

Dementia Care an Holistic Approach

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Dementia the art of care



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Today's session – what we will cover

- Defining Dementia
- Types of Dementia
- Prevalence and Impact
- Common risk factors
- Pharmacological interventions
- Medications and their effects – risks and benefits, managing adverse effects
- Non-drug strategies, lifestyle modifications

What is Dementia?

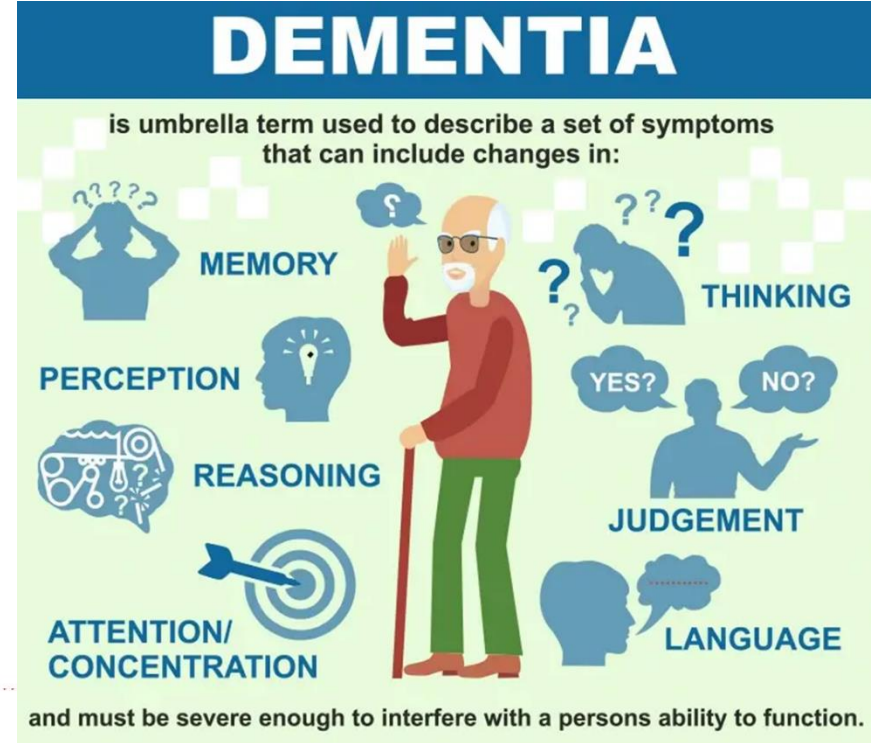
The word Dementia is used to describe a group of symptoms and consists of a wide range of diseases and disorders of the brain.

The symptoms result in progressive deterioration of a person's

- Intellectual function
- Decline in memory & cognitive performance

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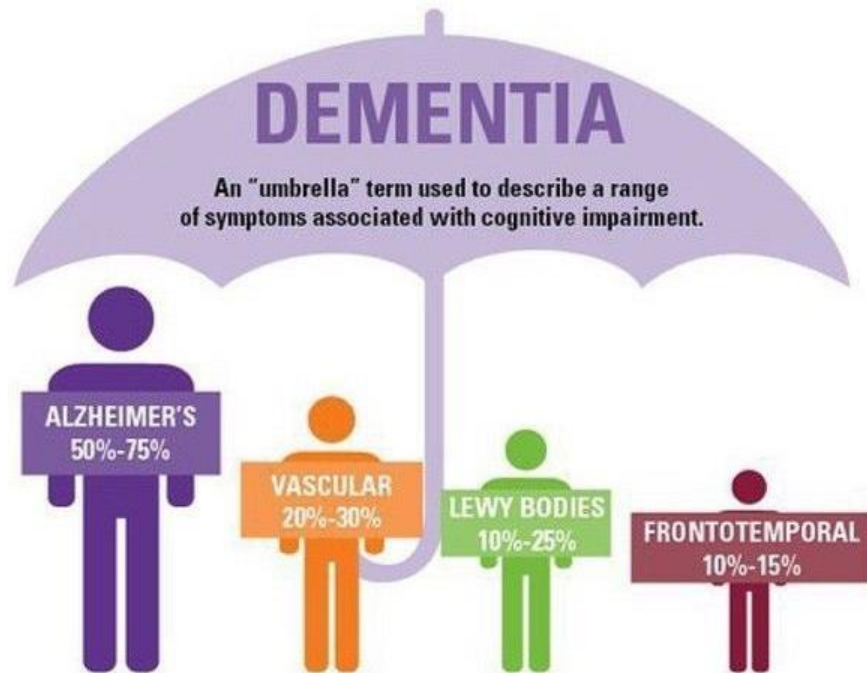


Different Types of Dementia

Each type of dementia affects a person in a different way and trying to understanding the person's sense of reality is essential.

