Diagnosing advanced dementia and behaviour that challenges in care homes

Mark Kitchingham

Nurse Consultant/Lecturer

KMPT

Acacia Sookal

Lead Integrated Care Pharmacist

NHS Kent & Medway ICB

Learning outcomes

- To understand the benefits of a diagnosis of dementia
- To explore behaviour that challenges in the context of dementia care and models underpinning this
- To introduce the role of pharmacological and non-pharmacological interventions in the care planning and treatment of behaviour that challenges in dementia

Introduction

- We have an ageing population in the UK meaning there are likely to be an increasing number of people living with dementia
- Dementia is one of the leading causes of death in the UK
- ¼ of all hospitals beds are currently occupied by someone living with dementia
- There is an estimated 25,984 people living with dementia in Kent and Medway
- Dementia is a key national priority highlighted by the then Prime minister in 2015 with the ‘Prime Minister’s Challenge on Dementia 2020’
- This key priority has set a target for 2/3rds of people living with dementia to have a formal diagnosis
- It is estimated that 70 per cent of people in care homes have dementia or severe memory problems

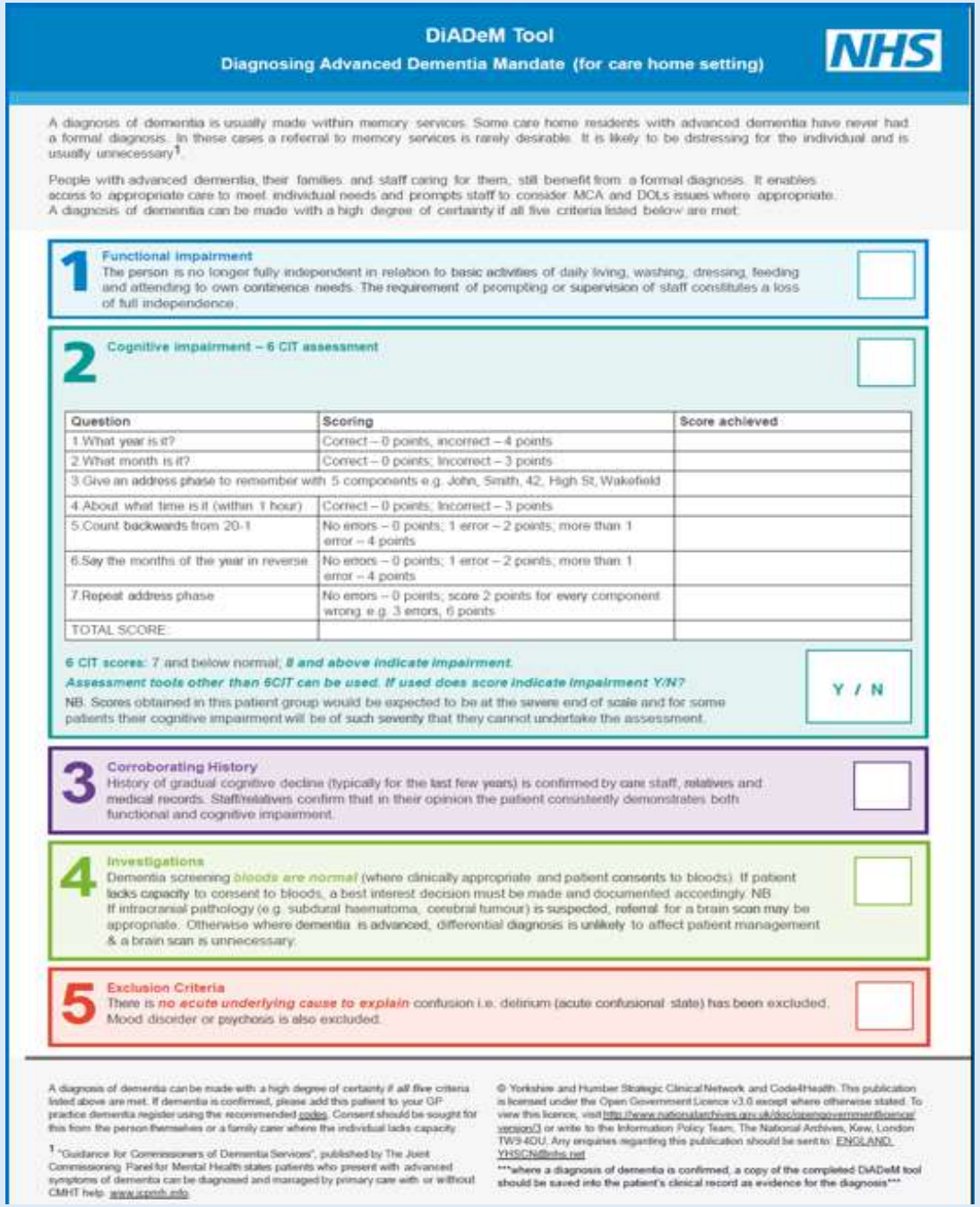
Benefits of making a diagnosis

- Opportunities for review of exacerbating factors, e.g medications
- Opportunities for treatment and interventions, both pharmacological and non
- Tailored support for carers and families
- Inform advanced care planning
- Access to the right support at the right time
- Consideration of MCA and DOLS issues

DiADeM

5 parts:

1. Functional impairment
2. Cognitive impairment - uses 6-CIT or GPCOG
3. Corroborating history
4. Investigations
5. Exclusion criteria



DiADeM Tool

Diagnosing Advanced Dementia Mandate (for care home setting)

NHS

A diagnosis of dementia is usually made within memory services. Some care home residents with advanced dementia have never had a formal diagnosis. In these cases a referral to memory services is rarely desirable. It is likely to be distressing for the individual and is usually unnecessary[1].

People with advanced dementia, their families and staff caring for them, still benefit from a formal diagnosis. It enables access to appropriate care to meet individual needs and prompts staff to consider MCA and DOLs issues where appropriate.
A diagnosis of dementia can be made with a high degree of certainty if all five criteria listed below are met:

1 Functional impairment

The person is no longer fully independent in relation to basic activities of daily living, washing, dressing, feeding and attending to own continence needs. The requirement of prompting or supervision of staff constitutes a loss of full independence.

2 Cognitive impairment – 6 CIT assessment

Question	Scoring	Score achieved
1.What year is it?	Correct – 0 points, incorrect – 4 points	
2.What month is it?	Correct – 0 points; Incorrect – 3 points	
3.Give an address phase to remember with 5 components e.g. John, Smith, 42, High St, Wakefield		
4.About what time is it (within 1 hour)	Correct – 0 points; Incorrect – 3 points	
5.Count backwards from 20-1	No errors – 0 points; 1 error – 2 points; more than 1 error – 4 points	
6.Say the months of the year in reverse	No errors – 0 points; 1 error – 2 points; more than 1 error – 4 points	
7.Repeat address phase	No errors – 0 points; score 2 points for every component wrong e.g. 3 errors, 6 points	
TOTAL SCORE:		

6 CIT scores: 7 and below normal; ***8 and above indicate impairment.***

Assessment tools other than 6CIT can be used. If used does score indicate impairment Y/N?

