

# Pain in dementia

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Disclaimer

# Pain

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What is pain?

# Pain

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Pain is what the patient says it is

# Pain

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An unpleasant sensory or emotional experience associated with actual or potential tissue damage or described in terms of such damage

# Types of pain

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- Nociceptive
- Neuropathic
- Central, phantom
- Psychogenic

# Some causes of pain

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- Arthritis/fracture/bone
- Cancer
- Trauma, burns
- Angina
- Headache/mouth/teeth/throat/eyes/ears
- Abdominal: constipation, IBS, ulcer, gallstone, bladder, perforation
- Neuropathic
- Skin, pressure ulcer
- Infections, post infection
- Vasculitis/temporal arteritis

# Pain dimensions

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- Sensory-discriminative  
(intensity, location, duration, quality)
- Motivational-affective  
(unpleasantness, urge to escape)
- Cognitive-evaluative  
(meaning, culture, distraction)

# Dementia

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## A. Multiple cognitive deficits

1. Memory impairment

2. One or more of:

(a) aphasia

(b) apraxia

(c) agnosia

(d) disturbance in executive functioning

B. Impairment in social or occupational functioning, decline from a previous level of functioning.

C. Gradual onset, progressive decline.

D. Not due to specified other conditions...

E. ... or delirium.



# Dementia subtypes

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- Alzheimer's disease (31%)
- Vascular (22%)
- Mixed (25%)
- Lewy body (11%)
- Fronto-temporal (8%)
- Rarities

# The problem with dementia

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- Reasoning, decision making
- Communication
- Activities of daily living
- Behavioural and psychological symptoms
- Carer strain
- Progression to end of life care

# Experience of dementia

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- Neurological impairment
- Personality
- Biography
- Mental and physical health
- Social environment and relationships

# Is pain different in dementia?

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- Physiology
- Autonomic responses
- Painful conditions
- Presentation and assessment

# Prevalence of pain

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	No dementia	Dementia	Reference
Canadian Study of Health & Aging n=5703	56%	52%	Shega 2004
US NH residents n=3736	40%	52%	Wu 2010

# End of life problems

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- Confusion 83%
- Urinary incontinence 72%
- Pain 64%
- Low mood 61%
- Constipation 59%
- Poor appetite 57%

Regional Study of Care of the Dying 1997

# Why assessing pain can be difficult

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- Forgetful
- Poor abstract thinking
- Poor receptive and expressive language problems
- Outpacing, overwhelming questions
- Co-morbidities (deaf, vision, delirium)
- Reliance of proxy (collateral) reports

# Behaviours that may indicate pain

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- Shouting
- Resisting care, aggression
- Immobility
- Depression, withdrawal
- Poor appetite, difficulty chewing, swallowing
- Poor sleep
- Restlessness



