Distress in Dementia – Managing BPSD

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For
Primary Care Dementia Day 2023

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What we will cover

- Differential diagnosis
- Behavioural and Psychological Symptoms in Dementia (BPSD) or Distress in Dementia (DiD)
- Bio/Psycho/Social approach to management
- A glimpse at legal frameworks
- Scenarios

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Differential Diagnosis of 'challenging behaviour'

- Dementia
- Delirium (and all the myriad causes of that)
- Terminal Agitation
- Other mental illness
- Premorbid personality
- A combination of the above

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Distinguishing Dementia from Delirium

Dementia	Delirium
Almost always GRADUAL onset (months / years)	ACUTE onset (hours / days)
Caused by pathology in brain	Caused by physical illness – meds, infection, metabolic disturbance etc
There may be no change in routine bloods	Usually altered bloods; most commonly CRP↑, WCC ↑, Na↓
Classic symptom is loss of memory (and so much more)	Classic symptom is disturbance of arousal / attention – person may be drowsy, hypervigilant
More likely in older people, neuropathology present	Can occur at any age and in the absence of neuropathology
Many different courses, but apart from DLB, don't tend to fluctuate much in course of the day or from day to day	Tends to fluctuate
Dementia and delirium have complex relationship (dementia risk factor for delirium, delirium can precipitate dementia, the two can co-exist)	
Delirium is common, is a medical emergency and is often missed.	

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Understanding Terminal Agitation

- Can be understood as delirium occurring in the last hours or days before death
- Can occur in dementia, as well as other terminal illnesses
- Often expressed as restlessness and aggression
- Manage by recognising possible causes – pain, hypoxia, urinary retention, emotions, medications – and managing them as appropriate

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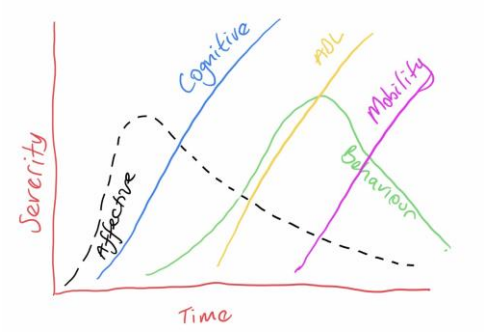

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Behaviour as communication

We can interpret behaviour in dementia as a way of communicating something to us

Our first step, having determined that the person has dementia and / or delirium is to try to treat the delirium if present

Then, work out what is being 'said'

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Suggestions? What might people be expressing?

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Possibilities	
Anger	Attraction
Fear	Interest
Pain	Need the loo
Hunger	Want to go outside
Loneliness	Curiosity
Boredom	Excitement
Restlessness	
Sadness	
Disorientation	
Tired	

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Initial management

Address	Address physical needs – hunger, thirst, toilet
Exclude	Exclude delirium – physical and bloods
Treat	Treat pain – try paracetamol
Assess	Assess for obvious causes – boredom, loneliness etc
Try	Try activities, time outside, company

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Interpreting the different syndromes of behaviour

Depressive	Psychotic	Manic	Apathy
Agitation / Anxiety / Fear	Pain	Aggression	Disintegration

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Depressive Symptoms

- Sad
- Tearful
- Hopeless
- Irritability
- Guilt, shame
- Suicidal

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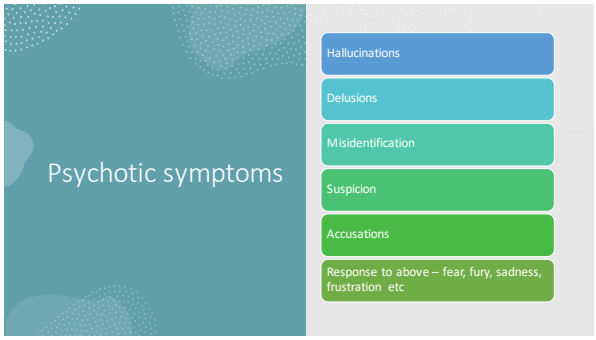
Psychotic symptoms
Hallucinations
Delusions
Misidentification
Suspicion
Accusations
Response to above – fear, fury, sadness, frustration etc