NB. Scores obtained in this patient group would be expected to be at the severe end of scale and for some patients their cognitive impairment will be of such severity that they cannot undertake the assessment.

Y / N

3 Corroborating History

History of gradual cognitive decline (typically for the last few years) is confirmed by care staff, relatives and medical records. Staff/relatives confirm that in their opinion the patient consistently demonstrates both functional and cognitive impairment.

4 Investigations

Dementia screening *bloods are normal* (where clinically appropriate and patient consents to bloods). If patient lacks capacity to consent to bloods, a best interest decision must be made and documented accordingly. NB If intracranial pathology (e.g. subdural haematoma, cerebral tumour) is suspected, referral for a brain scan may be appropriate. Otherwise where dementia is advanced, differential diagnosis is unlikely to affect patient management & a brain scan is unnecessary.

5 Exclusion Criteria

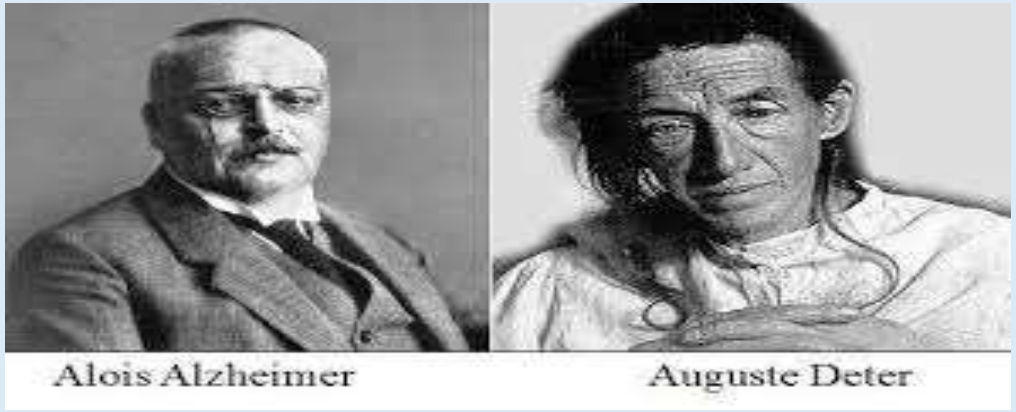
There is ***no acute underlying cause to explain*** confusion i.e. delirium (acute confusional state) has been excluded. Mood disorder or psychosis is also excluded.

A diagnosis of dementia can be made with a high degree of certainty *if all five* criteria listed above are met. If dementia is confirmed, please add this patient to your GP practice dementia register using the recommended codes. Consent should be sought for this from the person themselves or a family carer where the individual lacks capacity.

[1] "Guidance for Commissioners of Dementia Services", published by The Joint Commissioning Panel for Mental Health states patients who present with advanced symptoms of dementia can be diagnosed and managed by primary care with or without CMHT help. www.jcpmh.info

where a diagnosis of dementia is confirmed, a copy of the completed DiADeM tool should be saved into the patient's clinical record as evidence for the diagnosis

What's in a name?

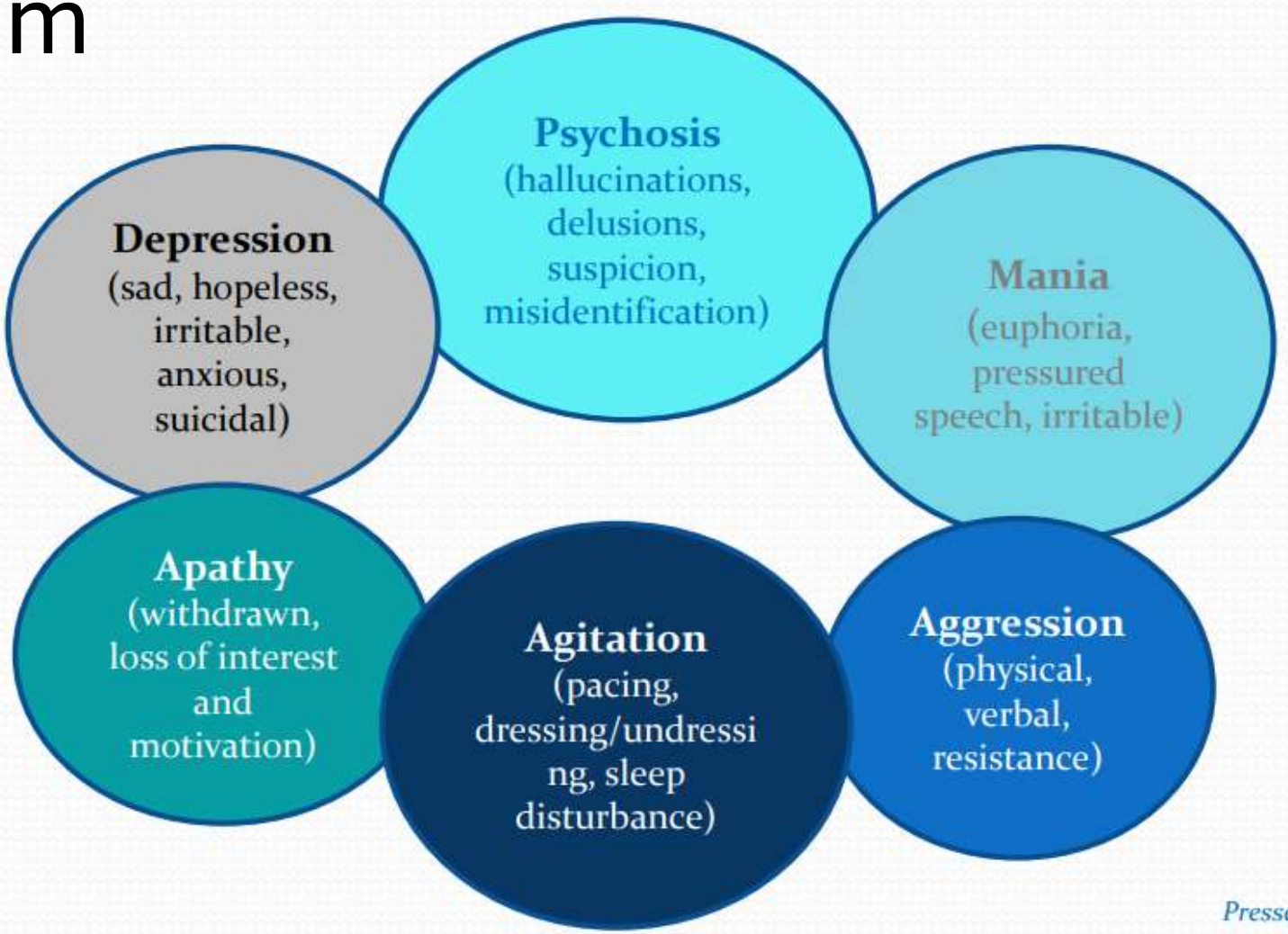


- Alois Alzheimer identified in patient August D; paranoia, delusions, vocal disruption and hallucinations
- Influence of Kitwood suggested a change of focus to care givers (“malignant social psychology” and “personhood”)
- International Psychogeriatric Association Consensus group (1999) replaced behavioural disturbance with Behavioural and Psychological Symptoms of Dementia (BPSD)
- AKA neuropsychiatric symptoms, non-cognitive symptoms, behaviour that challenges others, unmet needs

