Managing dementia and delirium

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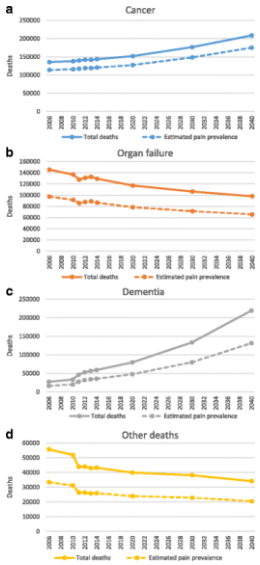
Overview

- Set the scene
- Settings
- Challenges
- Carers
- Principles of management
- Dementia- specific issues
- Delirium- specific issues
- Case

What is dementia?

- Dementia is not just forgetfulness
- Dementia is a progressive neurodegenerative disease
- The experience is unique for each individual but comprises:
  - Short term memory problems
  - Difficulties in day to day function
  - Speech and language problems

Deaths due to dementia will increase



If current trends continue, numbers of deaths in care homes will increase by 108.1% with care home the most common place of death by 2040
(Bone et al. 2018)

Etkind et al 2017

Where do people with dementia die ?

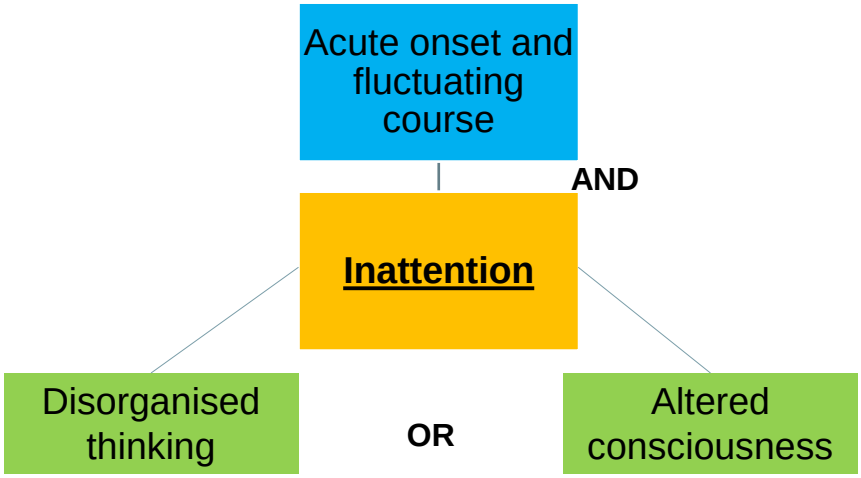
Place of death	Percentage of all deaths (%)
Home	5.8
Hospital	38.0
Care home	52.8
Hospice	0.0
Other communal establishment	3.1
Elsewhere	0.3

Marie Curie 2015

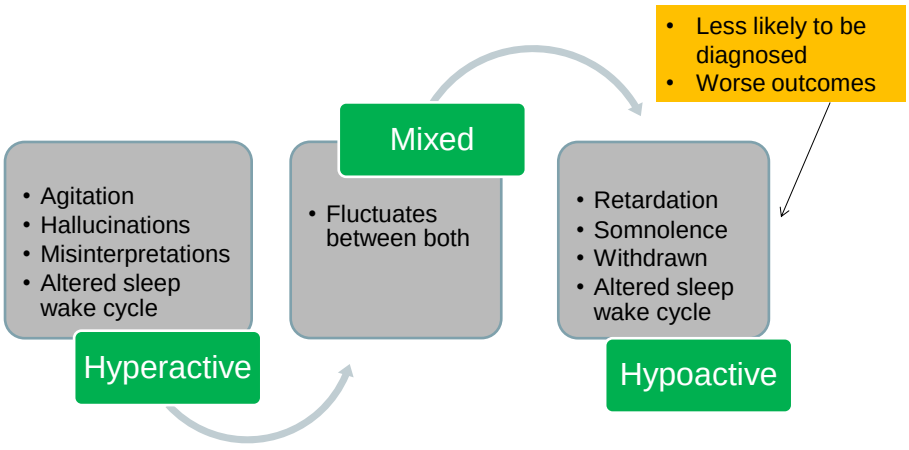
Why is dementia important for palliative care?