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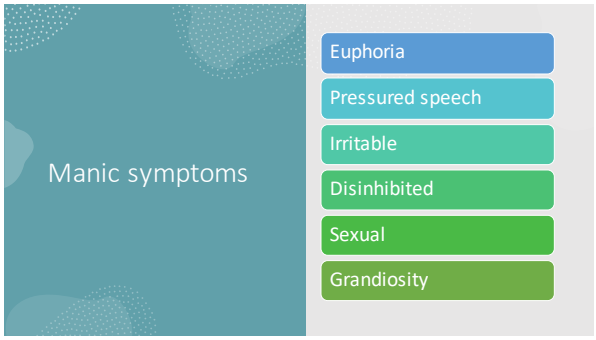
Manic symptoms
Euphoria
Pressured speech
Irritable
Disinhibited
Sexual
Grandiosity

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Apathy
Withdrawn
No interest
No energy
No motivation
Little pleasure

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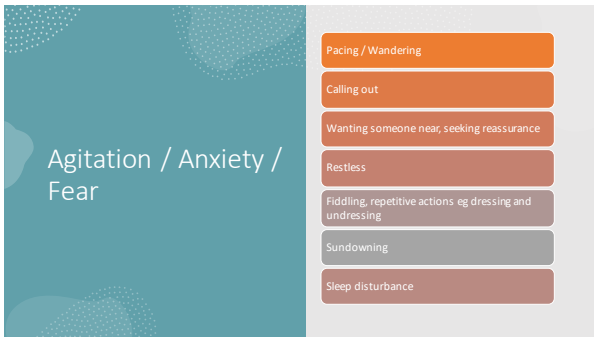
Agitation / Anxiety / Fear
Pacing / Wandering
Calling out
Wanting someone near, seeking reassurance
Restless
Fiddling, repetitive actions eg dressing and undressing
Sundowning
Sleep disturbance

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Aggression
Physical aggression
Verbal aggression
Aggressive resistance to care
Protective of personal space

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Disintegration of Perception
Frustration at not being able to express self
Lying on floor because unsteady / cant interpret input
Not eating and drinking as don't recognise signals
Incontinence for same reasons
Reliving past trauma
Climbing furniture
Disinhibition

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Management

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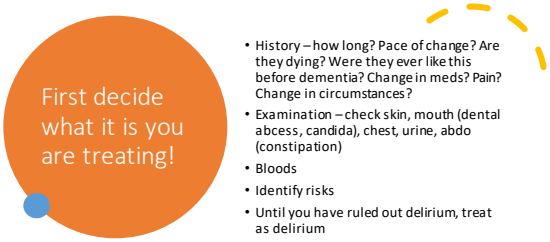
First decide what it is you are treating!
History – how long? Pace of change? Are they dying? Were they ever like this before dementia? Change in meds? Pain? Change in circumstances?
Examination – check skin, mouth (dental abcess, candida), chest, urine, abdo (constipation)
Bloods
Identify risks
Until you have ruled out delirium, treat as delirium

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Differential Diagnosis

- Dementia
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- Terminal Agitation
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Once determined the cause of the distress is dementia.....

- Balance of risks helps you decide how you proceed
- Depends a great deal on individual circumstances
- Consider
  - location
  - who is doing the caring and how they are
  - personality of person with dementia
  - likelihood of compliance with treatment

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Risks to consider

To Self
- Neglect
- Injury
- Suicide

To others (and what do they think of it?)
- Neglect
- Injury
- Suicide
- Special consideration if there are children or other vulnerable people in the household

To property

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Bio – Psycho – Social Approach

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Biological

- Pain. If unsure, regular PCM and review
- Review meds / toxins
- Treat anything that could be causing delirium on top of dementia
- Nutrition and hydration
- Glasses, hearing aids, teeth
- Medication for the symptoms when appropriate (not usually first line)

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Psychological

- Sleep
- Therapy
- One to one to ensure stays in quiet, calm environment with appropriate activity
- Familiar carers / loved ones
- Communication style
- Behavioural analysis and care plan
- This is me book

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Sleep

- sleeping environment
- caffeine
- light
- time outside
- melatonin
- minimising naps in day
- bath before bed

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Therapy

- Art
- Music
- Animals
- ? EMDR

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Communication style

- Quiet,
- Simple
- Avoid questions
- Flexible.
- Generally; agree, reassure, distract, allow dignity
- Avoid 'no' or correcting people
- No-one wins an argument with someone with dementia
- Avoid 'Elderspeak'

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Social

- Safeguarding?
- Meaningful activity – valued, purpose, spiritual
- Exercise
- Access to outside, sunshine, fresh air
- Educate and support family / carers
  - Communication
  - Behaviours expected
  - How to support
- Environment
  - draw curtains,
  - cover mirrors,
  - quiet, calm, homely, warm enough

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Practically, what does that mean?