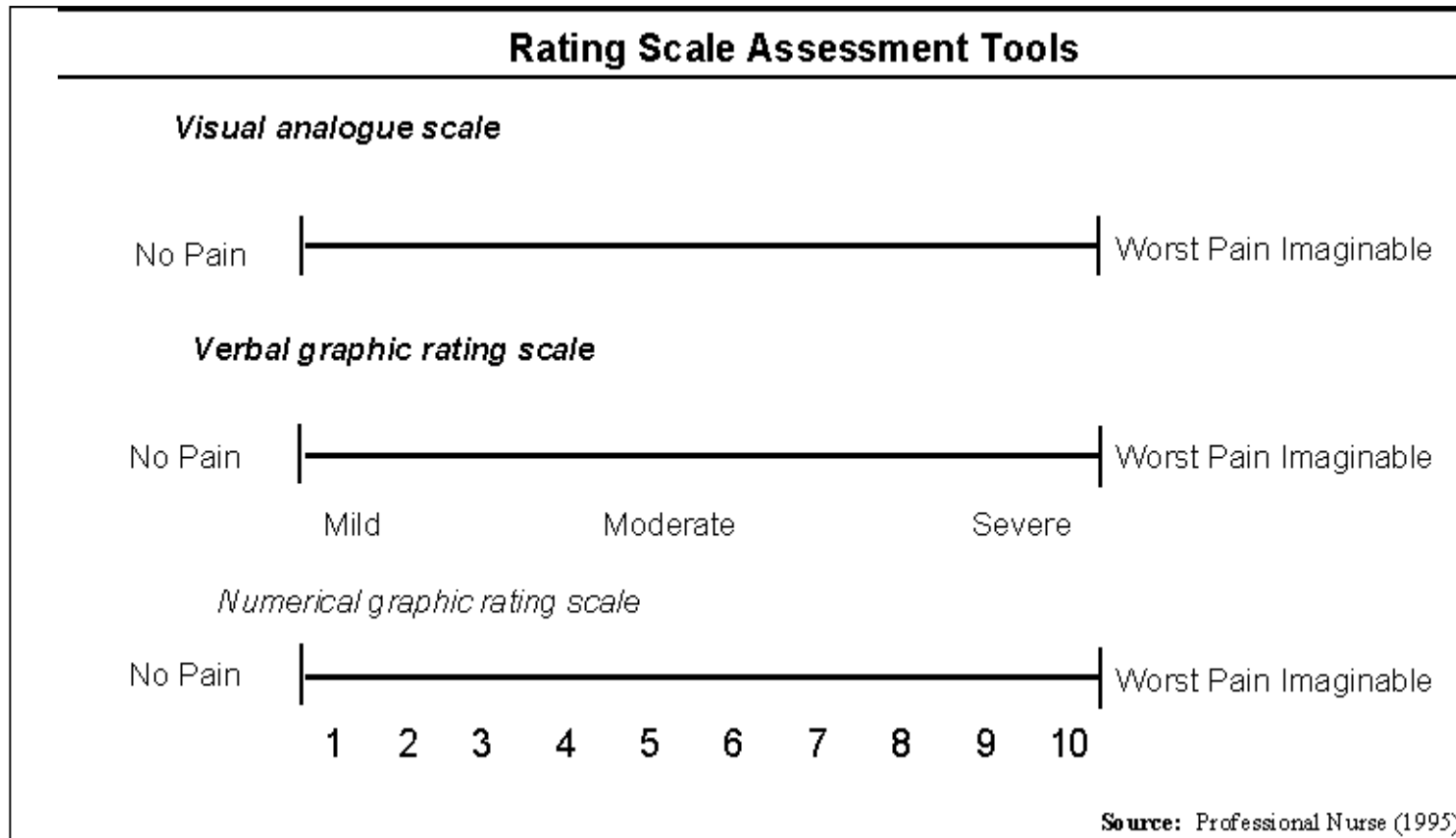
# Making communication easier

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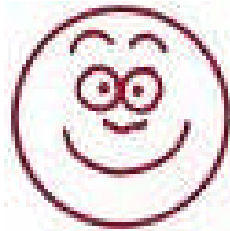
- Introduce yourself. Say what you are doing.
- Simplified language, slow down, repeat.
- Facilitated: objects, pictures, demonstrations
- Non-verbal: posture, touch, tone of voice
- Get or confirm factual information from others
- Talk through procedures to alleviate fear
- Interpret emotions, meaning, understanding
- Don't contradict, confront, embarrass or humiliate