The main types are:

- Alzheimer – 50% - 75%
- Vascular – 20% - 30%
- Lewy Bodies – 10% - 25%
- Frontotemporal – 10%-15%
- Mixed Dementia

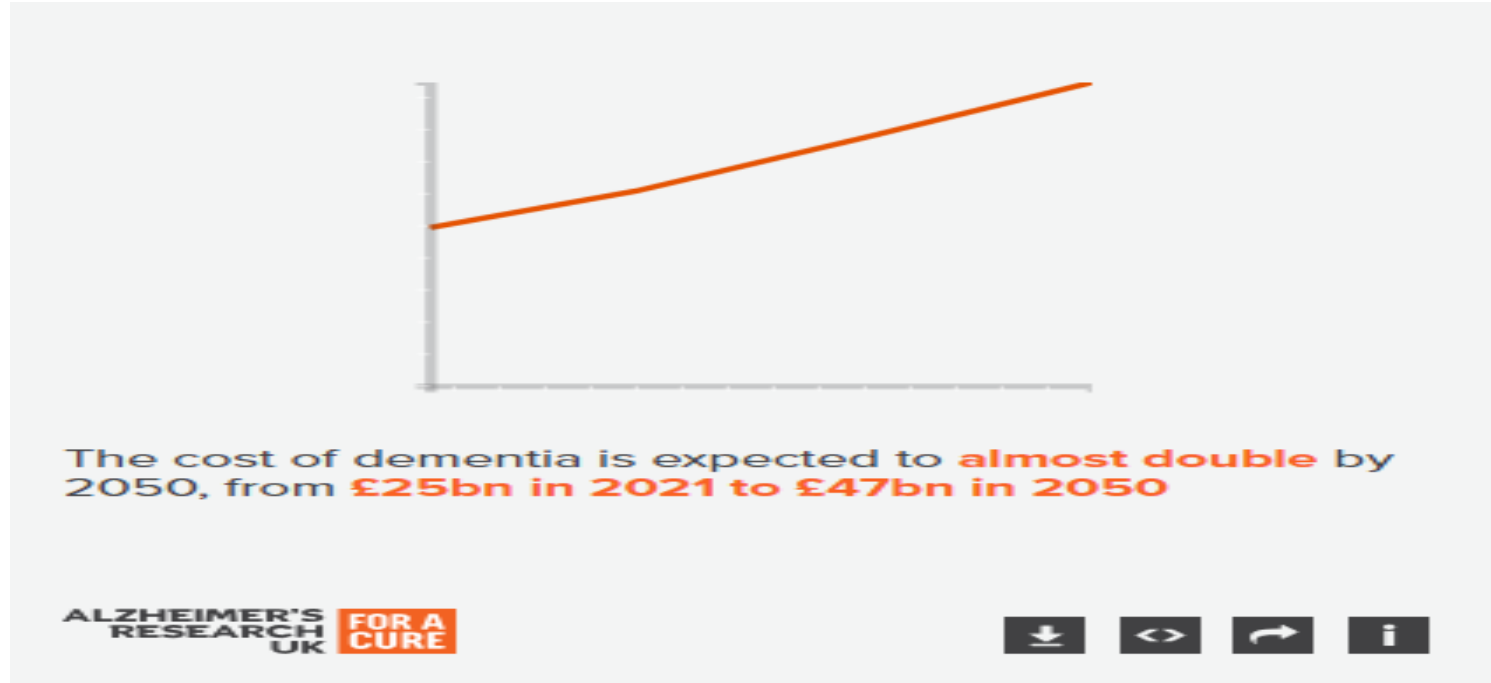


Prevalence of dementia

- 900,000 people are estimated to be living with a dementia diagnosis in the UK (2019) – this equates to £34.7billion.¹
- Alzheimer's – this represents approximately two thirds of cases.
- Vascular – up to 20 percent of dementias have a vascular cause.
- LBD – this is the third most common cause at 10 to 15 percent.
- Frontotemporal Dementia – this represents less than 5 percent of cases.

References :Alzheimer's Society. What are the costs of dementia care in the UK. [accessed 20 September 2023].
Alzheimer's Society. Alzheimer's Society's view on demography. December 2021 .