- Managing distress in dementia needs a team
- Its exhausting
- Needs multiple skill sets

- Contact CMHT, Admiral nurses, Alzheimer's society

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What to prescribe in insomnia?

- Insomnia?
  - Deprescribe caffeine
  - Melatonin is safe, fairly effective – doesn't increase sedation / falls
  - Give 2mg 2 hours before bed
  - Only licensed for 3 months
  - Many people use bigger doses and for longer

- If doesn't work consider risks of using / not using a Z drug
  - Some people at more risk of falls without hypnotic
  - Zolpidem can be given in food if can't take tablets

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What to prescribe in depression

- Everything takes a while to work – 6 weeks rather than 2 to see Δ
- Trials of antidepressants in dementia are not overwhelming
- SSRIs – I favour sertraline.
- Trazodone if need something more sedating
- Venlafaxine or mirtazapine if mixed anxiety and depression

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What to prescribe in anxiety / agitation

- SSRI – citalopram, sertraline
- Trazodone, mirtazapine
- Memantine can be great (remember to lower dose to 10mg or less if eGFR <60)
- Benzos if looking at palliative situation or all else fails
- Cholinesterase inhibitors – sometimes make worse, but not always

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What to prescribe in urgent aggression?

- Consider cause – is the person aggressive because of anxiety? Psychotic symptoms? Premorbid personality?
- Try to treat the cause first etc
- Document risks / benefits
- If sure no delirium, consider benzo – lorazepam (change to clonazepam if likely to be long term)
- If LBD, consider AChEI
- May need to look at antipsychotic
  - Discuss with team
  - Should do ECG first (QT interval), not always possible
  - Olanzapine 2.5mg (remember sub-lingual available) – long half life
  - Risperidone (can use tiny doses eg 0.25mg and build up) - licensed

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Risks of antipsychotics for your risk / benefit analysis

- Stroke
- Death
- EPSEs
- Postural hypotension and falls
- Sedation
- Cardiac
- Increased confusion
- Withdrawal effects on stopping abruptly

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Risks of benzos for your risk / benefit analysis

- Sedation
- Muscle weakness and falls
- Impaired memory
- Increased confusion
- Make delirium worse
- Light headedness
- Slurred speech
- Nausea
- Withdrawal

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What to prescribe in psychosis

Acetyl Cholinesterase Inhibitor eg Aricept – esp if think may be LBD or PDD

Otherwise, its reasonable to prescribe an antipsychotic

Best to get ECG, discuss risks and benefits with family, document

I tend to start with risperidone

I use olanzapine if I need sedation / increased appetite

I use aripiprazole if there are cardiac concerns

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What to prescribe for manic symptoms

Antidementia drugs?

After that I'd ask the CMHT, but if urgent

Benzos

Antipsychotics

Lithium is specialist option

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What to prescribe for the disintegrative behaviours

Nothing specific

Make sure antidementia drugs have been tried if appropriate.

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Talking to families about antipsychotics

- I recommend the NICE decision aid
- 'Antipsychotic medicines for treating agitation, aggression and distress in people living with dementia
- Outlines the options and good practice eg review every 6 weeks
- Mentions side effects
- Has a nice graphic showing likelihood of harm from stroke and risk of death

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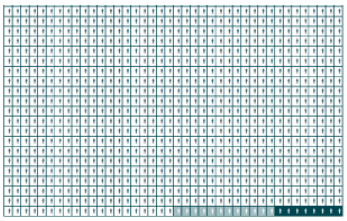
Part of the NICE antipsychotic graphic



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Graphic explained

- For every 1,000 people living with dementia who have hallucinations, delusions or agitation and who take an antipsychotic for 6 to 12 weeks, while they are taking it **on average**:
- 980 people do not have a stroke, whether they take an antipsychotic or not.
- 8 people have a stroke, whether they take an antipsychotic or not.
- 12 people have a stroke **because** they take an antipsychotic.