- 30% of those over the age of 60 will die with dementia (Brayne et al 2006)
- 50%of those with dementia admitted to UK acute hospital die, within 6 months (Sampson et al 2012)
- People who died with dementia in 2012 spent more than 50 days of their final year of life in hospital (Marie Curie 2014)
- Older people will have increased multiple health conditions and frailty-people don't just die from severe dementia

What is delirium?



Subtypes and symptoms



Prevalence of delirium

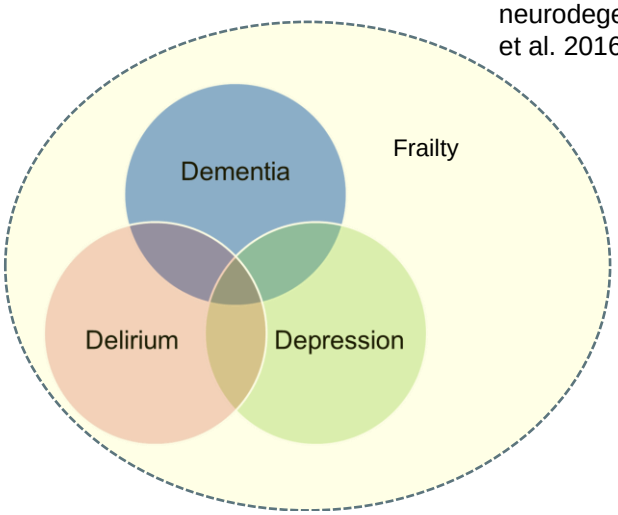
- 20% of acute hospital inpatients (Ryan et al. 2013)
- Palliative care inpatient units:
  - Prevalence on admission:13-42%
  - During admission: 26-62%
  - Near death: 58-88%
  - Incidence after admission to a palliative care unit: 33-45% (when screened daily) (Hosie et al. 2013)
- 80% of patients with cancer in the last two weeks of life (Bush et al. 2018)

Why is delirium important for palliative care?

- May be mistaken for “terminal phase”
- May indicate “terminal phase”
- Distress for family, friends and staff
- Adverse events
  - Falls
  - Pressure sores
- System impact
  - Increases cost
  - Staff burnout

The unholy trinity

1/3rd of patients with delirium in acute hospital have a previously undiagnosed dementia or neurodegenerative disease (Jackson et al. 2016)



Challenges of dementia and delirium

- Capacity
- Loss
  - Relationships
  - Autonomy
  - Function
- Under diagnosis / mis diagnosis
- Stigma and fear
- Lack of prioritisation in service provision and funding
- Lack of “cures”
- Complexity and unpredictability

During delirium

After delirium

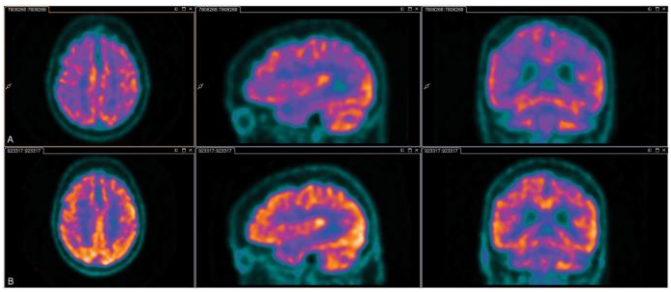
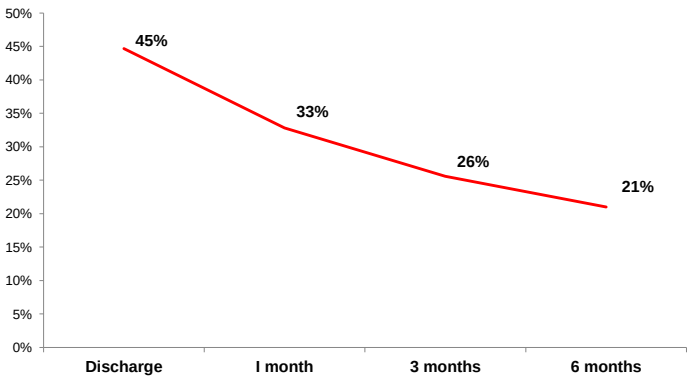


Figure 1. 2-18F-fluoro-2-deoxy-D–glucose positron emission tomography during and after delirium. Legend: The top row (a) is the delirium scan, while the bottom row (b) is the scan taken after delirium. Darker colours indicate lower metabolism. The top row illustrates marked global hypometabolism during delirium. The bottom row illustrates an overall improvement, but not normalisation, in metabolism.

