as a form of communication or a response to unmet needs. Check through several possible factors to help you understand their behaviour better:

- What is the environment like? Is this distressing the person? Has something significant changed/been moved (for example a photo or a piece of furniture)?
- What is going on physically for the person? (for example is the person walking in response to the need for exercise)?
- Is the person in pain? *Bolton Pain Assessment* is the assessment tool of choice at FHFT for patients with dementia and patients with communication problems.
- Are they communicating with you? Think about what they may have done in the past, for example the job they had and what it involved, what they did with their family such as walking their children home from school.
- Most importantly consider what is happening within the interaction. Is the person being, ignored, shouted at, blamed, or handled insensitively?

When a person is angry and distressed there is no 'correct' way to respond and communicate with the person. It is useful to consider the following general points when responding to the person with dementia who is demonstrating angry behaviour.

- Think if there is anything you are doing or responding which is making the situation worse.

- Think of the environment. Be aware of noise levels, people in the room and potential weapons i.e., walking sticks.
- Identifying any underlying cause / triggers i.e., pain, hunger, or strong emotional memories or previous experiences?
- Give the person space and back away if necessary.
- Stay calm, speak slowly and gently.
- Calm and clear messages about what you need the person to do.
- Use of validation to identify and connect with how the person is feeling i.e., '*I can see you are upset'*.
- Use of distraction such as finding something for the person to focus on or walking or other forms of exercise.

Use caution when reorienting a person with dementia as reality may shift for a person with middle- or late-stage dementia. For example, a person may think it's 1969, or that it's morning when it's midnight. People with early-stage dementia and mild cognitive limitations can be oriented to the correct time and place. People with middle- or late-stage dementia have significant cognitive limitations and will become agitated and possibly angry if someone tries to convince them that they are wrong. If a person thinks it is time to go to work, then for that person, it is. Sometimes, orientation statements such as "it's lunchtime or "it's Tuesday" will work.

6. **Working with Carers - The Triangle of Care**

The Triangle of Care for Dementia describes how meaningful involvement and inclusion of carers can lead to better care for people with dementia. In an ideal situation the needs of the carer and the person with dementia are both met.

Carers have a crucial role to play in the care of people with dementia. When a person with dementia develops a physical health problem and/or their behaviour changes the carer is often the first to be aware of this. If that person is admitted to hospital, it is often the carer who knows the person's history and can provide hospital staff with crucial information.

Staff need to identify who the carer(s) is, that is the person who is providing significant support, their relationship with the person with dementia and the level of support they provide. Staff also need to understand and appreciate the carers' perspective. This requires listening empathetically to the experiences and concerns of carers and knowing how to respond. They should be made to feel part of the care team and encouraged to be involved in providing care for the person as they would at home, if this is what they want to do. For example, assisting the person at mealtimes or with personal care or just sitting with them to reassure them or engage them in conversation or activities.

Carers can also help support communication and share information with the person with dementia. This helps to ensure that the right care and treatment is provided which considers additional support needs and preferences. The carer may also have lasting power of attorney and should be consulted about future and best interest decisions if the person has lost capacity.

Admission into hospital whether as a result of crisis or through planned admission, both the carer and person with dementia are likely to be anxious about what lies ahead. Carer and the person with dementia should be kept informed about the progress and should be actively involved in discharge planning as well as being told the likely date of discharge in advance so they can organise things prior to discharge.

It is also important to recognise that a carer may need a break whilst the person living with dementia is in hospital. It is our responsibility to look after carers needs as well as the patients. All carers should be offered referral for Carer's Needs Assessment. Some may decline for good reasons at that point, but their decision should be revisited from time to time. The Care Act 2014 puts in place significant new rights for carers in England. Carers have a right to a carer's assessment based on the appearance of need and for eligible needs to be met. The purpose is to ensure carers' own needs are recognised and met, and that they are aware of their rights to support, financial and other help in carrying out their carer responsibilities. Carers' needs assessments are the responsibility of the specific local authority. When a carer consented for a Carer's Needs Assessment, a referral is generated through FHFT- IRIS team.

Frimley Health NHS Foundation Trust Supports 'John's Campaign'
'John's Campaign' was launched in November 2014. The aim of the campaign is to give the carers of those people living with dementia the right to stay with them in hospital offering support and reassurance when they need it most. Visiting times can be arranged with the ward staff to ensure up-to-date visiting guidelines are followed.

7. Other practical tips

- **Take vision problems into account**. To avoid confusing or startling people with dementia, approach them from the front, preferably angling your body off to one side, as this is a safer position. Staff also need to get down to the same level as people with dementia to speak face to face.
- **Take hearing problems into account**. Hearing loss is an invisible sensory deficit that has pronounced physical, mental, and psychological effects. People with dementia may not have their hearing loss identified unless they use hearing aids. Whether they use hearing aids or not, people with dementia may be easily startled when you move into view. This stress may further interfere with their ability to hear and comprehend. Before speaking, lightly touch their forearm or hand if it is safe to do so or establish eye contact. If they have hearing aids, ensure that they are wearing them, if possible.
- **Allow people with dementia to wander and rummage safely**. People with dementia may spend a lot of time walking around and rummaging or picking up various items. Provide areas where people can safely wander and collect items. For example, they should have access to indoor and outdoor areas where they can explore independently. Provide opportunities for physical activity, such as singing and rhythmic movements, particularly when people with dementia are waiting for a meal or activity to start.
- **Distract with objects or activities.** Use meaningful activities or items to distract. Encourage people with dementia to engage in activities they enjoy (for example, talk about their families or sing a song), or provide an object to hold or carry (for example, a face cloth). Distraction can also work when people with dementia exhibit obsessive or repetitive behaviours, such as making the same motion or asking the same question over and over. Family carers can suggest the person engage in a favourite activity such as walking. Do not remind the person that you have already answered the question because this may be upsetting. Simply answer again in a calm voice.