The cost of dementia – not only economic



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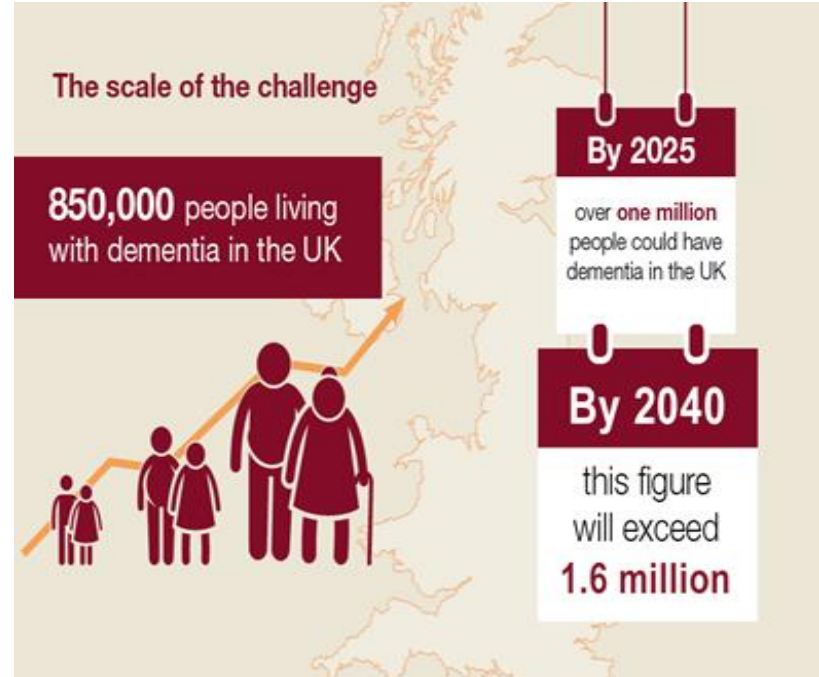
Diagnosis Rate Why Is It Important

The dementia diagnosis rate in England was 65.4% in August 2024.

- Diagnosis unlocks access to personalised care and support
- Access to clinical trials
- Current medicines that might support function
- Validation

Scale of the challenge?

- 1 in 6 people over the age of 80 have dementia.
- 70% of people in care homes have dementia or severe memory problems.
- There are over 40,000 people under 65 with dementia in the UK.
- More than 25,000 people from black, Asian and minority ethnic groups in the UK are affected.



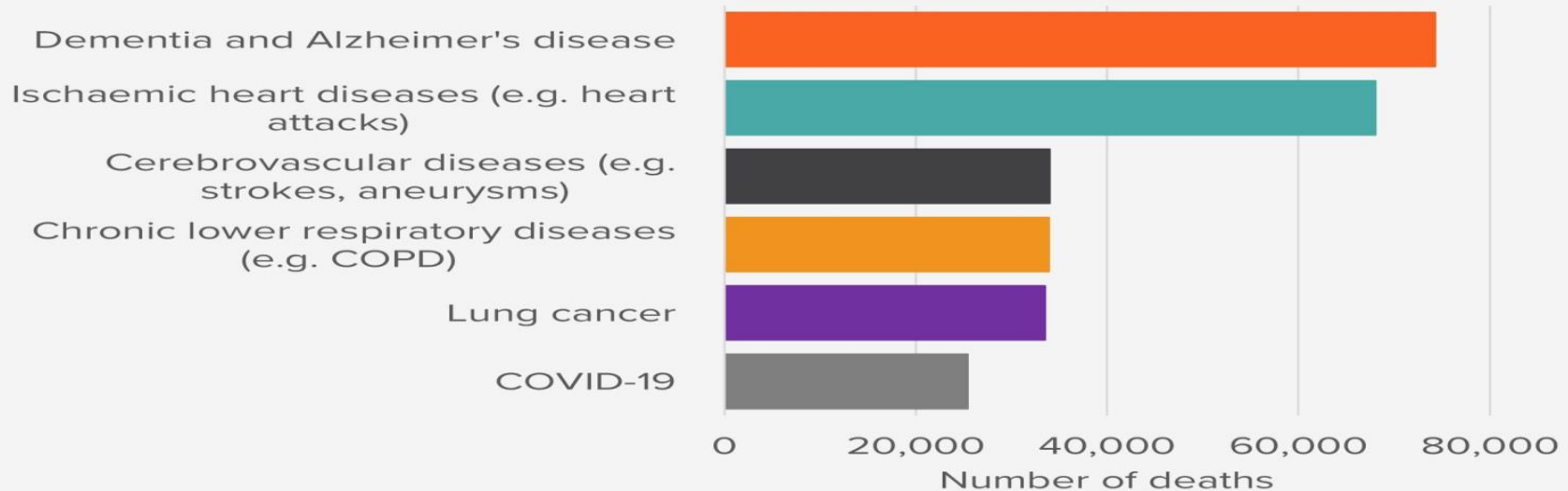
Inequalities in dementia

Dementia affects people from all backgrounds and communities. However, there are significant inequalities in dementia risk, incidence, diagnosis and management. Some of these include:

- Sex and Gender
- Socioeconomic status
- Ethnicity

Dementia is the only major cause of death without a treatment to prevent, slow or stop disease progression.