Persists at least 3 months after delirium resolves

Published in: Lucy R Haggstrom; Julia A Nelson; Eva A Wegner; Gideon A Caplan; *J Cereb Blood Flow Metab* 37, 3556-3567.
DOI: 10.1177/0271678X17701764

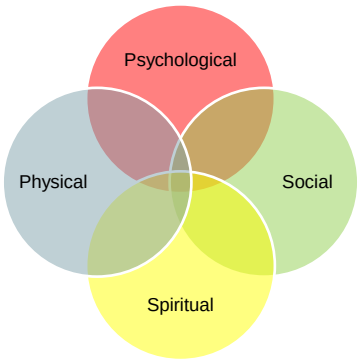
The persistence of delirium



Cole et al 2008

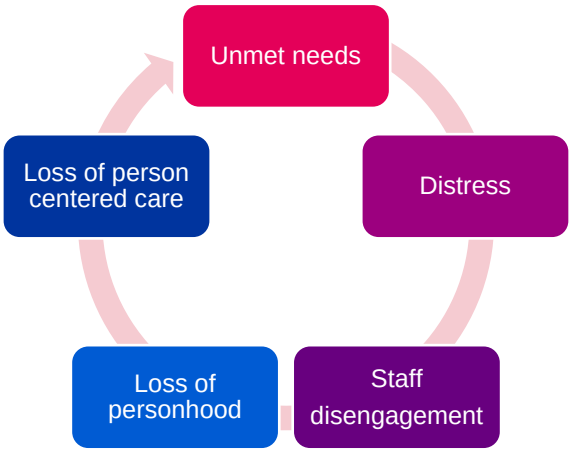
"A short term problem with long term implications"

Principles of management



- Needs-based
- Holistic
- Detailed assessment
- Person-centred
- Support QoL
- Carers

Breaking the cycle



Dementia- key issues

WHEN should we “start” palliative care

- 25-30% live to advanced stages
- Characteristics of people who die in earlier stages of dementia not well defined
- Shift from prognosis based to needs based access?
- Policy push is towards point of diagnosis

N=1400 Aworinde et al. 2018

Symptoms of advanced dementia

	18 months Mitchell et al. 2009	last 30 days DiGiulio et al. 2008	last week Aminoff & Adunsky 2005	last week Hendriks et al 2014	last 4 days Sampson et al 2013*
Dyspnoea	**46%**	**39%**	**~**	**35%**	**~**
Pain	**40%**	**26%**	**18%**	**52%**	**50%**
Pressure Ulcers	**39%**	**47%**	**70%**	**~**	**27%**
Agitation /restlessness	**54%**	**20%**	**72%**	**35%**	**56%**
Aspiration	**41%**	**~**	**~**	**~**	**~**
Eating problems	**86%**	**~**	**95%**	**~**	**~**

What is “advanced” dementia

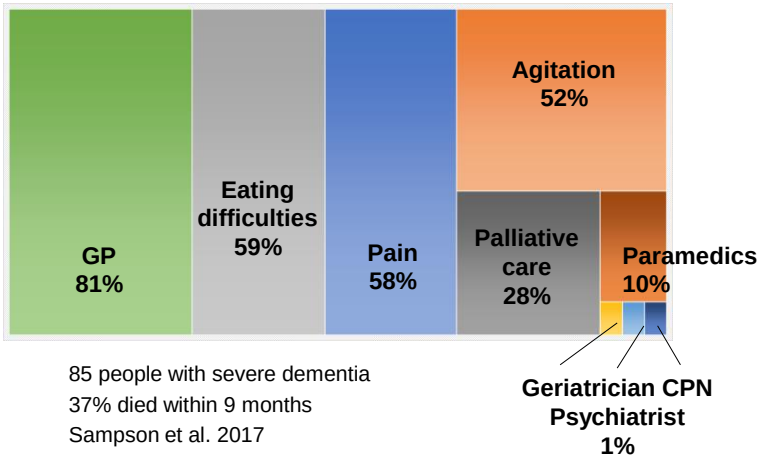
A biomedical model

- Severe cognitive impairment
- Able to speak only a few words
- Mobility limited
- Double incontinence
- Difficulties swallowing
- Pressure sores