- **Provide small snacks or beverages between meals.** Before providing care, consider the time of day and when the person with dementia last ate. Blood sugars are often low late at night and early in the morning. Try giving people a light snack such as juice or toast before getting them out of bed or providing care. Finger foods are suitable for those who wanders around and small appetite. A person with dementia engages better at mealtime if the food offered is familiar to them and it invoke happy memories.
- **Avoid disagreeing with harmless delusions**. Remember that often the disease is speaking, not the person. Do not disagree with people with dementia regarding what they perceive to be real. If their delusions are harmless, then no intervention is required. Try distracting the person with a favourite activity. For misplaced objects, remind people with dementia where their valuables are stored, or keep a spare set of items that are frequently missed close at hand (for example, a purse, keys, or glasses).
- **Validate feelings.** When people with dementia feel that their problems are acknowledged, understood, and accepted, their anxiety decreases. Staffs should work to identify with the feelings that people with dementia are trying to express. You can agree with what a person wants to do (for example, drive to work or go home) and why they might want to do it, but then gently redirect them to do something else.
- **Dementia and decision-making.** Decisions cannot be made for a person with dementia unless there is evidence that they can't make the decision themselves. The process of working out whether someone can make a specific decision, at the time it needs to be made, is called *a mental capacity assessment***.** Staff need a valid assessment that shows someone lacks capacity to make a decision before doing anything in their best interests. But it is important to remember that people can make unwise decisions – even in relation to their own – if they understand the consequences. For further guidance on DoLS, MCA and Safeguarding refer to the FHFT Safeguarding policy or speak to your Adult Safeguarding Lead.

Sundowning

Sometimes you might see changes in the person's behaviour in the later afternoon or towards the end of the day. During this time the person with dementia may become intensely distressed, agitated and have hallucinations or delusions. This may continue into the night, making it hard for them to get enough sleep.
This is known as '**sundowning**' but is not necessarily linked to the sun setting or limited to the end of the day. Sundowning can happen at any stage of dementia but is more common during the middle stage and later stages. There are several theories which propose to explain why this occurs could be changes in natural daylight creating a trigger to move around, feeling a need to be occupied at this time of day, or as a response to a feeling of crisis.

Tips for reducing sundowning

- Sometimes what seems like 'sundowning' could be the person trying to communicate a need. This could be needing the toilet, feeling hungry or being in pain.
- Think whether something that's happened during the day has affected them. If they seem agitated, try to calm them by distracting them, perhaps talking about a favourite memory or event they enjoy thinking about.
- If they remain agitated, it could be that they have a need that is not being met.

Learning Disabilities and Dementia

People with learning disabilities, particularly those with Down's syndrome, are at increased risk of developing dementia. If a person with a learning disability develops dementia, they will face different and additional challenges to people who do not have a learning disability. A learning disability is a lifelong condition that affects someone's learning, communication and understanding. The person may require support with some aspects of their life, including planning, learning new skills, and socialising. There are estimated to be about 700,000 people living with a learning disability in the UK, although this may be an underestimate.

People with learning disabilities are at increased risk of developing dementia as they age, compared with others without a learning disability, although the figures vary according to how the diagnosis is made. About 1 in 5 people with a learning disability who are over the age of 65 will develop dementia. People with learning disabilities who develop dementia generally do so at a younger age. This is particularly the case for people with Down's syndrome: a third of people with Down's syndrome develop dementia in their 50s.

Superimposed Delirium on dementia

Delirium is a sudden change in mental state that disturbs attention, thinking, and sleep patterns, causes confusion, and changes behaviour. A person with dementia is at higher risk of delirium. If the person with dementia exhibits a sudden change in behaviour, this may be the result of delirium and not part of the dementia process. Delirium is a medical emergency, and it is crucial that the cause of delirium is identified and treated. Delirium is a serious condition that is sometimes mistaken for dementia or, more rarely, depression. **Think delirium!**

Depression

Depression is a condition that can last for several weeks or months. When a person has depression several negative feelings can dominate their life, including sadness, hopelessness, and a loss of interest in things they used to enjoy.
At least one in five people in the UK will have depression at some time in their lives. However, it is more common in people with dementia, particularly if they have vascular dementia or Parkinson’s disease dementia. Depression is often diagnosed when a person is in the early stages of dementia. However, it can develop at any stage. Depression can also come and go**.**

END

Dementia Team

Ablen Dacalos
FHFT Lead Dementia Clinical Specialist Nurse
Ablen.dacalos@nhs.net
01276536383

Marilie Ofquila
Dementia Specialist Nurse for Frimley Park Hospital and Farnham
Marilie.Ofquila@nhs.net
01276526383
Bleep 15800

Alice Teixeira
Dementia Specialist Nurse for Heatherwood and Wexham Park Hospital
Alice.Teixeira@nhs.net
07770728168

Esme Smith
Dementia Associate Practitioner for Frimley Park Hospital
Esme.Smith@nhs.net
01276 526383
Bleep 15853

Peter Clarke
Dementia Associate Practitioner for Heatherwood and Wexham Park Hospital
Peter.Clarke@nhs.net
07388832233

Reference

Mehrabian, Albert (1971) ‘Silent Messages’, Wadsworth Publications Co.