Join at menti.com | use code 4926 3263

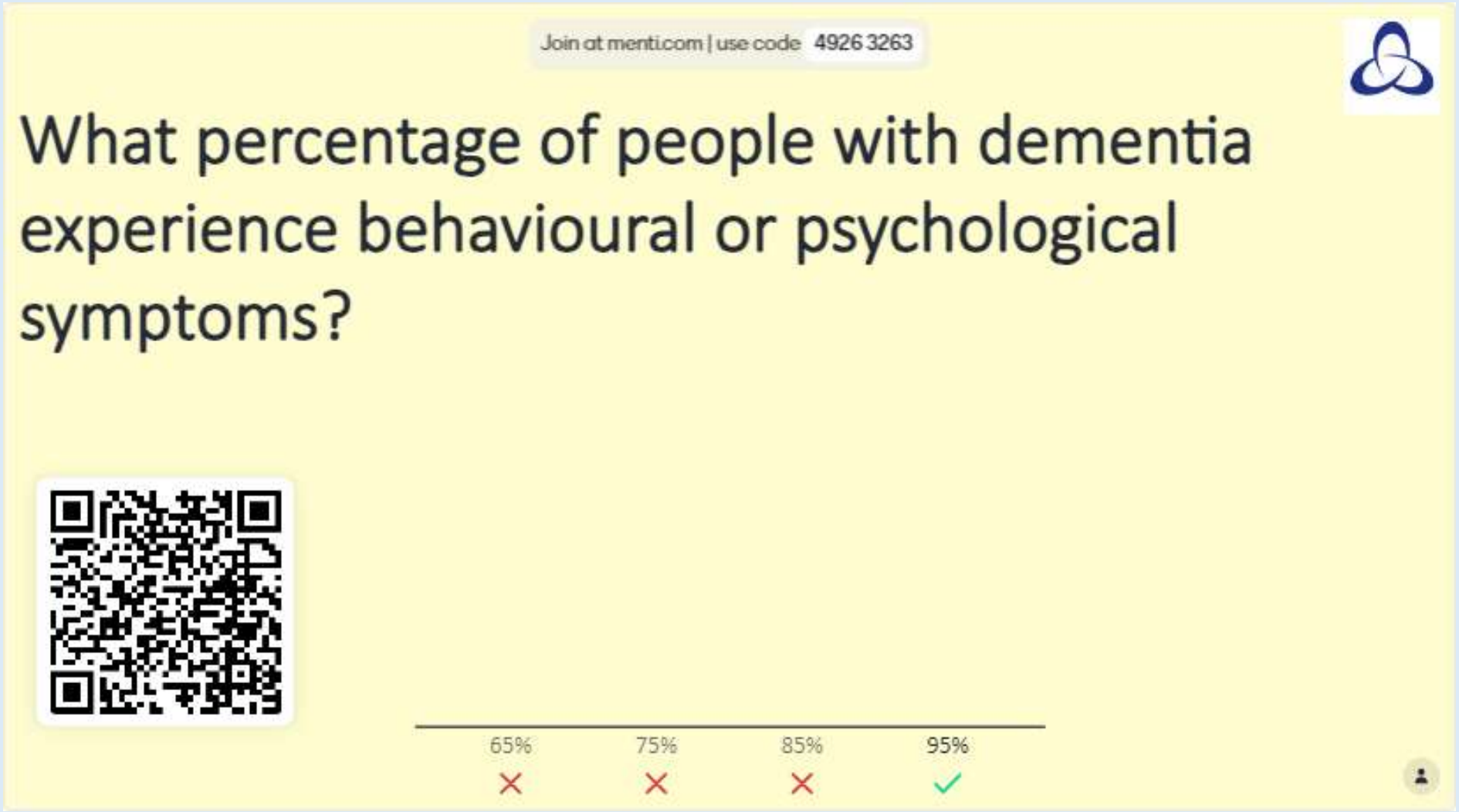
What different types of behaviour that challenges others can you think of?

Diagram



Pressqipp antipsychotics in dementia

Poll 1


Join at menti.com | use code 4926 3263
What percentage of people with dementia experience behavioural or psychological symptoms?
65%
75%
85%
95%

Prevalence of BPSD

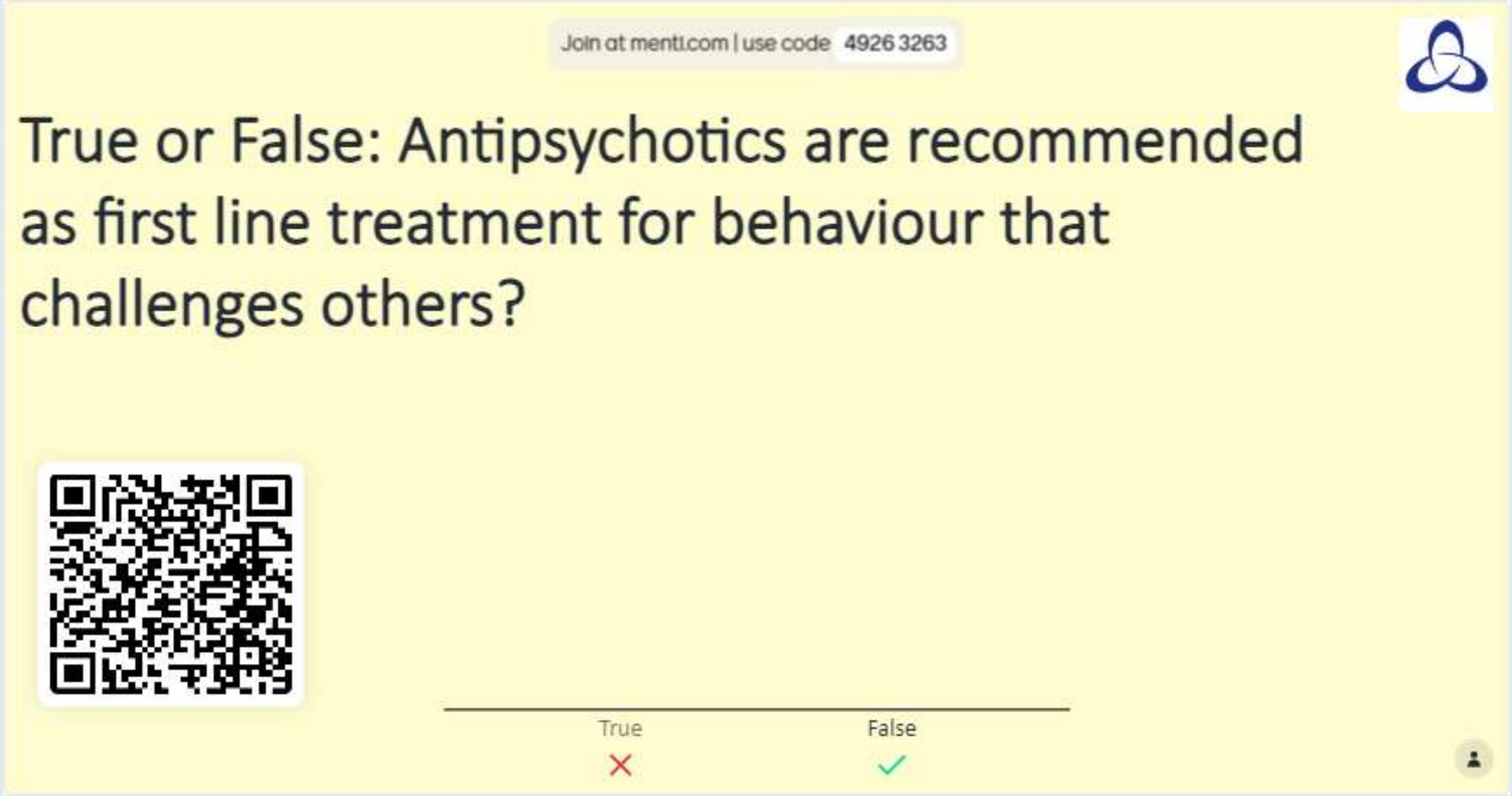
- 95% of patients with dementia will experience behavioural or psychological symptoms
- Strongly correlated with degree of cognitive/functional impairment
- Nearly 2/3 of PWD in care homes will have BPSD at any one time
- Up to 50% of BPSD will resolve without Intervention within 4-6 weeks