A psychosocial model

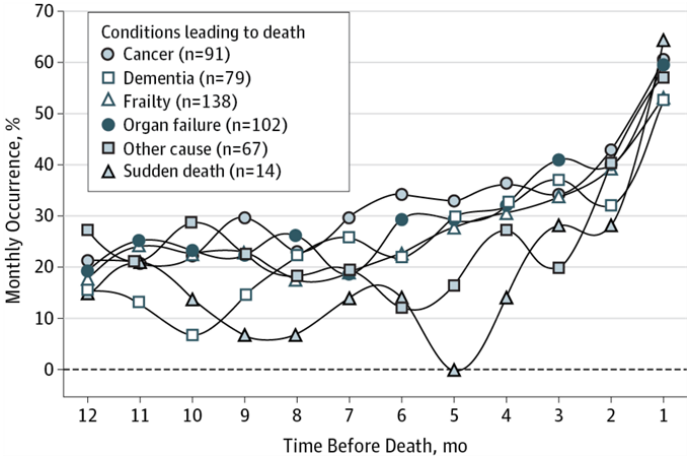
- May still recognise some family and friends
- Able to enjoy sensory experience
- Continue to express a sense of self
- Able to make meaningful connections

Why is more support needed?



85 people with severe dementia
37% died within 9 months
Sampson et al. 2017

Symptoms increase before death



Chaudhry et al. JAMA Intern Med. 2013

Recent evidence on advance care planning

For

- Policy push
- It seems like a good idea (!)
- It gives people choice and control
- It gives a sense of relief and less worry (Poppe 2013)
- Reduces family carer uncertainty in decision-making and improves perceptions of quality of care (Brazil et al. 2017)
- In other disease i.e. cancer it influences preferred place of death (Deterring 2011)

Against

- Lose capacity relatively early (Harrison Dening 2016)
- False promise-can't deliver
- Proxies find it stressful (Fetherstonhaugh 2017)
- Proxies are not good at predicting (Harrison Dening 2017)
- Professional ownership (Robinson 2015)
- Response shift (Jongsma 2016)

Van den Block, Palliative Medicine 2019
https://toolkit.modem-dementia.org.uk/wp-content/uploads/2016/07/ACP-Intervention-Summary.pdf

Agitation and distress

Issues

- Distressing
- Finding the cause
- Hopeless and helpless
- Consider pain
- Consider psychosis
- Consider delirium

Solutions

- Acknowledge and support
- Detailed assessment
  - Sometimes its inherent
- Engage-"this is me" etc
  - Distraction
  - Stimulation
- Empirical trial analgesia
- (Neuroleptics)
- 30% spontaneously resolve

