

Dementia Awareness

Direct and Non-Direct Clinical Staff

Three Yearly

- Avoid printing this document if possible
- **Please ensure you complete and sign the declaration form once completed**

Learning Outcomes

- Understand what is meant by the term dementia, common causes, signs and symptoms and related risk factors.
- Understand how individuals may experience dementia due to factors such as age, type of dementia and level of ability and disability.
- Be advised of local policy and how the Trust aim to support people with dementia and their carers.

Introduction

Dementia is one of the biggest challenges faced by communities and health and social care providers in England.

One in 6 people over **80 years** of age suffer from dementia.

40,000 people under the age of **65**.

225,000 people will develop dementia this year – that's **one every 3 minutes**.

At present it is estimated that **850,000** people in the UK have some form of dementia.

Future projections suggest that by **2025** there will be **1 million** sufferers and by **2051**, there will be **2 million** sufferers.

(Alzheimer's Society 2016)

Dementia is used to describe the symptoms that occur when the brain is affected by specific diseases/conditions. Dementia is a chronic progressive cognitive problem which is the failure of the brain's functions. Dementia affects people at different stages of life and affects people at different speeds.

Common Types of Dementia

- Alzheimer's Disease
- Parkinson's Disease with Dementia
- Vascular Dementia
- Frontal- temporal Dementia (PICKS)
- Lewy Bodies
- Korsakoffs Syndrome

Alzheimer's: This is the most common form of dementia. This changes the brain's structure leading to the death of brain cells and disrupting the brain's usual activity. People with Alzheimer's have a shortage of chemicals that transmit messages to the brain.

Vascular Dementia: This is also a common form of dementia, triggered by blockages to blood vessels in the brain. There is not enough blood and oxygen reaching the nerve cells, causing them to die. Areas of brain that have died are called infarcts. This is also known as Multi Infarct Dementia.

Frontal Temporal Dementia: This is also known as Pick's disease, although this term is no longer commonly used. The damage is focused on the front part of the brain. It affects personality and behaviour and typically the onset occurs between 40 and 70 years of age.

Lewy Bodies: This can affect as many as one in ten people with dementia. Lewy bodies are tiny deposits of protein in nerve cells. Researchers don't have a full understanding of why Lewy bodies appear in the brain, or exactly how they contribute to dementia. However, their presence is linked to low levels of important chemical messengers and to a loss of connections between nerve cells. Over time, there is progressive death of nerve cells and loss of brain tissue.

Korsakoffs Syndrome: A brain disorder associated with heavy drinking and drug misuse over a long period. Although not strictly a dementia, individuals experience short term memory loss which can develop into Vascular Dementia or Alzheimer's. Unlike other dementias it can be cured. The person needs to be without drugs or alcohol for 6 weeks to be properly diagnosed.

Person Centred Dementia Care

- Promoting person centred care on acute wards
- Treating everyone with dignity and respecting their privacy
- Communicating with people with dementia and their families
- Understanding the behaviour of people with dementia
- Considering the environment for people with dementia

It sees patients as equal partners in planning, developing and accessing care to make sure it is most appropriate for their needs. It involves putting patients and their families at the heart of all decisions.

Communicating with families

We know from some reports families can feel left out and due to time restraints, meaningful communication with them can be difficult.

Communicating our needs, wishes and feelings is vital- not only to maintain our quality of life, but also to preserve our sense of identity. A large proportion of our communication is non-verbal, which takes place through gestures, facial expressions and touch. Non – verbal communication is particularly important when a person with dementia is losing their language skills. This may also mean that a person with dementia behaves in ways that those caring for them find difficult and this may be because they are trying to communicate something.

As dementia develops, it can cause behaviour changes that can be confusing, irritating or difficult for others to deal with, leaving carers, partners and family members feeling stressed. It is not unusual for a person with dementia to go through the motions of the activity they may previously have carried out at work. This can indicate a need to be occupied and to feel there is a purpose and structure to their life.

Right Care: Right Place

- Community Advanced Nurse Practitioners (ANPs)– to avoid inappropriate admissions
- A supportive new emergency department (ED)
- Frail Elderly Pathway (FEP) Team on the AAU & ACU

Hospital plays an important role in many people's journeys that have dementia.

Community ANPs have extended and expanded their scope of practice and are working at an advanced practice level to enhance service delivery and improve health outcomes.

Now upgraded EDs – creates an environment that is calmer and more relaxed with photos of local areas, large clocks and where staff are more visible.

FEP promotes safe discharges home and may need to signpost to other agencies. They may need to provide low level equipment such as commodes and Zimmer frames. They may also need to arrange follow up visits from the physiotherapist or Occupational Therapy.

Right Care: Right People

- SYSTM One bed management module- alerts when patients with dementia are admitted
- John's Campaign
- The Butterfly Scheme

System1

This identifies on admission those patients who have dementia. This emails the Practice Development Sister for Older People. It is also now flagged electronically on the interactive ward boards.