NPI BPSD Items	Point Prevalence at Baseline (%)	Five year Period Prevalence (%)
Delusions	18	60
Hallucinations	10	38
Agitation/Aggression	14	45
Depression/Dysphoria	29	77
Apathy/Indifference	20	71
Elation/Euphoria	1	6
Anxiety	14	62
Disinhibition	7	31
Irritability/Lability	20	57
Aberrant Motor Behavior	7	52
Any Symptom	56	97

Variation with diagnosis

- Alzheimer's disease – psychosis more common
- Vascular dementia – depression, emotional instability and apathy more common
- Mixed (Alzheimer's and vascular) – highest prevalence overall (agitation followed by depression/apathy)
- Dementia with Lewy Bodies – visual hallucinations
- Fronto-temporal dementia - impulsivity

Poll 2


Join at menti.com | use code 4926 3263
True or False: Antipsychotics are recommended as first line treatment for behaviour that challenges others?
True
False

The role of antipsychotics

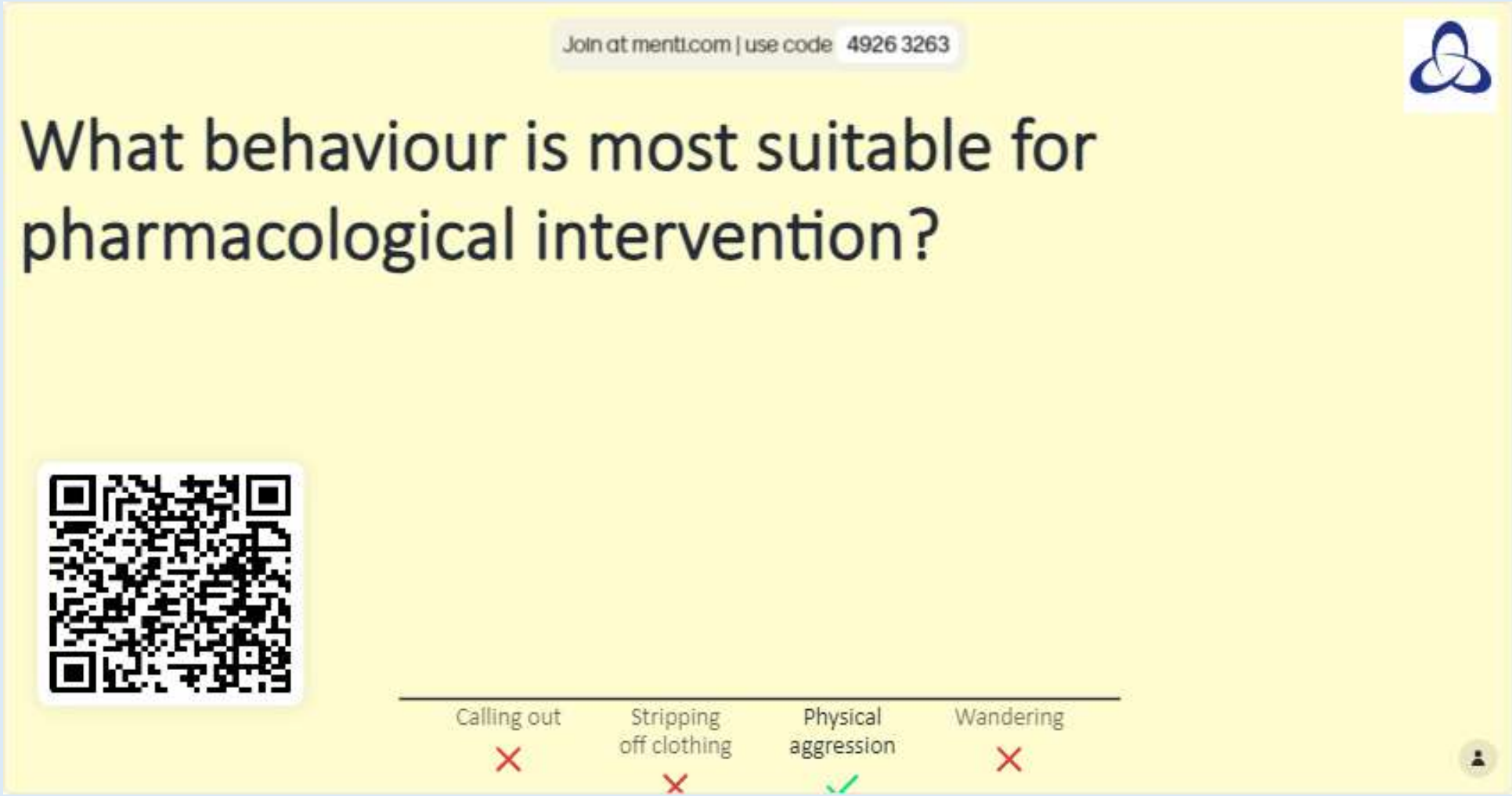
- NICE recommends that a person should only try an antipsychotic if they are at risk of harming themselves or others, or if they are severely distressed or agitated
- Only Risperidone and Haloperidol are licensed for treatment of non-cognitive symptoms
- Patients should be reassessed every 6 weeks to confirm whether they still need the medication, used at the lowest dose for the shortest time.
- Treatment with antipsychotic medication should be stopped if the person is not getting a clear ongoing benefit