- This is the **average**: some people will be at greater or lower risk of stroke. **It is not possible to know in advance what will happen to any individual person.**

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Documenting antipsychotics

- Whether person has capacity
- Who you have discussed with
- Whether in patient's best interest (need to use MHA if not) – explain risk / benefit analysis
- What symptoms targeting
- When will review (6 weeks or less)

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Contacting your Old Age Psychiatrist

Patch based service, aligned to surgeries

If you are a GP, you probably know who your OA psych is

If they are on leave, there are cross cover arrangements

- Simon Vann Jones and Sadir Altaan
- Vandana Mate and Tim Booth
- Audrone Kaskeleviciute and Ciaran Abbey
- There are two locums in the far west, covering empty posts
- Community hospital based? probably need a map

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Contacting an AMHP

In hours, contact the DOLS team

01872 322991 and ask to speak to the duty AMHP

OOH contact Bodmin Switchboard

01208 251300

But speak to psychiatrist / CMHT first if in hours

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When to call the Police

- When there has been a crime
- When the person with dementia may have caused a death
- When there is risk to life or limb

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What can the Police do?

- **Section 135** allows the Police to enter someone's home and take them to a PoS (and keep them there) so that a MHAA can be done. Must have a Magistrate's warrant to get in to the home, using reasonable force if necessary.
- **Section 136** allows the Police to take you to a PoS (and keep them there) if
  - appear to have a mental disorder and
  - not in a house and
  - in need of immediate care and control
- And obviously they can arrest and charge

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When should DOLS be applied?

- Person has impairment of mind or brain
- Lacks capacity for that decision
- There is deprivation of liberty eg can't leave, covert meds, one to one
- The DOL is in the person's BI, least restrictive
- DOLS are part of MCA, which can only be used in BI
- Would normally have a BI meeting or discussion
- For care or treatment in hospital or care home
- (must be over 18)

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When to use MHA and detain in hospital

- Person has mental disorder
- Of a nature or degree to warrant or make necessary treatment in hospital
- For health, safety, or protection of others
- Cant be provided otherwise

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Scenario 1

OOH Call

Naked elderly woman on approach to Tamar Bridge

Approaching vehicles, trying to flag them down

Passenger in a car is local, knows the lady is registered with your surgery so rang you

Who are you going to call?

What is likely to happen?

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Scenario 2

Elderly man in residential care home post CVA

Mobility not great and needs help with personal care but normally cognitively fairly intact

Increased confusion over 2 weeks

Now refusing personal care, not eating well

Aggressive if staff come close

What might be wrong?

How would you manage the situation?

What legal framework might be applied?

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Woman with YOD, lives with husband

Spends a lot of time pacing and screaming, been getting worse over months and years

But also resistive of care – will scratch, bite, punch, kick, headbutt

Skin is breaking down

What would you do?

What legal frameworks might be appropriate?

Scenario 3

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Scenario 4 – how would you manage him?

Older man, widow for one year, family think he is depressed

Admitted community hospital after #NOF

Behaviour was deteriorating prior to admission, aggression

Rehab successful but

- Forgets zimmer, forgets he's at risk of falls
- Angry that he has to wait for support at home
- Doesn't remember why he has to be in hospital
- Throws zimmer
- Thinks other patients stealing his things, making threats to kill them
- Trying to leave

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Key actions

Deprescribe

Review

Communicate

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Thank you – feedback welcome

- I particularly want to know
  - If you learnt anything
  - How I can make it better

- vicky.brown32@nhs.net

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What are the challenging behaviours we see in dementia?

What behaviours do you encounter?

How do you interpret them?

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Behaviour	Immediate Cause	Underlying Cause
Aggression	Pain / infection due to hearing aid battery in ear	Dementia / Delirium
Aggression	Loss of insight into why can't go out during lockdown	Dementia
Aggression	Disorientation and fear during personal care	Dementia
Aggression	Loss of insight into his lack of safety driving	Dementia / pre-morbid personality
Fatal aggression	Disinhibition, lack of tolerance of other people with dementia	Dementia / pre-morbid personality

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Behaviour	Immediate Cause	Underlying Cause
Self neglect	Loss of interoception and executive function, probably sensory impairment	Dementia
Aggression	Disoriented, confused, frightened	Cholangitis, Delirium
Calling family day and night	Loneliness, forgetfulness	Dementia
Trying to pull out eyes, headbanging, trying to eat own excreta	Huge distress	Psychosis
Sexually inappropriate with children	Disinhibition	Personality, Dementia

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