Pain

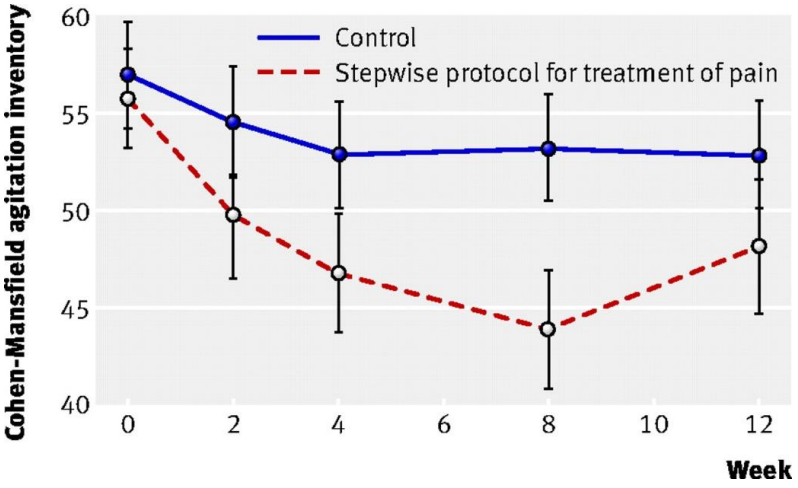
Issues

- Recognition
- Discomfort vs. pain
- Specific pain
- Use of analgesics

Solutions

- Observation
  - Mood and function change
  - Low index of suspicion
- Holistic detective work
- Consider ALL causes
- Tailored
  - Type
  - Mode of delivery
  - Regular
  - Monitored

It is worthwhile treating pain



Husebo et al BMJ 2011

Eating and drinking

Issues

- Food “refusal”
- Swallowing problems
- Aspiration
- Tube feeding

https://www.nice.org.uk/guidance/ng97/resources/enteral-tube-feeding-for-people-living-with-severe-dementia-patient-decision-aid-pdf-4852697007

Solutions

- This is me
  - Presentation / environment
  - Timing / meaning / Pleasure
- Assessment-SALT
- Family discussion, care planning, team based approach
- If you start:
  - Manage expectations
  - Decide when to stop
  - No evidence of long term effectiveness

Carers

Issues

- Provide over half of the dementia care in the UK (£12.4 billion)
- Health
- Finances
- Pre-death grief and loss
- Feelings of relief ….and guilt after bereavement

Solutions

- Statutory carer needs assessment
- Citizens Advice-finances
- Alzheimer’s society:

https://www.alzheimers.org.uk/

- Dementia UK:

https://www.dementiauk.org/

- CRUSE:

https://www.cruse.org.uk/

“Placement”, funding, service access

Issues

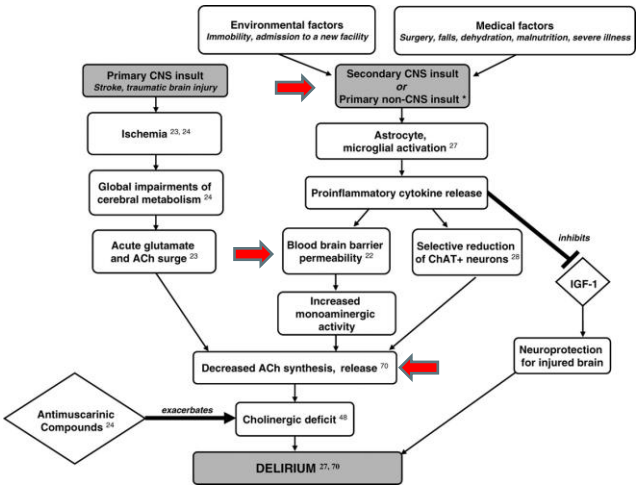
- Prognostication
- “6-month” rule & fast-track
- Access to services
- Continuing care funding

Solutions

- Needs-based approach
- Multi-morbidity & frailty agenda
- Discussion, networks, outreach
- Detailed documentation of need, dementia diagnosis, consult all notes, keep trying

Delirium-key issues

Underlying mechanisms



Tammy T. Hshieh et al. J Gerontol A Biol Sci Med Sci 2008;63:764-772

"Delirogenic" environment

- La
- In ontrol
- Er
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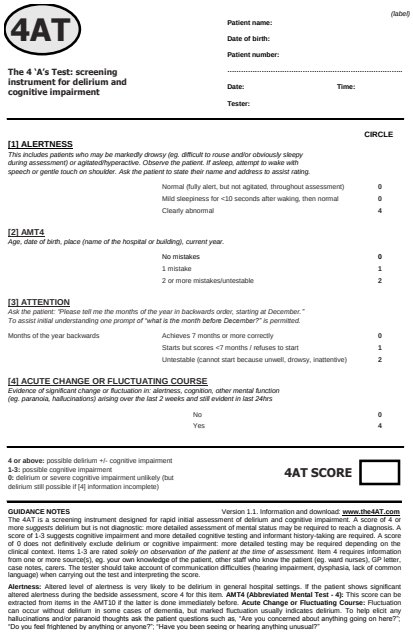
- D
- S and vision)