NICE dementia guidelines (2018)

Side-effects

- Drowsiness (so increased risk of falls and fractures)
- Postural hypotension (further increasing risk of falls and fractures)
- Worsening of dementia symptoms
- Parkinsonism (shaking and unsteadiness)
- Increased risk of death
- Stroke

Poll 3


Join at menti.com | use code 4926 3263
What behaviour is most suitable for pharmacological intervention?
Calling out
Stripping off clothing
Physical aggression
Wandering

Behaviours likely not amenable to medication

- Apathy
- Repetitive vocalisation, eg/ shouting out/screaming
- Inappropriate urination/defaecation
- Inappropriate dressing/undressing
- Hiding/hoarding
- Repetitive activities, eg/ pulling on locked doors
- Wandering
- Eating in edibles
- Distress and anxiety during personal care
- Uncooperativeness in the absence of aggression or risk

Covert Administration:

Covert administration is only likely to be necessary or appropriate where:

- a **person actively refuses their medicine** and
- that person is assessed **not to have the capacity to understand the consequences of their refusal. Such capacity is determined by the Mental Capacity Act 2005** and
- the **medicine is deemed essential to the person's health and wellbeing.**

What is covert administration?

- Medicines **could be hidden in food, drink or given through a feeding tube without the knowledge** or consent of the person receiving them.
- This means the person **does not know they are taking a medicine.**
- If a person **has mental capacity to make the decision** about whether to take a medicine, **they have the right to refuse that medicine.**

5 Considerations for Covert Administration:

1. **You must assume they have capacity to do so unless it is proved otherwise.** Every adult has the right to make his or her own decisions.
2. **Establish Capacity** You should make every effort to encourage and support people to make the decision for themselves.
3. **People have the right to make decisions that others might regard as unwise**. Everyone has their own values, beliefs and preferences which may not be the same as those of other people.
4. **Anything you do or decide for or on behalf of a person who lacks mental capacity must be in their best interests.**
5. When deciding or acting on behalf of a person who lacks capacity, you must consider:
    - whether **there is a way that would cause less restriction to the person's rights and freedoms of action**
    - **whether there is a need to decide or act at all**
    - **Any intervention should be the result of the person's circumstances.**

Consent and Capacity

- Assessment of Capacity must be completed under the Mental Capacity Act 2005 **before COVERT administration is considered**.
- There **must be clear documentation** of any decisions made
- A **best Interest meeting** must be carried out
- Deprivation of Liberty Safeguards (DoLS) may be authorised to reasonably restrict a person's liberty in their best interests if they are under continuous supervision, if deemed appropriate that they lack mental capacity to decide on their care and treatment.
  - NB This must include medication.

Collaboration

- Covert medication should only be given to adult patients who have been assessed as lacking capacity, and a **best interest meeting conducted**.
  - The purpose of the **best interest meeting is to discuss the treatments options for the resident in light of their capacity** and whether it is in the patient's best interests to have his/her medications administered covertly.

- A **management plan should be agreed as part of the best interest meeting including the rationale** for decisions made on behalf of the resident's well-being and care

- Should include care home staff, relevant healthcare professionals, a person acting on behalf of the resident (e.g., family, friend, IMCA) and LPA (if appropriate).

Evidence and Documentation

- **Care Plans should show assessment of capacity** and assessment of need and who was involved in the assessment process and the best interest meeting.
- **Written agreement of the decision,** any actions taken and the names of all parties concerned should be obtained and documented in the resident's care plan and medicines profile.
  - This decision should be reviewed regularly, the timescale of the review should be based on the individuals circumstances.
- **Mental capacity assessments** should also be reviewed and recorded
- The decision should also be **documented on the resident's MAR** chart.
  - If not involved in the decision, the community pharmacy should be informed of the agreed administration information so that MAR charts can be updated accordingly.
  - **Details of how the medication will be administered** (e.g. Crushed on yogurt)

Considerations Before Administering Covert Medication:

- The resident’s doctor or pharmacist must be contacted to discuss alternative formulations prior to covert administration being considered.
- A medication review should be undertaken to determine that each medicine is necessary.
- Examples: swallowing difficulties, changing times of medicines, crushing medicines or mixing with food or drink (off-label use).

Learning/behavioural model (Cohen-Mansfield)

- Behaviour is a learned connection between antecedents, behaviour and reinforcements/consequences
- Many problem behaviours are learned through staff reinforcement providing attention when a problem behaviour is displayed
- ABC approach
  - Antecedents – triggering event for the behaviour
  - Behaviour – the behaviour of concern
  - Consequences – the consequence of that behaviour

- Therefore, changing the antecedent or consequence may change the behaviour

Environment vulnerability/Reduced stress threshold model

- Dementia process results in increased vulnerability to surroundings and a greater chance of events affecting behaviour
- People with dementia progressively lose their coping abilities and therefore perceive their environment as more stressful
- Therefore, the likelihood of being bothered by the environment increases and results in anxiety and inappropriate behaviour when the environmental stimuli exceeds to threshold for tolerating stress
- An environment of reduced stimuli limits the stress experienced and therefore the level of inappropriate behaviour

Unmet needs model for agitation

1. Behaviours to obtain or meet a need (eg/ pacing to provide stimulation)
2. Behaviours to communicate a need (eg/ repetitive questioning)
3. Behaviours that result from an unmet need (eg/ aggression triggered by pain or discomfort)

Cohen-Mansfield (2000)

Questions to ask?

- Is this a new behaviour?
- Does the behaviour pose danger for the resident or others?
- Whom is it really a problem for? (Resident? Staff? Family?)
- Look at each behaviour as a separate challenge.
- When did the behaviour start?
- Is the behaviour an expression of other illness?