DEMENTIA WAS THE UK'S LEADING CAUSE OF DEATH IN 2022

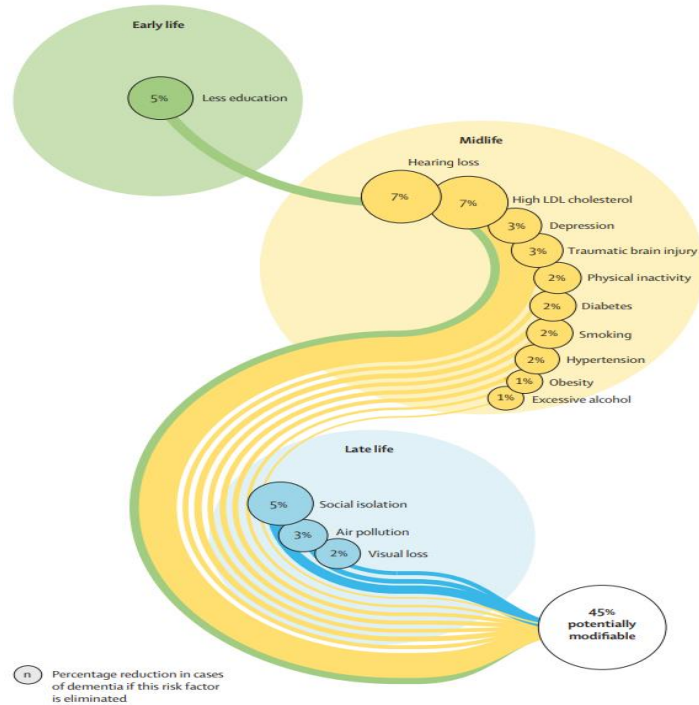


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Brain Health and risk reduction -The 14 risk factors are:



- Untreated vision loss
- High cholesterol
- Air pollution
- Low education
- Hearing loss
- Smoking
- Social isolation
- Traumatic brain injury
- Unmanaged high blood pressure
- Low physical activity
- Excessive alcohol consumption
- Obesity
- Type II diabetes

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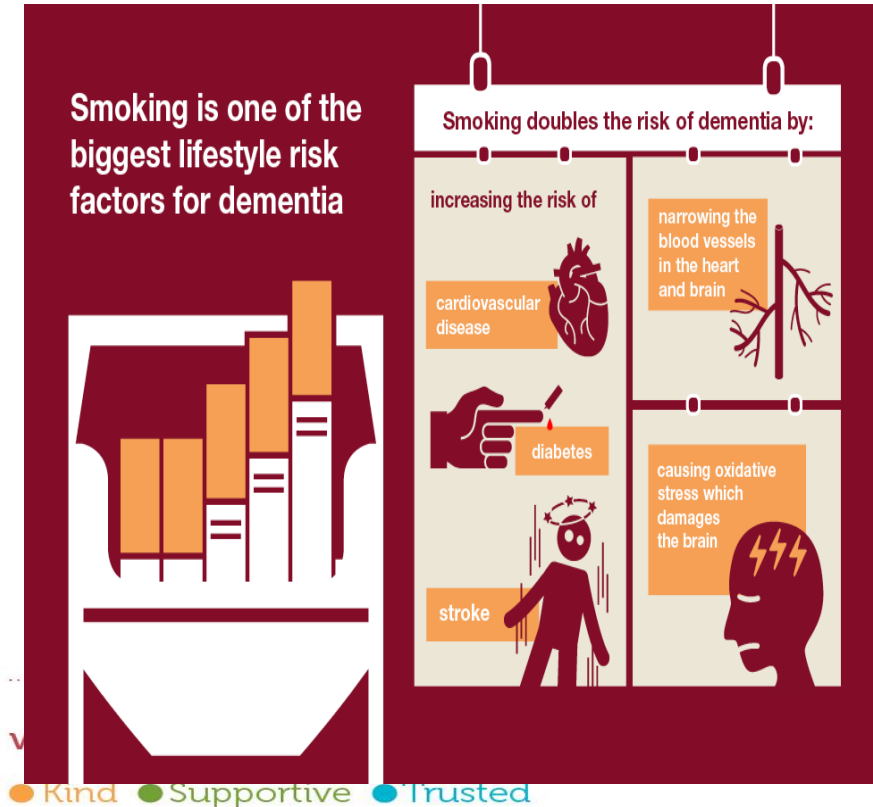
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Suvama Alladi, PhDg: et al

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Modifying Risk Of Dementia



- There is a lot of evidence that lifestyle choices can affect our risk of developing dementia. Dementia risk is lowest in people who have healthy behaviours in mid-life (aged 40–65). No single behaviour is guaranteed to prevent dementia, and some are more easy to change than others

And more

In January 2021

Alzheimer's Research UK wanted to change the conversation about dementia risk reduction, to empower more people to take positive steps to reduce their risk of developing the condition.