The Delirium SHOWSTOPPER: catheters, late night bed moves, drugs in, drugs out, unrecognised pain, constipation

Screening



4AT

The 4 'A's Test: screening instrument for delirium and cognitive impairment

(label)

Patient name:

Date of birth:

Patient number:

Date: **Time:**

Tester:

CIRCLE

[1] ALERTNESS

This includes patients who may be markedly drowsy (eg. difficult to rouse and/or obviously sleepy during assessment) or agitated/hyperactive. Observe the patient. If asleep, attempt to wake with speech or gentle touch on shoulder. Ask the patient to state their name and address to assist rating.

Normal (fully alert, but not agitated, throughout assessment)	0
Mild sleepiness for <10 seconds after waking, then normal	0
Clearly abnormal	4

[2] AMT4

Age, date of birth, place (name of the hospital or building), current year.

No mistakes	0
1 mistake	1
2 or more mistakes/untestable	2

[3] ATTENTION

Ask the patient: "Please tell me the months of the year in backwards order, starting at December." To assist initial understanding one prompt of "what is the month before December?" is permitted.

Months of the year backwards		
	Achieves 7 months or more correctly	0
	Starts but scores <7 months / refuses to start	1
	Untestable (cannot start because unwell, drowsy, inattentive)	2

[4] ACUTE CHANGE OR FLUCTUATING COURSE

Evidence of significant change or fluctuation in: alertness, cognition, other mental function (eg. paranoia, hallucinations) arising over the last 2 weeks and still evident in last 24hrs

No	0
Yes	4

4 or above: possible delirium +/- cognitive impairment
1-3: possible cognitive impairment
0: delirium or severe cognitive impairment unlikely (but delirium still possible if [4] information incomplete)

4AT SCORE

GUIDANCE NOTES Version 1.1. Information and download: **www.the4AT.com**

The 4AT is a screening instrument designed for rapid initial assessment of delirium and cognitive impairment. A score of 4 or more suggests delirium but is not diagnostic: more detailed assessment of mental status may be required to reach a diagnosis. A score of 1-3 suggests cognitive impairment and more detailed cognitive testing and informant history-taking are required. A score of 0 does not definitively exclude delirium or cognitive impairment: more detailed testing may be required depending on the clinical context. Items 1-3 are rated *solely on observation of the patient at the time of assessment*. Item 4 requires information from one or more source(s), eg, your own knowledge of the patient, other staff who know the patient (eg, ward nurses), GP letter, case notes, carers. The tester should take account of communication difficulties (hearing impairment, dysphasia, lack of common language) when carrying out the test and interpreting the score.

Alertness: Altered level of alertness is very likely to be delirium in general hospital settings. If the patient shows significant altered alertness during the bedside assessment, score 4 for this item. **AMT4 (Abbreviated Mental Test - 4):** This score can be extracted from items in the AMT10 if the latter is done immediately before. **Acute Change or Fluctuating Course:** Fluctuation can occur without delirium in some cases of dementia, but marked fluctuation usually indicates delirium. To help elicit any hallucinations and/or paranoid thoughts ask the patient questions such as, "Are you concerned about anything going on here?"; "Do you feel frightened by anything or anyone?"; "Have you been seeing or hearing anything unusual?"

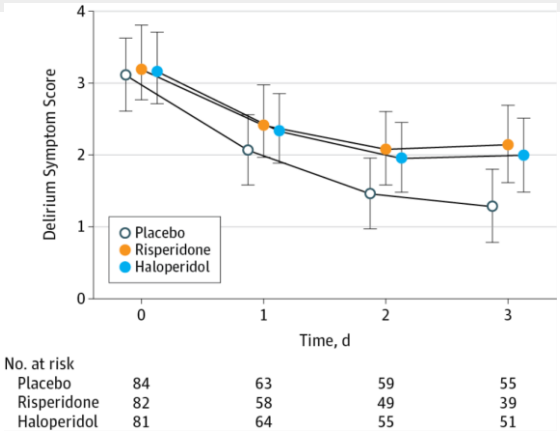
A useful differential diagnosis

- meds
- meds
- meds
- brain disease
- infection
- hypoxia
- metabolic
- some combination
- something else