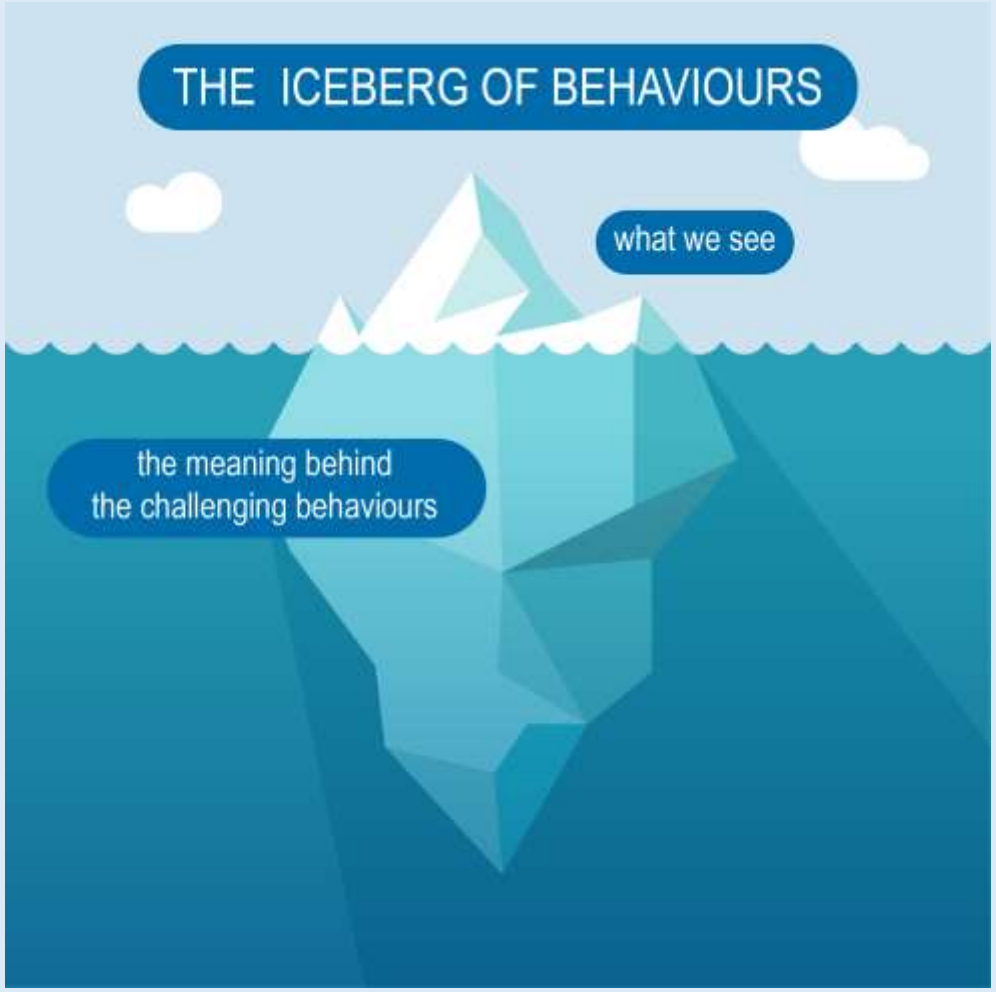
REMEMBER

- Behaviour has a reason!

Table 1. **Extract from Bob's ABC chart**

Date and time	Antecedent	Behaviour	Consequences	Any other comments	Initials
02/02/22 08:30	Bob sat at breakfast table pushing food around plate; staff encouraged him to eat	Bob pushed plate across table aggressively. It landed on the floor and broke	Bob paced up and down the hall, declined support and looked increasing agitated	Ate or drank very little	AA
02/02/22 10:30	Staff concerned as they hadn't seen Bob for a while so looked for him. Found him sat on toilet	Bob verbally aggressive, swore at staff to leave and threatened to hit member of staff	Staff left toilet and monitored at a safe distance. Bob left toilet five minutes later, looking agitated	Threats to harm very out of character	BB
02/02/22 12:30	Went to find Bob for lunch	Found Bob laying curled up on bed. He refused lunch and was verbally aggressive	Staff tried to encourage Bob to come and have something to eat. He agreed. Looked really uncomfortable mobilising	Bob offered pro re nata pain relief. Pain chart started	CC
03/02/2020 03.30	Bob not in bed when staff did 3.30am care round	Found Bob sitting on toilet in foyer area. Looked very uncomfortable, refused to leave bathroom. Verbally aggressive to staff	Left Bob and checked on him 15 minutes later. Still on toilet, refusing to leave. Bob went back to bed 40 minutes later		DD

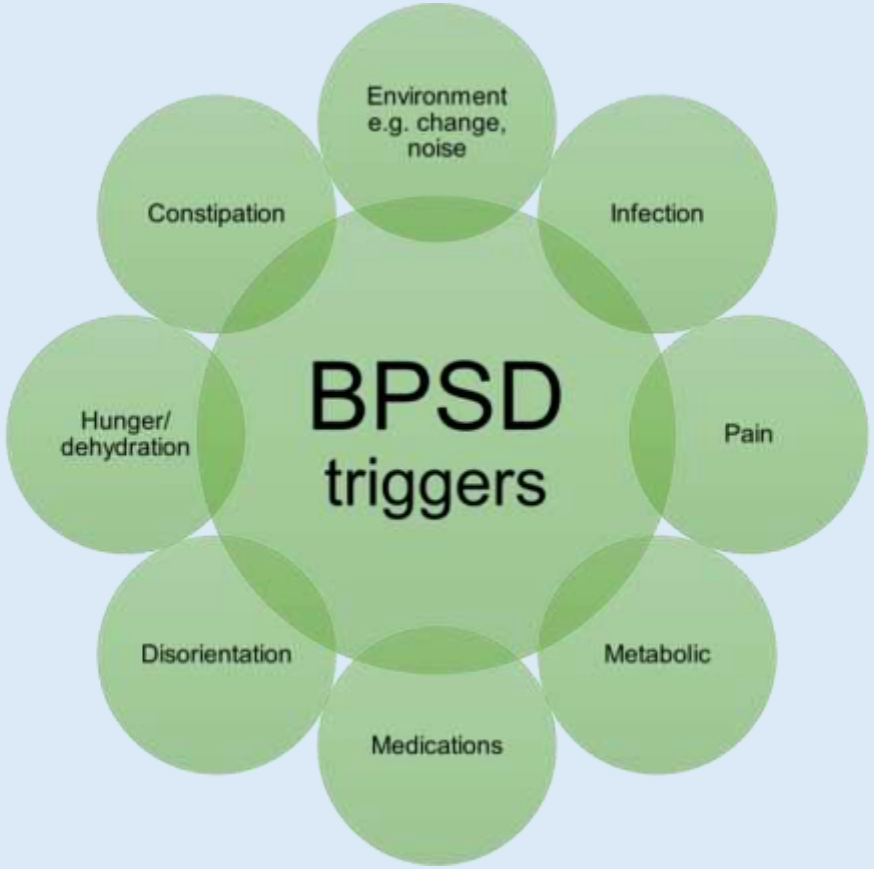
ABC = antecedent, behaviour, consequences.



PINCHME

- **P**ain
- **IN**fection
- **C**onstipation
- **H**ydration/Nutrition
- **M**edication
- **E**nvironment

Other factors to consider



- Sensory deficits
- Medication side-effects
- Reduced mobility
- Pain/physical discomfort
- Incontinence
- Reduced verbal communication
- Environmental factors – design of home, over/under stimulation, awareness of triggers

*

Physical factors	
Possible causes	Suggestions
• Pain; skin, dental, joints, constipation. • *>50% PWD at home daily pain,* • *60-80% NH residents in pain (1/3 mod-severe)*	• Pain scale, observe during care/transfers, try paracetamol. Check dentures. Acute or chronic, verbal and non-verbal cues. Bed sores
• Delirium *(PWD are incr. risk)* • *Up to 50%.* • ***NB** other risks - age, polypharmacy, hydration*	• Medical review
• Infections (UTI, chest, skin cellulitis)	• Medical review
• Sleep disturbance	• Sleep during day?, sleep hygiene, under-stimulated. Normal pattern. Personalised activity. AChEI S/E?
• Hearing/sight *(incr. risk of depression)*	• Clear communication (good ear), approach from "best" side (sight). Glasses, aides etc
• Medication S/E *(metabolic changes & reduced clearance)*	• Medical review, consider ACB