# Visual analogue scales

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# Faces scales



0  
No Hurt



1  
Hurts  
Little Bit



2  
Hurts  
Little More



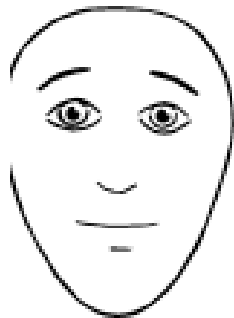
3  
Hurts  
Even More



4  
Hurts  
Whole Lot



5  
Hurts  
Worst



After Wong and Baker

# Abbey Pain Scale

Vocalisation – expressions of pain without using words e.g. whimpering; crying; groaning; gasps; sighs; grunting			
Absent 0 <input type="checkbox"/>	Mild 1 <input type="checkbox"/>	Moderate 2 <input type="checkbox"/>	Severe 3 <input type="checkbox"/>
Facial expression – e.g. wincing; tension; frowning; narrowed eyes; tight lips; teeth clenched; distorted expressions; looking frightened			
Absent 0 <input type="checkbox"/>	Mild 1 <input type="checkbox"/>	Moderate 2 <input type="checkbox"/>	Severe 3 <input type="checkbox"/>
Changes to body language – e.g. rocking; guarding part of the body; withdrawn; clutching or holding tight to things			
Absent 0 <input type="checkbox"/>	Mild 1 <input type="checkbox"/>	Moderate 2 <input type="checkbox"/>	Severe 3 <input type="checkbox"/>
Behavioural changes – e.g. confusion or increased confusion; restlessness; refusing food or fluids; irritability / agitation or withdrawal; resistance/pushing away			
Absent 0 <input type="checkbox"/>	Mild 1 <input type="checkbox"/>	Moderate 2 <input type="checkbox"/>	Severe 3 <input type="checkbox"/>
Physiological change – e.g. altered temperature or BP outside usual pattern; perspiring; flushing; pallor; cold & clammy			
Absent 0 <input type="checkbox"/>	Mild 1 <input type="checkbox"/>	Moderate 2 <input type="checkbox"/>	Severe 3 <input type="checkbox"/>
Physical changes – e.g. skin tears/bruising; pressure ulcers; arthritis; contractures; other injury (e.g. fracture); potential injury (e.g. recent fall)			
Absent 0 <input type="checkbox"/>	Mild 1 <input type="checkbox"/>	Moderate 2 <input type="checkbox"/>	Severe 3 <input type="checkbox"/>

Match acquired pain score in the table below:

0 – 2 No Pain (0)	3 – 7 Mild Pain (1)	8 – 13 Moderate Pain (2)	14 + Severe Pain (3)
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# DOLOPLUS-2

DOLOPLUS-2 SCALE						
BEHAVIOURAL PAIN ASSESSMENT IN THE ELDERLY						
NAME :		Christian name :		DATES		
Unit :						
Behavioural records						
<b>SOMATIC REACTIONS</b>						
1*	Somatic complaints	<ul style="list-style-type: none"> <li>no complaint</li> <li>complaint expressed upon inquiry only</li> <li>occasional involuntary complaints</li> <li>continuous involuntary complaints</li> </ul>	0	0	0	0
			1	1	1	1
			2	2	2	2
			3	3	3	3
2*	Protective body postures adopted at rest	<ul style="list-style-type: none"> <li>no protective body posture</li> <li>the patient occasionally avoids certain postures</li> <li>protective postures continuously and effectively sought</li> <li>protective postures continuously sought, without success</li> </ul>	0	0	0	0
			1	1	1	1
			2	2	2	2
			3	3	3	3
3*	Protection of sore areas	<ul style="list-style-type: none"> <li>no protective action taken</li> <li>protective actions attempted without interfering against any investigator or nursing</li> <li>protective actions against any investigator and nursing</li> <li>protective actions taken at rest even when not approached</li> </ul>	0	0	0	0
			1	1	1	1
			2	2	2	2
			3	3	3	3
4*	Expression	<ul style="list-style-type: none"> <li>usual expression</li> <li>expression showing pain when approached</li> <li>expression showing pain even without being approached</li> <li>permanent (usually blank) but hoarse, staring, blank blank</li> </ul>	0	0	0	0
			1	1	1	1
			2	2	2	2
			3	3	3	3
5*	Sleep pattern	<ul style="list-style-type: none"> <li>normal sleep</li> <li>difficult to go to sleep</li> <li>frequent waking (restlessness)</li> <li>resorts to altering waking times</li> </ul>	0	0	0	0
			1	1	1	1
			2	2	2	2
			3	3	3	3
<b>PSYCHOMOTOR REACTIONS</b>						
6*	Activities of daily living (washing &/or dressing)	<ul style="list-style-type: none"> <li>usual abilities unaffected</li> <li>usual abilities slightly affected (barely but thorough)</li> <li>usual abilities highly impaired, washing &amp;/or dressing is laborious and incomplete</li> <li>washing &amp;/or dressing declared impossible as the patient resists any attempt</li> </ul>	0	0	0	0
			1	1	1	1
			2	2	2	2
			3	3	3	3
7*	Mobility	<ul style="list-style-type: none"> <li>usual abilities &amp; activities remain unaffected</li> <li>usual activities are reduced (the patient avoids certain movements and reduces his/her walking distance)</li> <li>usual activities and abilities reduced (even with help, the patient curls down or his/her movements)</li> <li>any movement is impossible, the patient resists all persuasion</li> </ul>	0	0	0	0
			1	1	1	1
			2	2	2	2
			3	3	3	3
<b>PSYCHOSOCIAL REACTIONS</b>						
8*	Communication	<ul style="list-style-type: none"> <li>unchanged</li> <li>heightened (the patient demands attention in an unusual manner)</li> <li>lessened (the patient cuts him/herself off)</li> <li>absence or loss of any form of communication</li> </ul>	0	0	0	0
			1	1	1	1
			2	2	2	2
			3	3	3	3
9*	Social life	<ul style="list-style-type: none"> <li>participates normally in every activity (meals, entertainments, therapy workshops)</li> <li>participates in activities when called to do so only</li> <li>sometimes refuses to participate in any activity</li> <li>refuses to participate in anything</li> </ul>	0	0	0	0
			1	1	1	1
			2	2	2	2
			3	3	3	3
10*	Problems of behaviour	<ul style="list-style-type: none"> <li>normal behaviour</li> <li>problems of a positive reactive behaviour</li> <li>problems of a passive reactive behaviour</li> <li>permanent behaviour problems (without any external stimulus)</li> </ul>	0	0	0	0
			1	1	1	1
			2	2	2	2
			3	3	3	3
				SCORE		