They published - Brain Health: A new way to think about dementia risk reduction

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Diagnosis and support – Well Pathway

PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
 <p>Risk of people developing dementia is minimised</p>	 <p>Timely accurate diagnosis, care plan, and review within first year</p>	 <p>Access to safe high quality health & social care for people with dementia and carers</p>	 <p>People with dementia can live normally in safe and accepting communities</p>	 <p>People living with dementia die with dignity in the place of their choosing</p>
<p>"I was given information about reducing my personal risk of getting dementia"</p>	<p>"I was diagnosed in a timely way"</p> <p>"I am able to make decisions and know what to do to help myself and who else can help"</p>	<p>"I am treated with dignity & respect"</p> <p>"I get treatment and support, which are best for my dementia and my life"</p>	<p>"I know that those around me and looking after me are supported"</p> <p>"I feel included as part of society"</p>	<p>"I am confident my end of life wishes will be respected"</p> <p>"I can expect a good death"</p>
<p>STANDARDS:</p> <p>Prevention⁽¹⁾ Risk Reduction⁽⁵⁾ Health Information⁽⁴⁾ Supporting research⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Diagnosis⁽¹⁾⁽⁵⁾ Memory Assessment⁽¹⁾⁽²⁾ Concerns Discussed⁽³⁾ Investigation⁽⁴⁾ Provide Information⁽⁴⁾ Integrated & Advanced Care Planning⁽¹⁾⁽²⁾⁽³⁾⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Choice⁽²⁾⁽³⁾⁽⁴⁾. BPSD⁽⁶⁾⁽²⁾ Liaison⁽²⁾. Advocates⁽³⁾ Housing⁽³⁾ Hospital Treatments⁽⁴⁾ Technology⁽⁵⁾ Health & Social Services⁽⁵⁾ Hard to Reach Groups⁽³⁾⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Integrated Services⁽¹⁾⁽³⁾⁽⁵⁾ Supporting Carers⁽²⁾⁽⁴⁾⁽⁵⁾ Carers Respite⁽²⁾. Co-ordinated Care⁽¹⁾⁽⁵⁾ Promote independence⁽¹⁾⁽⁴⁾ Relationships⁽³⁾. Leisure⁽³⁾ Safe Communities⁽³⁾⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Palliative care and pain⁽¹⁾⁽²⁾ End of Life⁽⁴⁾ Preferred Place of Death⁽⁵⁾</p>

References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.

Dementia – onset and time frames

- Dementia affects everyone differently. This makes it hard to know exactly how and when it will change over time. However, for some people with dementia the symptoms will progress in a broadly similar way. It can be helpful to think of this progression in three ‘stages’.
- Early stage
- Middle stage
- Late stage or advanced

And more

Dementia doesn't follow an exact or certain set of steps that happen in the same way for every person with dementia. It can be difficult to tell when a person's dementia has progressed

Speed of progression is very individual and will depend on:

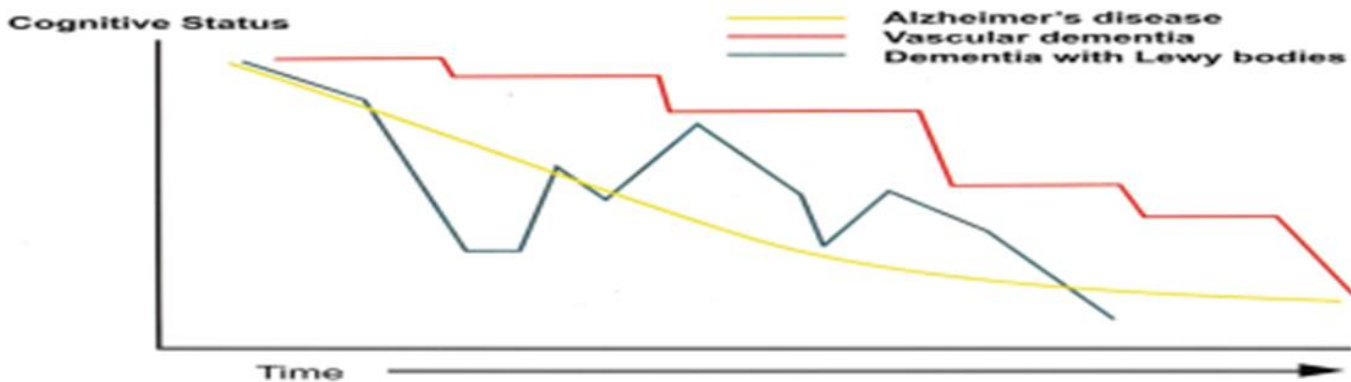
- type of dementia – for example, Alzheimer's disease tends to progress more slowly than the other types
- a person's age – for example, Alzheimer's disease generally progresses more slowly in older people (over 65) than in younger people (under 65)