*

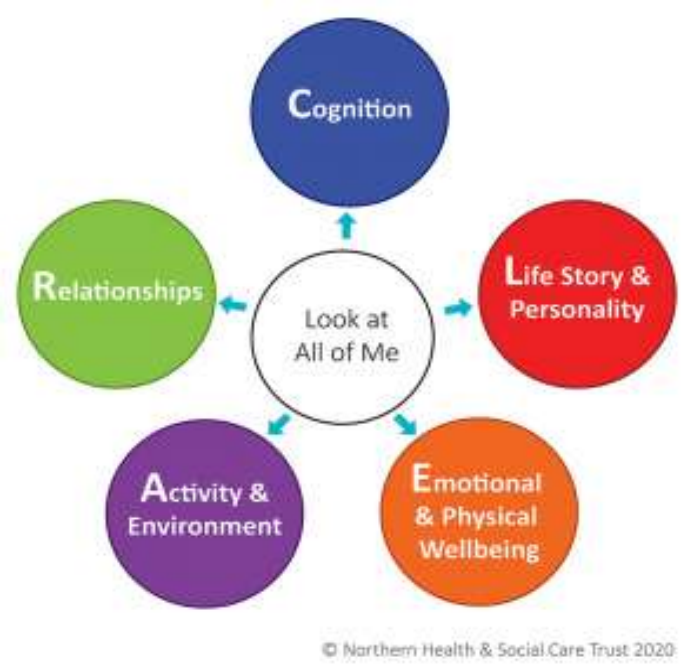
Environmental factors	
Possible causes	Suggestions
• Environment/Design of home. DCM link - https://www.dementiacarematters.com/	• Getting used to new home? Lighting, signage, personal objects, pictures, colours, outside space. Assistive technology
• Under stimulation	• Life story work, "This is me". Social area/space, activity.
• Over stimulation	• Too noisy? Afternoon nap, calming music
• Awareness of triggers	• Identify, document, be consistent. Related to visitors? Refer MH services for functional analysis and interventions

Nonpharmacological interventions

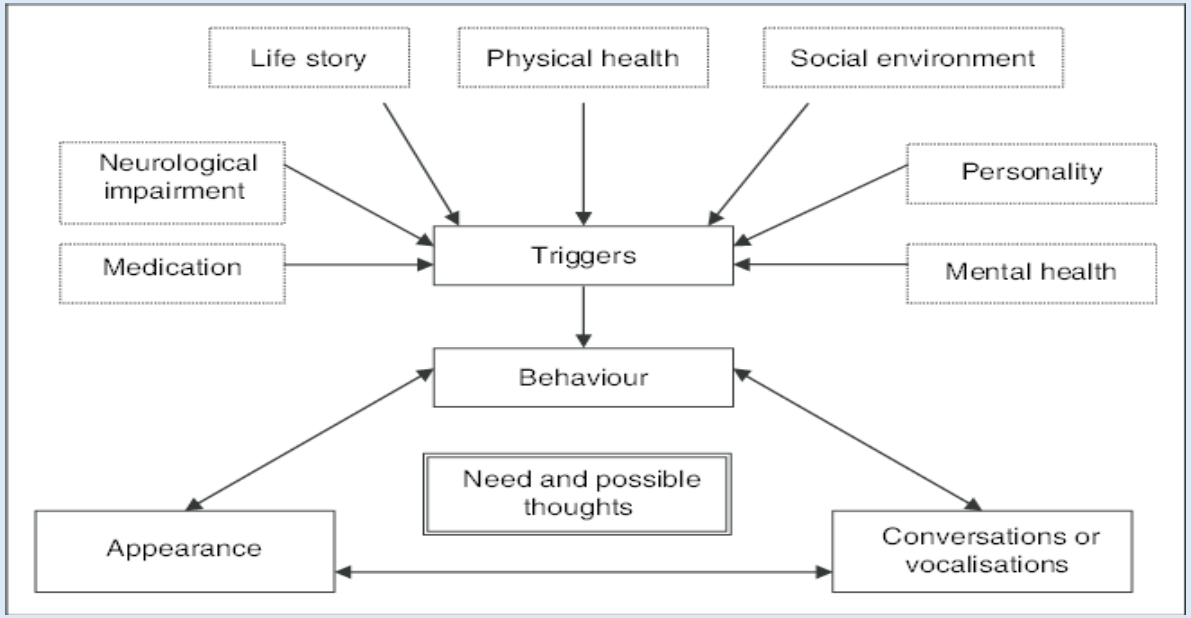
- Increased activity
- Reminiscence
- Doll therapy
- Music
- Physical activity
- Animal therapy

Best evidence (modest!) for music therapy and behavioural management interventions (Abraha et al, 2017)