## DOLOPLUS2: 10 items scored 0-3

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- Somatic complaints 3= continuous involuntary
- Protective body posture 3= unsuccessful
- Protection of sore areas 3= spontaneous
- Expression 3= blank expression
- Sleep problems 3= tired by day
- ADL 2= unable 3= resisted
- Mobility 3= immobile, resists
- Communication 3= no communication
- Social life 3= no participation
- Problem behaviours 3= unprovoked

# MOBID-2 Pain scale

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- Mobilisation
- Observation
- Behaviour
- Intensity
- Dementia
- Verbal
- Facial expression
- Defence

## Appendix

APPENDIX

# MOBID-2 Pain Scale

MOBILIZATION - OBSERVATION - BEHAVIOUR - INTENSITY - DEMENTIA

Patient's name: \_\_\_\_\_

Date: \_\_\_\_\_

Time: \_\_\_\_\_

Unit: \_\_\_\_\_

Pay attention to the patient's pain behaviour during morning care. Observe the patient before you start mobilization. Explain clearly what is going to happen. Guide the patient carefully through the activities 1-5. Reverse the movement immediately if pain behaviour is perceived. Rate your observation after each activity:

### Pain Behaviour

Tick the boxes for Pain noises, Facial expression and Defence, whenever you observed such pain behaviour



#### Pain noises

Ouch!  
Groaning  
Gasping  
Screaming



#### Facial expression

Grimacing  
Frowning  
Tightening mouth  
Closing eyes



#### Defence

Freezing  
Guarding  
Pushing  
Crouching

### Pain Intensity

Based on pain behaviour, rate the pain intensity with a cross on the lines (0-10)

YOU MAY TICK SEVERAL BOXES FOR EACH ACTIVITY

HOW INTENSE DO YOU REGARD THE PAIN TO BE?

0 is no pain and 10 is as bad as it possibly could be

1. Guide to open both hands, one hand at a time




0 1 2 3 4 5 6 7 8 9 10

2. Guide to stretch both arms towards head, one arm at a time




0 1 2 3 4 5 6 7 8 9 10

3. Guide to stretch and bend both knees and hips, one leg at a time




0 1 2 3 4 5 6 7 8 9 10

4. Guide to turn in bed to both sides




0 1 2 3 4 5 6 7 8 9 10

5. Guide to sit at the bedside




0 1 2 3 4 5 6 7 8 9 10

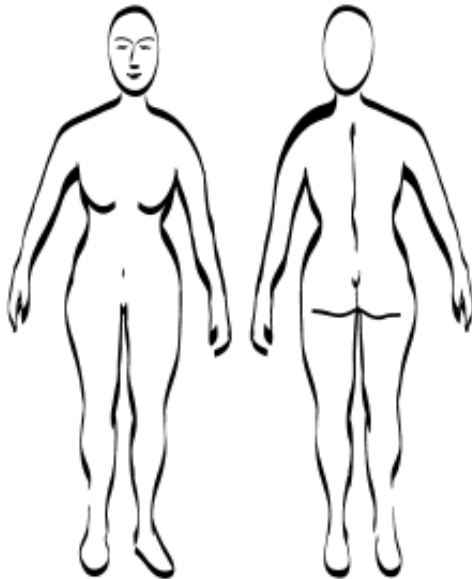


APPENDIX

Did you observe, today or in the last days (one week), that the patient expressed pain behaviour related to head, internal organs and/or skin, which may be caused by a disease, wound, infection and/or injury?