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Progression



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Medicines

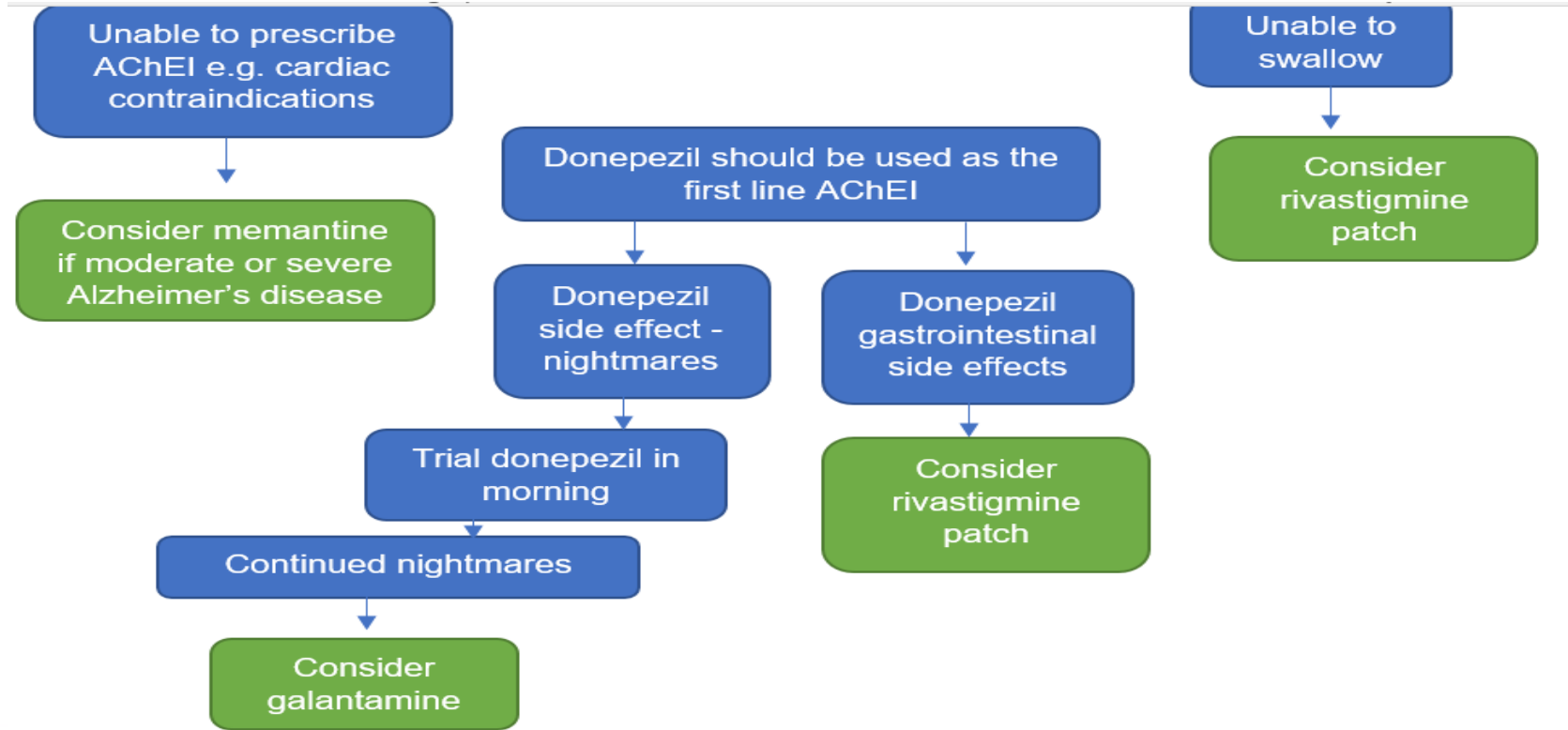
- There are four medications approved in the UK to ease a person's dementia symptoms, including memory and thinking problems and neuropsychiatric symptoms
- donepezil
- rivastigmine
- Galantamine
- memantine.

Medicines



- These medicines approved by NICE historically have not altered the disease pathology but may slow down progression for a period of time.
- Or support the person to maintain patterns of daily living
- Aducanumab is designed to target and clear amyloid, one of the hallmark proteins that builds up in the brains of people with Alzheimer's, at an early stage of the disease. This is similar to the mode of action of newer Alzheimer's drugs, lecanemab – also made by Biogen – and Eli Lilly's donanemab.

Before prescribing consider



Adverse effects

Side effects of donepezil, rivastigmine and galantamine

The most common side effects of donepezil, rivastigmine and galantamine are:

- loss of appetite
- feeling sick (nausea)
- diarrhoea or vomiting
- headaches
- feeling tired or dizzy
- difficulty sleeping well.