CLEAR
Dementia Care
App



Newcastle model



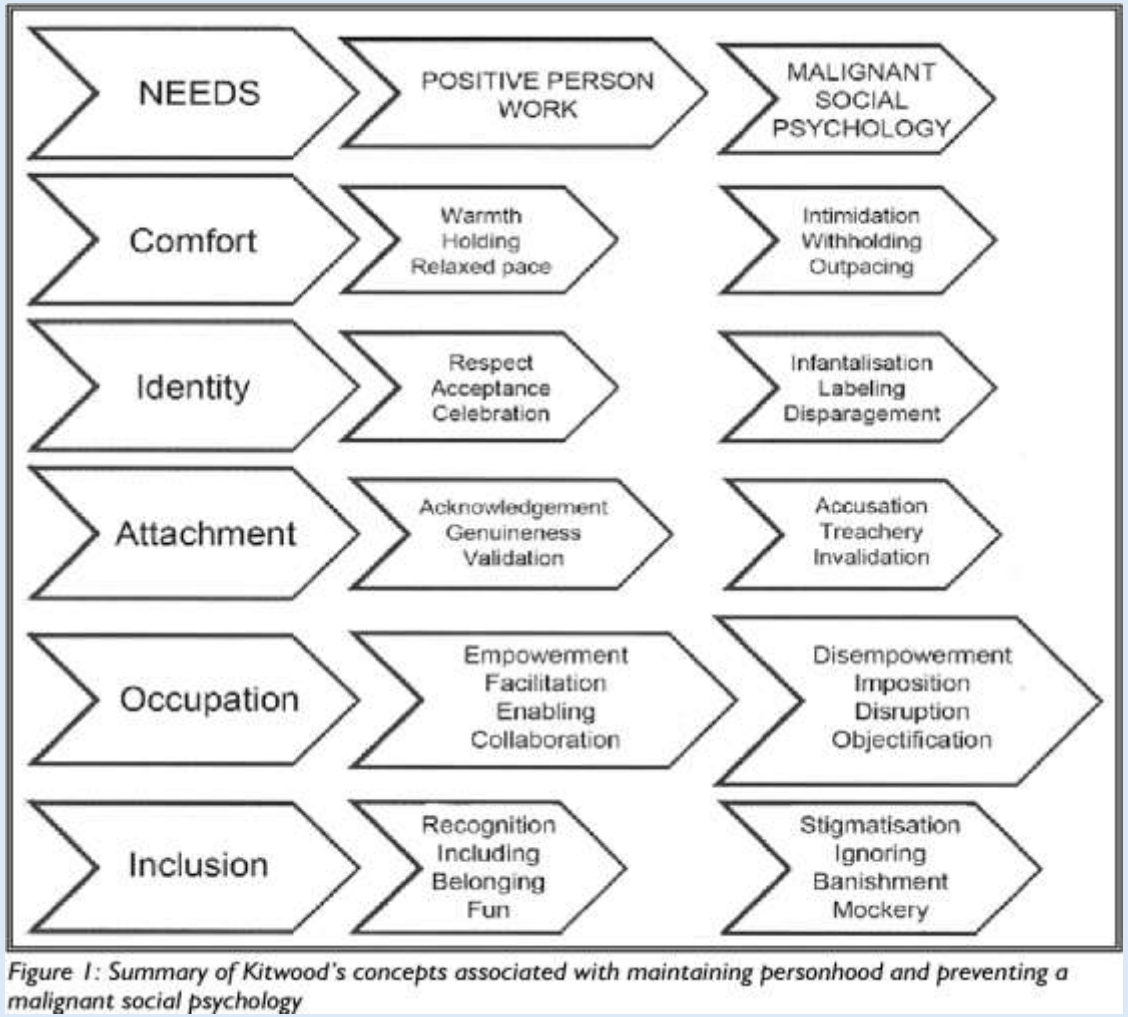
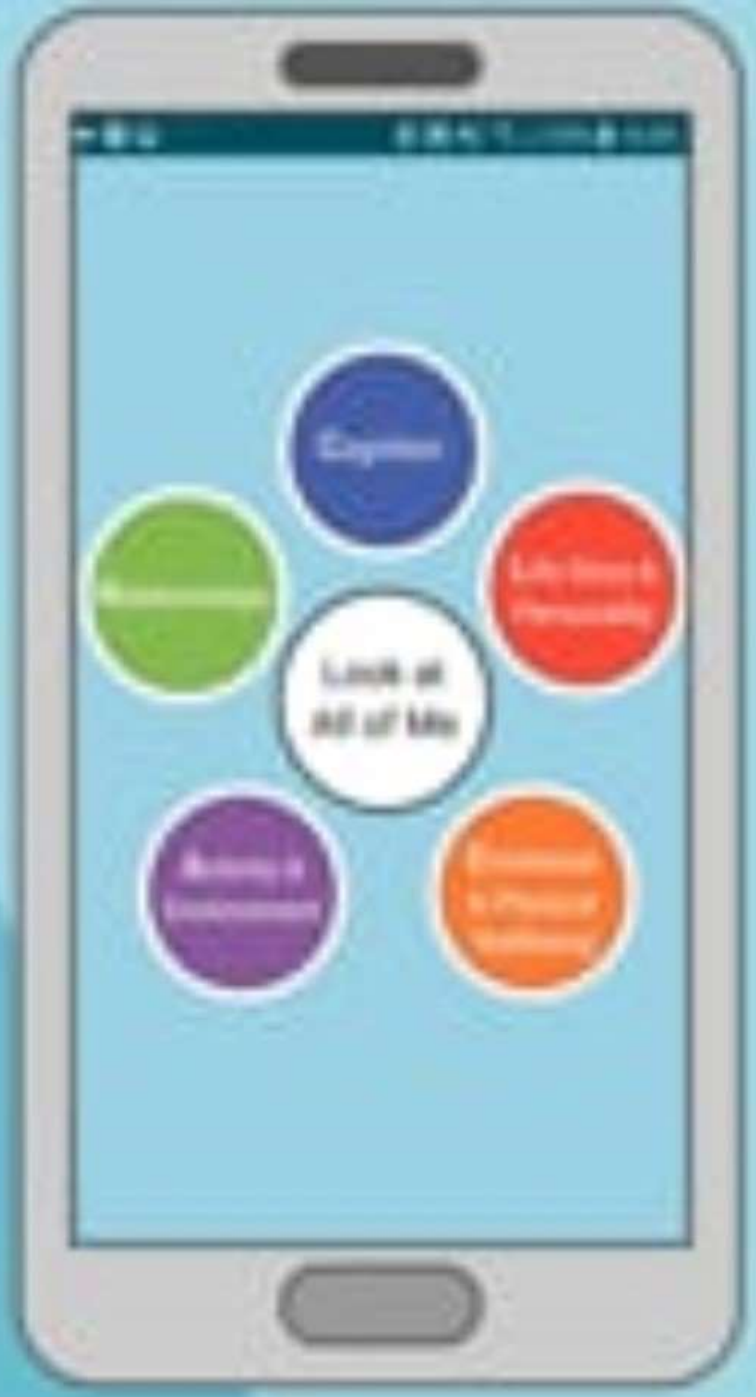


Figure 1: Summary of Kitwood's concepts associated with maintaining personhood and preventing a malignant social psychology

Dementia Care Mapping

Welcome to the CLEAR Dementia Care App



Case study

Brian is a 68-year-old gentleman with a diagnosis of dementia residing in a care home who you have been contacted by. He is reported to be physically fit and well. He has smoked throughout his life and can still communicate verbally to a certain extent, enjoyed socialising, and used to work as a gardener. Most of the other residents are in their 70's and 80's and are in the advanced stages of dementia. The incident occurred on consecutive days around lunchtime. Brian was seen walking around the corridors and was banging on the door to the garden which is always locked. On one occasion a member of staff asked him to stop, and he banged on the door harder and pushed the staff member away and they fell and hit her head on the wall and have made a complaint. A nurse from the home has contacted you and asked you to prescribed Risperidone, they consider his behaviour attention seeking.

Key messages

- There are benefits to a diagnosis of dementia even if this is at an advanced stage
- Behaviour that challenges others is very common in dementia but most will resolve without intervention in 4-6 weeks
- Non-pharmacological approaches are first line
- Antipsychotics should only be used in high risk situations with the lowest dose for the shortest time and have significant side-effects
- Always look for any underlying causes of any changes in behaviour, ie/ pain, constipation, sensory issues, unmet needs, over/under stimulation

References

- Kennedy, S (2021). Antipsychotic Use in Dementia.
- Dementia, Medications and Non-Pharmacological Approaches. Presentation by Katherine Roper de Leake NMP/ Matron. NSFT Older Persons Community Services. GY&W Care Group.
- Ton, J., Ramji, J., & Allan, G. M. (2018). Antipsychotics for agitation in dementia. *Canadian family physician Medecin de famille canadien*, *64*(5), 369.
- Yorkshire and the Humber Clinical Network and London Clinical Network NHS England (2022). Appropriate prescribing of antipsychotic medication in dementia
- NICE dementia guidelines (2018)