### Pain Behaviour

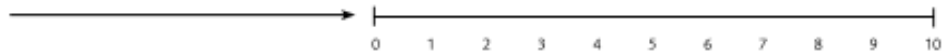
Make one or more cross/es on the pain drawing (front and back), according to observed pain behaviour (Pain noises, Facial expression and Defence)



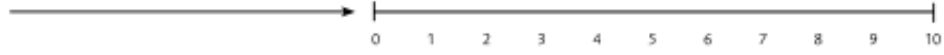
### Pain Intensity

Based on pain behaviour, rate the pain intensity with a cross on the lines (0–10)

6. Head, mouth, neck



7. Heart, lung, chest wall



8. Abdomen



9. Pelvis, genital organs



10. Skin



HOW INTENSE DO YOU REGARD THE PAIN TO BE?

0 is no pain and 10 is as bad as it possibly could be

Based on all observations, rate the patient's overall pain intensity



# Prevalence of pain

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	Score>0 (any pain)	Score >3 (moderate pain)
Hands	27%	18%
Arms	47%	33%
Legs	57%	47%
Turn over	44%	29%
Transfer/sit	36%	22%
Head, mouth	25%	16%
Heart, chest	17%	12%
Abdomen	27%	17%
Pelvis/genitals	30%	21%
Skin	22%	14%
<b>Overall</b>	<b>81%</b>	<b>64%</b>

77 Norwegian NH residents with severe dementia

Husebo et al 2010

# Managing pain

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- Try to explain it
- If there is a specific treatment use it
- Are there local treatments (topical NSAID, capsaicin, injected steroids)
- Or other non-pharmacological measures (seating, pressure area care, spasticity management, catheter removal, splints, slings)
- Analgesic ladder
- Alternatives and adjuncts
- End of life options

# Analgesic ladder

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- Paracetamol
- Add weak opiate or NSAID
- Substitute strong opiate

# Issues

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- NSAID adverse effects (ulcers, renal, fluid retention)
- Opiate adverse effects (constipation, delirium, anorexia, nausea)
- Oral intake (number of tablets)
- Dependency and addiction
- Review (how do you tell if it has worked?)

# Opioid conversion table

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<b>Oral morphine equivalent (mg/day)*</b>	<b>10</b>	<b>15/20</b>	<b>30/40</b>	<b>45</b>	<b>60</b>	<b>90</b>	<b>120</b>	<b>180</b>	<b>270</b>	<b>360</b>
Codeine (mg/day) <sup>1,2</sup>	60	120	240							
Tramadol (mg/day) <sup>3</sup>	50	100	200							
<b>Transdermal buprenorphine (µg/h)<sup>4</sup></b>	<b>5</b>	<b>10</b>	<b>20</b>		<b>35</b>	<b>52.5</b>	<b>70</b>			
Transdermal fentanyl (µg/h) <sup>4</sup>	-	-	-	12		25		50	75	100

These are approximate guidelines only, and not a guide to equianalgesia for an individual patient. Interpatient variability requires that each patient is carefully titrated to the appropriate dose. The calculated doses have been approximated to allow comparison with currently available preparations.