Thanks to Rowan Harwood and Ken Rockwood 2001

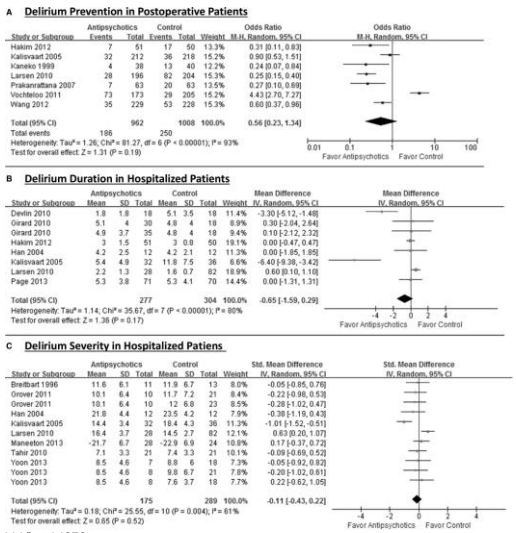
From: **Efficacy of Oral Risperidone, Haloperidol, or Placebo for Symptoms of Delirium Among Patients in Palliative CareA Randomized Clinical Trial**

JAMA Intern Med. 2017;177(1):34-42. doi:10.1001/jamainternmed.2016.7491



Secondary Multivariable Mixed-Model Analysis of Delirium. The dependent variable was delirium score at each day. The independent variables comprise the covariates in Table 2, group, time, and 2 interaction terms, time × risperidone and time × haloperidol. The relative difference in improvement between groups at 72 hours was determined using the lincom function in Stata. Placebo vs risperidone: P < .001; placebo vs haloperidol: P = .002. Error bars indicate 95% CIs.

Antipsychotic Medication for Prevention and Treatment of Delirium in Hospitalized Adults: A Systematic Review and Meta-Analysis



Journal of the American Geriatrics Society
Volume 64, Issue 4, pages 705-714, 23 MAR 2016 DOI: 10.1111/jgs.14076
http://onlinelibrary.wiley.com/doi/10.1111/jgs.14076/full#jgs14076-fig-0002

Evidence for the use of other drugs in delirium

- "no evidence to support the use of benzodiazepines in the treatment of non-alcohol withdrawal related delirium among hospitalised patients" (Cochrane 2009)
- Cholinesterase inhibitors- no evidence of effectiveness , may be harmful (van Eijk 2011)

When to use drugs (never if possible)

- De-escalate first
- Distressed, a risk to themselves or others and behavioural management ineffective or inappropriate
- Short-term (usually for 1 week or less)
- Start at the lowest clinically appropriate dose and titrate cautiously according to symptoms
- Use one drug at a time
- Consider age, weight and degree of agitation
- Discontinue

Consider the legal framework in which you are doing this

Why use drugs?

Sedate

Lorazepam

- Oral: 1-2mg (max 4mg/24)
- Additional dose 45-60 mins
- Peak effect 90 minutes
- IM: 1-2mg (max 4mg/24)
- Peak effect 60-mins
- ⚠ Flumazenil
- ⚠ Watch respiration

Antipsychotic

Risperidone

- Give at NIGHT
- 0.25-0.5mg ON for elderly patients with dementia
- 1mg ON for younger patients
- Max 6mg daily
- Please also discuss with liaison psychiatry team
- STOP

Haloperidol

- Oral: 0.5-1mg bd (max 20mg/24)
- Additional doses every 4 hours
- Peak effect 4-6 hours
- IM: 0.5-1mg (max 12mg/24)
- Peak effect 20-40 mins
- ⚠ Decreases fit threshold
- ⚠ Acute dystonia
- ⚠ NMS
- ⚠ ECG-Prolongs Q-T
- ⚠ Avoid in dementia-LBD Avoid in with drug/alcohol withdrawal and excited delirium

⚠ ***Haloperidol should only be used when all other environmental, behavioral and drug options have been exhausted. The use of haloperidol in older people and those with pre-existing neurodegenerative disease is strongly discouraged.***