Cholinergic Pharmacology

Anticholinergic medication

- Block acetylcholine from attaching to the AchRs so acetylcholine is unable to pass messages on in the brain.
- Evidence shows increased risk of dementia, worsening of symptoms of dementia, increased risk of stroke and early mortality.¹

Acetylcholinesterase inhibitors

- Stop the breakdown of acetylcholine so there is more neurotransmitter available for the brain.
- Donepezil, rivastigmine, galantamine.²

Memantine can cause different side effects

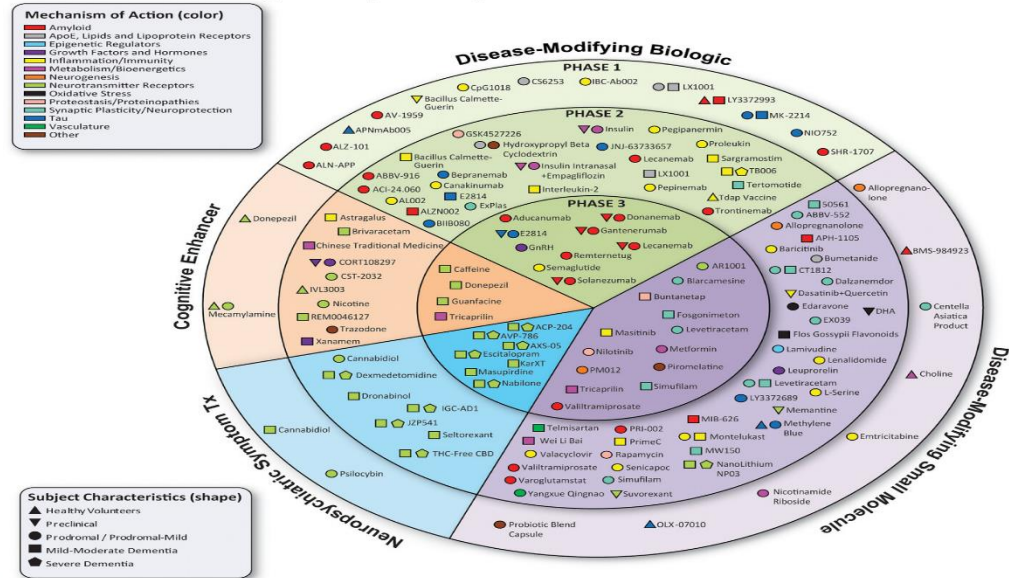
These include:

- headaches
- dizziness or problems with balance
- tiredness or shortness of breath
- raised blood pressure
- constipation.

Research into new treatments is ongoing

- There are 127 drugs in the Alzheimer's drugs pipeline

2024 Alzheimer's Drug Development Pipeline



Is it BPSD- Behavioural and Psychological Symptoms in Dementia

Non-cognitive neuropsychiatric symptoms typically as part of the severe stages of dementia. Includes:

- Agitation
- Aggression
- Apathy
- Depression
- Psychosis
- But also... unmet needs (pain, hunger, inactivity, psychological etc)

Consider and carry the following statements with you when thinking about distress

- Beneath every behaviour is a feeling, beneath every feeling is a need. And when we meet that need rather than focus on the behaviour, we begin to deal with the cause and not the symptom.”
- Psychologist Ashleigh Warner
- All behaviour is a form of communication and is often driven by need. To fully understand the meaning of a person's behaviour it is important to try and understand the behaviour from the perspective of the person with dementia.



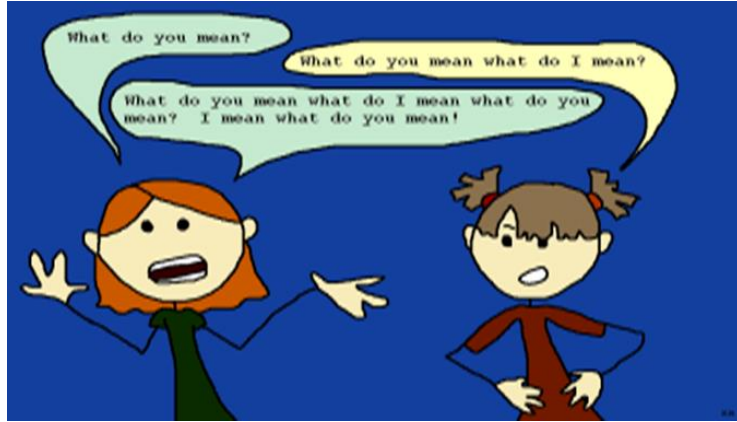
Why do these behaviours surface?

The reasons are not always clear but we know that the majority of PWD will experience them at some point.



- Always think about acute illness and or untreated pain
- Environmental pressure –noise
- Tiredness, hunger, sadness, boredom
- Lack of life routine – Material Citizenship™
- They may be partly to do with the progression of dementia and partly due to the distress that it brings.
- This could be delirium if the change emerges quickly

Communication skills are key - it's not all about words - non verbal signs often tell us a lot



**WHEN YOU ARE
FRUSTRATED WITH ME
BECAUSE OF THE THINGS
I CAN NOT DO, JUST
IMAGINE HOW
FRUSTRATED I MUST BE
BECAUSE I AM NOT ABLE.**

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Communication tips for carers