John's Campaign

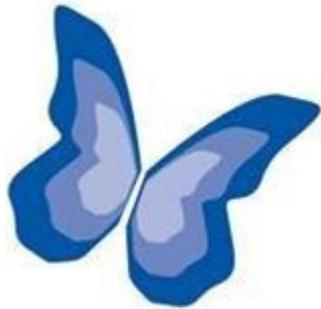
John's Campaign is a new initiative to allow carers to stay with their loved one outside of normal visiting hours (including overnight), and ensuring that hospitals are becoming more dementia friendly.

This enhances the environment for carers, standardising relatives' rooms to allow access to chair/sofa bed, blankets and pillows. Providing tea/coffee making facilities, travelling mugs, fridge, and microwave. Carers passport/stay with me pack entitling the carer to a parking permit, access to sleeping facilities, discounted snacks or vouchers and practical items such a toothbrush, blankets and hot drinks.

Carers Resource – offers a range of services to individuals in the local area including: information, carer support groups and activities, benefits and financial advice, grant sourcing and emotional support tailored and personalised to the individual carer.

Carers Resource Support Worker to visit Ward 4 once a month to support carers with relatives in hospital.

Delirium Guidelines – the aim of these guidelines is to aid in the prevention of delirium, where possible and in those patients where delirium occurs to facilitate early detection and to provide clear guidance on the management of this highly complex condition.



The Butterfly Scheme

- Opt in scheme – Permission sought and documented for people with a formal diagnosis of dementia.
- If agreed, a butterfly placed around the bed area and on the status board.
- Reminds all staff and teams to apply REACH response and to a care plan kept at the end of the bed.

The Butterfly Scheme provides a system of hospital care for people living with dementia of who simply find that their memory isn't as reliable as it used to be. Memory impairment can make hospitalisation distressing.

In hospital, dozens of staff can pass through a patient's life each day and in order to deliver appropriate care, they need to know that a patient has dementia of memory impairment and how to support them.

This is where the Butterfly Scheme comes in.

The Butterfly Scheme has now been adopted by over a hundred hospitals across the length and breadth of the UK. Hospital staff do want to care well for patients and they typically enjoy using the skills and systems provided by the Butterfly Scheme, enabling them to care appropriately for this patient group.

It comes in the form of a care plan:

Butterfly Scheme Care plan

Patient Sticker



This document will help hospital staff to care for you. You can complete it with a member of staff, by yourself or with a family member/ carer.

(Staff should use this plan to support assessment, care planning and providing individualised care. Please keep this with the bedside documentation and refer to it on a regular basis)

Commenced by (staff member) :

Date and time commenced:

My personal history
My name is:
I prefer to be called:
My family members are:
I was born in (Date and place):

The jobs I have had include (my hours or work were...)

My hobbies and interests include:

My usual routines are: (daily routine, places I visit regularly etc)

What I like to talk about: (good conversation topics)

I am left or right handed:

I use the following memory aids: (notebooks/ checklists/ alarms etc)

My behaviour

Things which may worry me, make me anxious or frightened



Things that make me feel happy, comfortable or safe:



You know when I am in pain by:

This is how I react to the following investigations:

Blood pressure:

Taking blood:

X-rays:

ECG:

Eating and Drinking

Food likes and dislikes:



Drink preferences:



Sleeping

My usual sleep pattern and bedtime routine is:

Communication

I use the following communication aids: (sounds, gestures, visual aids)

Care and safety

These are the things I do to help to prevent me from falling:

These are the things I do to help me take my medicines (e.g, with hot water, after my meal)

Any specific toileting needs e.g.: Do you wake up in the night? How many times would you go in the day? Do you need prompting?

Carer and family support

Do you require any information about support as a carer for your relative?

Notes to staff:

Provide information to carer/ family about John's Campaign (allowing flexible visiting to continue caring for loved one)

Signpost to Carers' Resource (Bradford and Airedale) or Carers Link (Lancashire)

See Aireshare or website for information.

Reviewing the Plan- staff should review this care plan once a week to check if anything has changed for the patient. If the plan changes significantly a new version should be completed. Record the review information below.

Review date:

Signature:

Review date:

Signature:

Review date:

Signature:

Reach Response

- **Remind**....the patient what has led to this moment
- **Explain**....what is about to happen
- **Arrange**...the environment so it makes sense to the patient
- **Check**...well- being, including cleanliness and hydration
- **History**...of any kind must be verified from the records/carer, never taken exclusively from the patient, nor should instructions be lodged exclusively with the patient

Here to Care: Therapeutic Environments

- Bring the outside, inside – mural and image boards
- Reminiscence '50's style room
- Café area (Ward 4) – involves volunteers
- Music Therapy



Here to Care: Access to safe outdoors



Dementia Exercise

Read the following passage:

You are in a swirling fog, and in half-darkness. You are wandering around in a place that seems vaguely familiar, and yet you do not know where you are; you cannot make out whether it is summer or winter, day or night. At times the fog clears a little, and you can see a few objects really clearly; but as soon as you start to get your bearings, you're overpowered by a kind of dullness and stupidity; your knowledge slips away, and again you are utterly confused.