Management of delirium- TIME principles

- Think, exclude and treat possible triggers
  - Sepsis Six
  - Glucose
  - Medication
  - Pain
  - Retention/ constipation
- Investigate
  - Hydration
  - Bloods
  - Sepsis
  - ECG (troponin)
- Manage
- Engage

https://rcpsg.ac.uk/news/2709-sign-guideline-157-delirium

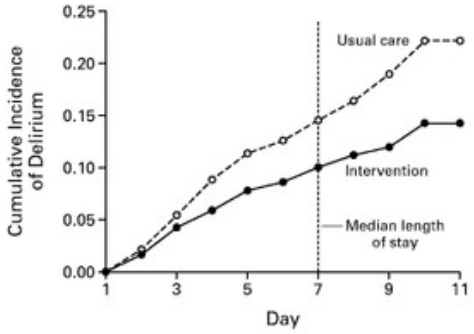
Further management

- Support patient and family-PTSD
- Leaflet
- Recheck cognition regularly
- Document clearly
- Ensure delirium is on discharge summary-ask GP to recheck cognition if necessary
- **Code**

Multi-component interventions

- Focus on modifiable risk factors(i.e. HELP) (Inouye 1999 USA)
  - cognitive impairment →re-orientation/occupation
  - sleep deprivation → daylight, non pharmacological protocol
  - immobility → daily exercise and walking)
  - vision and hearing impairment → ensure use of aids
  - dehydration → feeding support, consider fluids subcut
  - pain
- Outcomes
  - significant reduction delirium incidence; RR 0.66 (95% CI 0.46 to 0.95)
  - significant reduction in the total number of days of delirium amongst all patients in the group (105 versus 161 days)

HELP programme



Inouye et al. NEJM 2009

How to miss delirium

- Keep any talk with patients to a minimum
- Do not assess cognitive function
- Assume cognitive impairment is long-standing
- Never talk to nurses, especially night staff
- Don't talk to families either
- Just look at the blood test results
- If patient is withdrawn, start an antidepressant
- If patient is noisy, start a sedative

With thanks to Shaun O'Keefe and Rowan Harwood

A story-Mrs D

- Presenting problem
  - Brought to A&E 23/8/14
  - Nursing home “not coping” with care
  - Dehydrated, constipated, VaD
- History
  - Two years ago was living by herself
  - Moved in with daughter because of wandering
  - Daughter unable to manage her aggression
  - Moved to a residential home then a nursing home

- Problems
- “patient grabbing, scratching, hitting staff”
- “not engaging in therapy”
- “refuses-impossible to take obs”
- “lashed out with arm and attempted to kick”
- “lying in bed and shouting for daughter”
- “digging nails into staff during personal care”
- Care home refuses to have her back
- “when asked are you in pain says no”
- “restless and smearing faeces”

On assessment

- Trazodone 100mg bd
- Lansoprazole 15mg od
- Tamoxifen 20mg od
- Carbamezapine 100mg tds
- Fentanyl 50mcg/hr
- Quetiapine 50mg bd

Who is Mrs D ?

Woman with dementia

- Bites
- Scratches
- Resists care
- Refuses medication
- Smears faeces
- “Unsafe swallow”

Anne

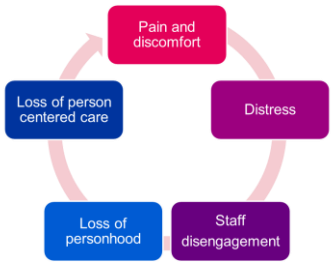
- Retired biology teacher
- Has a daughter, an AH
- Likes to hold a soft toy

“*Has cancer with bone mets and a pathological fracture of the humerus”*

Where to start?

Plan

- Regular PR Paracetamol
- Diclofenac or NSAID for bone pain
- Stopped other meds
- Decision for “comfort feeding”
- Consider covert medication as per policy
- Consult Pain team ? ↑Fentanyl patch
- Palliative care referral
- Support daughter to find new care home



Died in care home 3 months later

Thank you !

Empowering Better End of Life Dementia Care

http://www.ucl.ac.uk/mcpcrd/research/dementia

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