Never argue – Instead Agree

Never Reason – Instead Divert

Never Lecture – Instead Reassure

Never Shame – Instead Distract

Never say “Remember” – Instead Reminisce

Never Say “I told you” – Instead Repeat or Regroup

Never Say “You can’t” – Instead Do what they can

Never Condescend – Instead Encourage

Never Force – Instead Reinforce

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It isn't all about words

Steps to Successful Communication

GETTING STARTED	FACIAL EXPRESSION	TONE OF VOICE	BODY LANGUAGE
<ul style="list-style-type: none">• Approach from the front• Smile• Identify yourself• Use the person's name• If possible, be at eye level	<ul style="list-style-type: none">• Establish & maintain eye contact• Be friendly & relaxed• Always remember humor: smiles & laughter go a long way• Be patient and supportive	<ul style="list-style-type: none">• Speak slowly & clearly• Use a gentle & relaxed tone of voice• Convey an easy-going manner	<ul style="list-style-type: none">• Avoid sudden movement• Be open & relaxed with your stance• Remain calm & confident to provide reassurance• Use gestures such as pointing• Give visual cues

Medicines and BPSD

If its BPSD & there is no acute delirium medication approaches:

- 1. Stop anticholinergic medications/switch/rationalise
- 2. Ensure no unmet pain needs- regular paracetamol acute illness
- 3. Consider if would benefit from memantine for mod-severe dementia in Alzheimer's or BPSD.
- NB. Personalised approach

Low dose antipsychotics – what are the target symptoms



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Recording risks and benefits



There are several antipsychotic drugs that may be used. Each one has slightly different effects on the brain and has its own potential risks and side effects.

The drug with the most evidence to support its use in dementia is risperidone. -It is licensed for short term (up to six weeks) treatment of persistent aggression in people with moderate to severe Alzheimer's disease when there is risk of harm to the person or others. However, this is only if non-drug approaches have already been tried without success.

Risks associated with prescribing in dementia

Antipsychotics can eliminate or reduce the intensity of certain symptoms. However, they also have serious side effects. For people living with dementia, these include:

- Increased risk of death
- Stroke
- Drowsiness (so increased risk of falls and fractures)
- Postural hypotension (further increasing risk of falls and fractures)

And more

- Parkinsonism (shaking and unsteadiness)
- Worsening of dementia symptoms
- For people with dementia with Lewy bodies or Parkinson's disease dementia,
- antipsychotics can worsen the motor features of the condition, and in some cases
- cause severe antipsychotic sensitivity reactions.

Consider the benefit of review, trial reduction / withdrawal

- One death is prevented for every 6 dementia patients who have long term antipsychotic discontinued before it is taken for more than 1 year.
- One death is prevented for every 22 dementia patients who have short term antipsychotics discontinued after around 12 weeks.
- One death will be prevented for every 100 patients with dementia who avoid antipsychotic treatment for behavioural or psychological symptoms.
- One stroke is prevented for every 37 patients with dementia who avoid 8 - 12 weeks of antipsychotic treatment for behavioural or psychological symptoms.

<https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2022/10/Antipsychotic-Prescribing-Toolkit-for-Dementia.pdf>

What do these medicines **not help** with

- distress and anxiety during personal care
- repetitive vocalisations
- walking about
- social withdrawal
- changes in levels of inhibitions (for example, doing or saying things that may be inappropriate).

These changes are likely to need personalised non drug approaches

Its all about appropriate prescribing

Antipsychotic medication use in older people with dementia is associated with an increased risk of stroke and death. In addition, all antipsychotics have significant adverse side effects.

They should only be used as a last resort for a specific symptom for a specified time period, with regular monitoring of effect and any adverse effects

Behaviours and non pharmacological approaches

The only non-pharmacological therapy endorsed by NICE for improving cognitive symptoms is group cognitive stimulation therapy (CST).

However Quality standard [QS184] Published: 28 June 2019

Includes:

Activities such as exercise, aromatherapy, art, gardening, baking, reminiscence therapy, music therapy, mindfulness and animal-assisted therapy.

Cognitive stimulation / activities

- Reading, puzzles, art therapy, cooking, yoga, and physical exercises
- These can be done in groups or individually
- Music and singing can be very powerful ways to relive memories, and music is also used as a form of therapy.
- CBT
- Social prescribing

Sleep disturbance – Z drugs not the default position

This is very common with dementia:

- Ensure the person is supported with good sleep hygiene – non pharmacological approaches
- Normal routine and patterns are understood
- Specific dementia – LBD – REM sleep disorder

Patient Monitoring-Ongoing dementia assessment

- After diagnosis with dementia, the GP should arrange to check how the patient is managing.
- The memory service where the person was assessed may also continue to see you in the early stages.
- The GP and the specialist may also jointly prescribe medicines that may help some of the symptoms of dementia. But not everyone will benefit from these medicines.
- As the dementia progresses the MDT approach to include social support will become vital.

Thank You For Your Time

Thank you
for
listening!



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Any Questions



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