While you are stumbling in the fog, you have an impression of people rushing past you, chattering like baboons. They seem so energetic and purposeful, but their business is incomprehensible. Occasionally you pick up fragments of conversation, and have the impression that they are talking about you. Sometimes you catch sight of a familiar face; but as you move towards the face it vanishes, or turns into a Demon. You feel desperately alone, bewildered and frightened. In this dreadful state you find that you cannot control your bladder, or your bowels; you are completely losing your grip; you feel dirty, guilty, and ashamed; it's so unlike how you used to be that you don't even know yourself.

And then there are the interrogations. Official people ask you to perform strange tasks which you cannot fully understand such as counting backwards from 100 or obeying the instructions; "If you are over 50, put your hands above your head". You are never told the purpose or the results of these interrogations. You'd be willing to help, eager to co-operate, if only you knew what it was all about, and if someone took you seriously enough to guide you.

This is the present reality; everything is falling apart, nothing gets completed, nothing makes sense. But worst of all, it wasn't always like this. Behind the fog in the darkness there is a vague memory of good times, when you were able to perform daily tasks with skills and grace; once the sun shone brightly and the landscape of life had richness and pattern. But now all that has been vandalised, ruined and you are left in chaos, carrying the terrible sense of loss that can never be made good. Once you were a person who counted; now you are nothing and good for nothing.

A sense of oppression hangs over you, intensifying at times into naked terror; its meaning is that you might be abandoned forever, left to rot and disintegrate into unbeing.

How does this make you feel? Take a few minutes to really think about it.

Now read the following passage:

You are in a garden, at the start of a summer's day. The air is warm and gentle, carrying the sweet scent of flowers, and a slight mist is floating around. You can't make out the shape of everything, but you are aware of some beautiful colours; blue, orange, pink and purple, and the grass is as green as emeralds. You don't know where you are, but this doesn't matter. You somehow feel 'at home', and there is a sense of harmony and peace.

As you walk around, you become aware of other people. Several of them seem to know you; it is a joy to be greeted so warmly and by name. There are one or two of them whom you feel sure you know well. And then there is that one special person. She seems so warm, so kind and understanding. She must be your mother, and it is good to be back with her again. The flame of life now burns brightly and cheerfully within you. It hasn't always been like this. Somewhere, deep inside, there are dim memories of times of crushing loneliness and ice cold fear. When that was, you do not know; perhaps it was in another life. Now there is company whenever you want it and quietness when that is what you prefer. This is the place where you belong, with these wonderful people; they are like a kind of family.

The work that you do here is the best you have ever had. The hours are flexible and the job is pleasant; being with people is what you have always enjoyed. You can do the work at exactly your own pace, without any rush or pressure, and you can rest whenever you need. For instance, there is that kind man who often comes to see you – by strange coincidence his name is the same as that of your husband. He seems to need you, and to enjoy being with you. You, for your part, are glad to give time to being with him; his presence is strangely comforting.

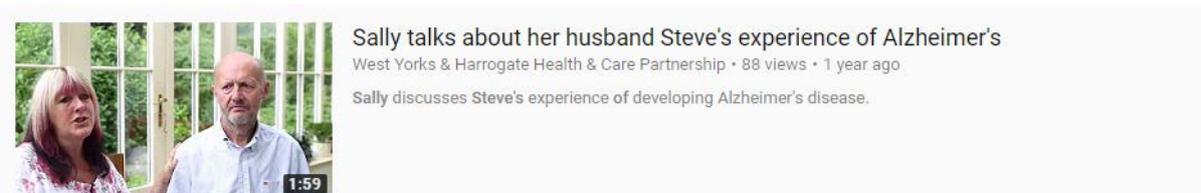
As you pass by a mirror you catch a glimpse of a person who looks quite old. Is it your grandmother, or that person who used to live next door? Anyway, it is good to see her too. Then you begin to feel tired; you find a chair and you sit down, alone. Soon you become aware of a chill around your heart, a sinking feeling in your stomach- the deadly fear is coming over you again.

You are about to cry out but then you see that kind mother-person, already there, sitting beside you. Her hand is held out towards you, waiting for you to grasp it. As you talk together, the fear evaporates like the morning mist and you are again in the garden, relaxing in the golden warmth of the sun. You know it isn't heaven itself, but sometimes it feels as if it might be halfway there.

How does this story make you feel?

Please now view this short film created by West Yorkshire & Harrogate Health & Care Partnership which features Airedale NHS Foundation Trust

['Sally talks about her husband Steve's experience of Alzheimers'](#)



Please now view this other short film by the Social Care Institute for Excellence (SCIE) which takes an innovative approach to what it might feel like to live with dementia. It features the voice of a woman, living with the condition, and the viewer gets a glimpse of life from her perspective.

[Dementia from the inside](#)



You have now finished the Dementia Awareness Workbook

Please complete and sign the workbook declaration sheet to confirm you have read and understood this workbook.

This must be submitted to: Training.dept2@anhst.nhs.uk