**\*Adapted from:**

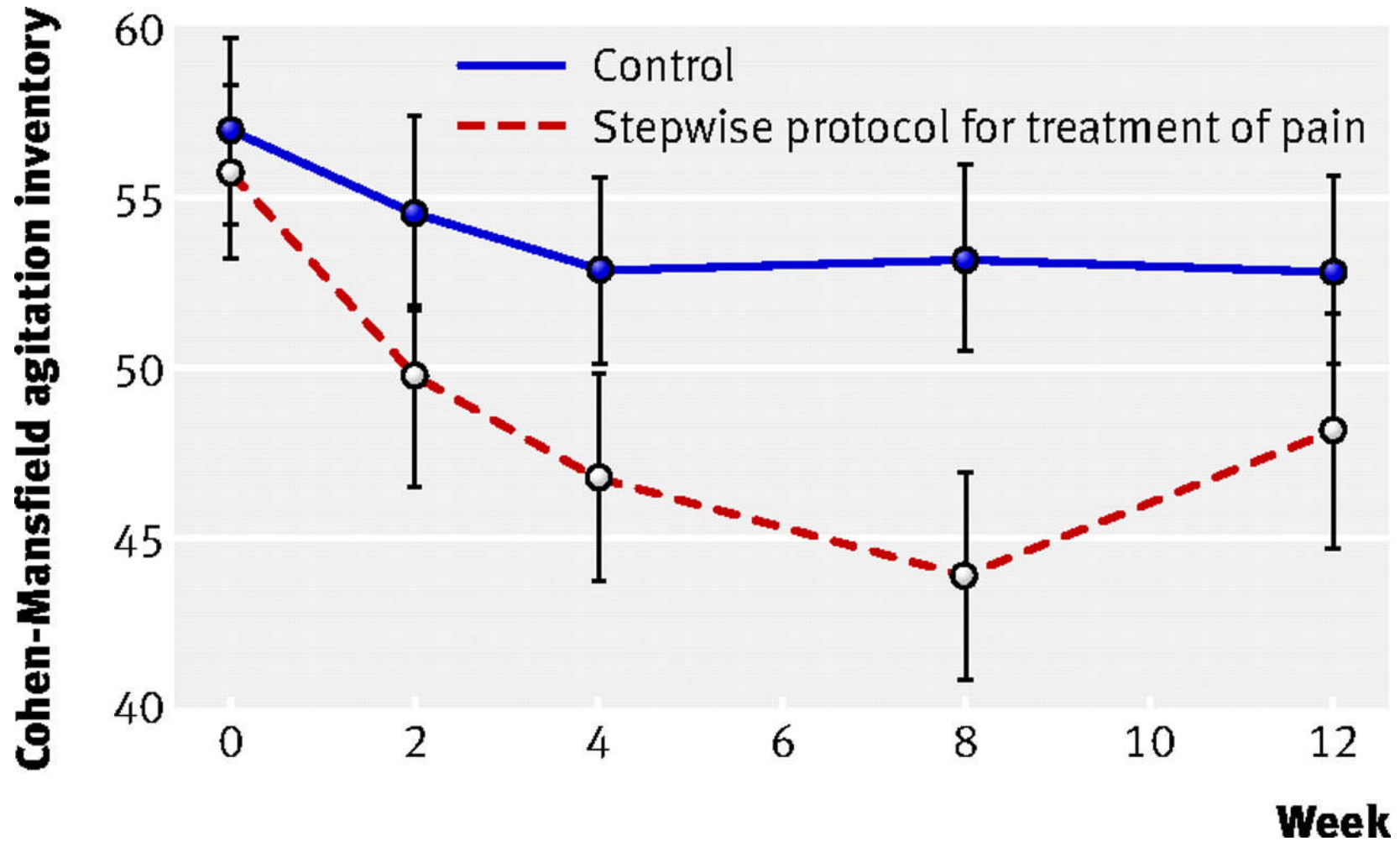
1. The British Pain Society. Opioids for persistent pain: good practice, 2010, p.12
2. Twycross R, et al., Palliative Care Formulary. 4th Edition.
3. Foley KM. New Engl J Med 1985;313:84-95.
4. The Scottish Intercollegiate Guidelines Network (SIGN). Control of pain in adults with cancer. A national clinical guideline. SIGN 106; November 2008. [Accessed June 2012]. [www.sign.ac.uk/pdf/SIGN106.pdf](http://www.sign.ac.uk/pdf/SIGN106.pdf)

# Approach to challenging behaviour

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- Assess
- Identify and address provoking and exacerbating factors
  - Physical problems, including pain, constipation, urinary symptoms, hunger, thirst
  - Activity related
  - Environmental
- Develop a person-centred care plan
- Watch and wait
- Identify target symptoms
- Consider psychotropic drug treatment

Cohen-Mansfield agitation inventory scores, with 95% confidence intervals, over study period.



Husebo B S et al. BMJ 2011;343:bmj.d4065





# Summary

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- Pain is difficult to assess in moderate-severe dementia
- And is almost certainly under diagnosed and treated
- Presentations may be behavioural or atypical
- You have to go looking for pain in dementia
- It may be worth a trial of analgesic treatment
- Always start with regular paracetamol
- Be cautious, but use low doses of strong opiates if necessary