

# Symptom assessment in patients with cognitive impairment

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# Outline

- The geriatric patient – some characteristics
  - Frailty
  - Cognitive impairment
- Comprehensive geriatric assessment (CGA)
- Assessment of pain in people with dementia
  1. Self report
  2. Search for potential causes
  3. Behavioral pain indicators
  4. Surrogate reports
  5. Analgesic trial
- Take home message

# Elderly people are heterogenous

Fit



Vera Nystel (75) satte onsdag verdensrekord i maraton i et løp i Alesund. (Foto: Lindesnes)

Vera (75) satte verdensrekord i maraton

Frail



FOTO: Gorm Kallestad / NTB scanpix

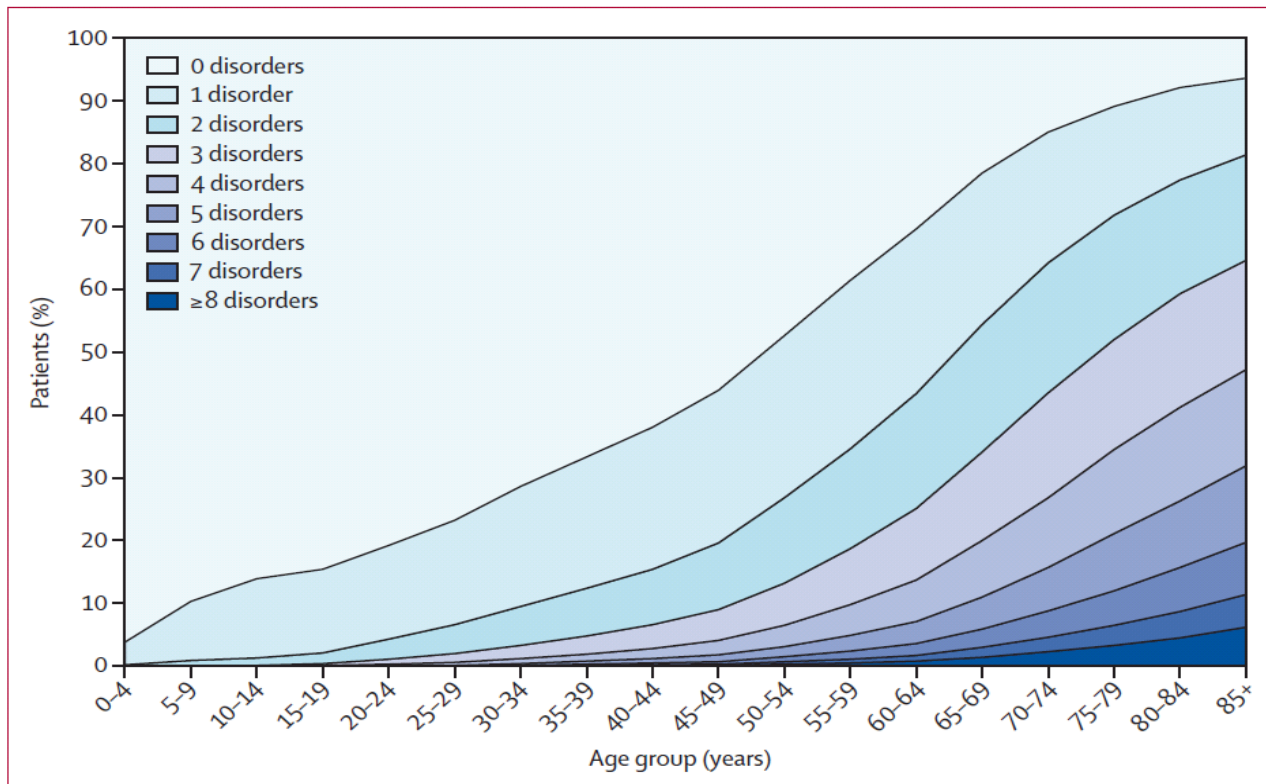
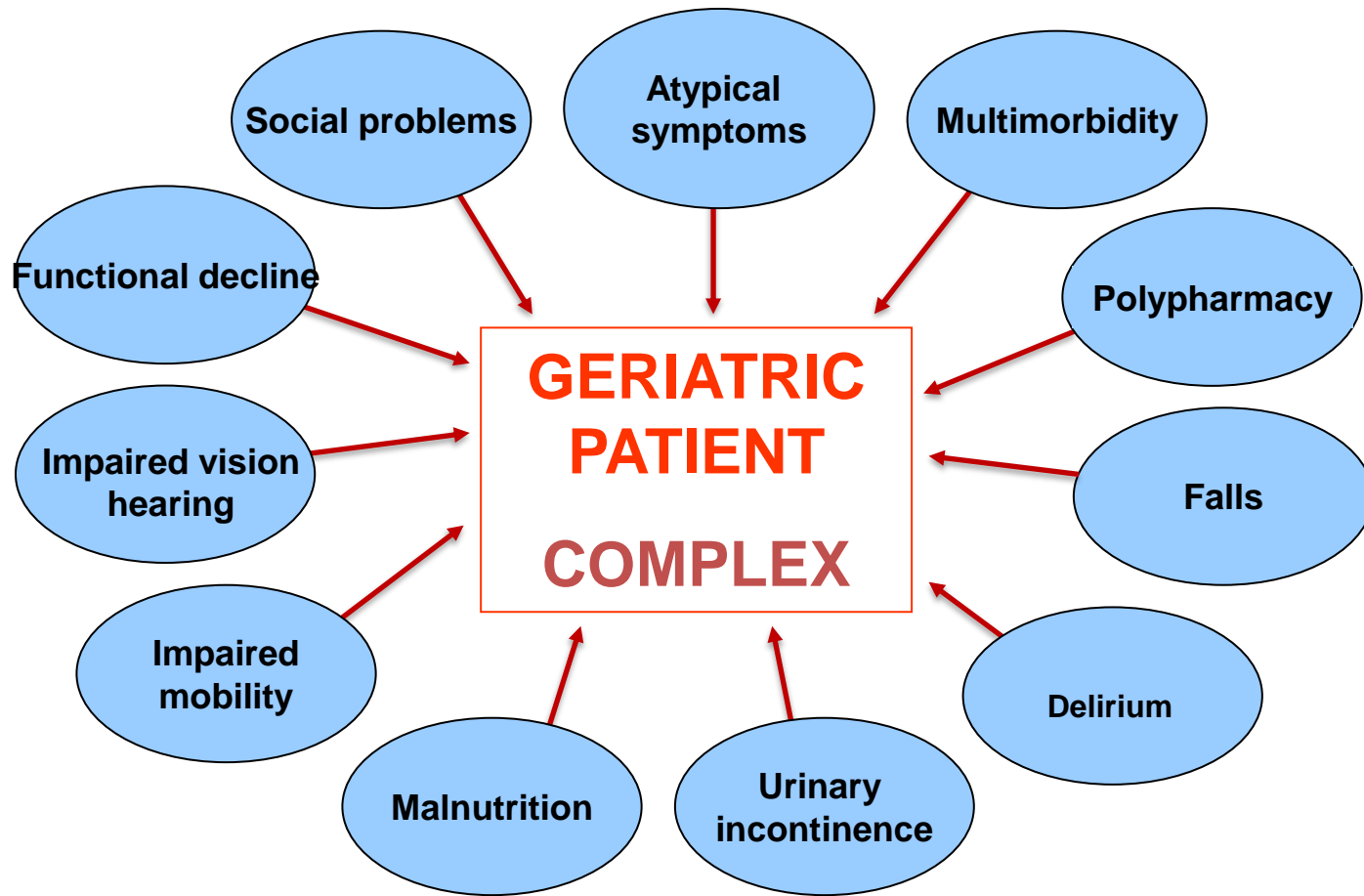


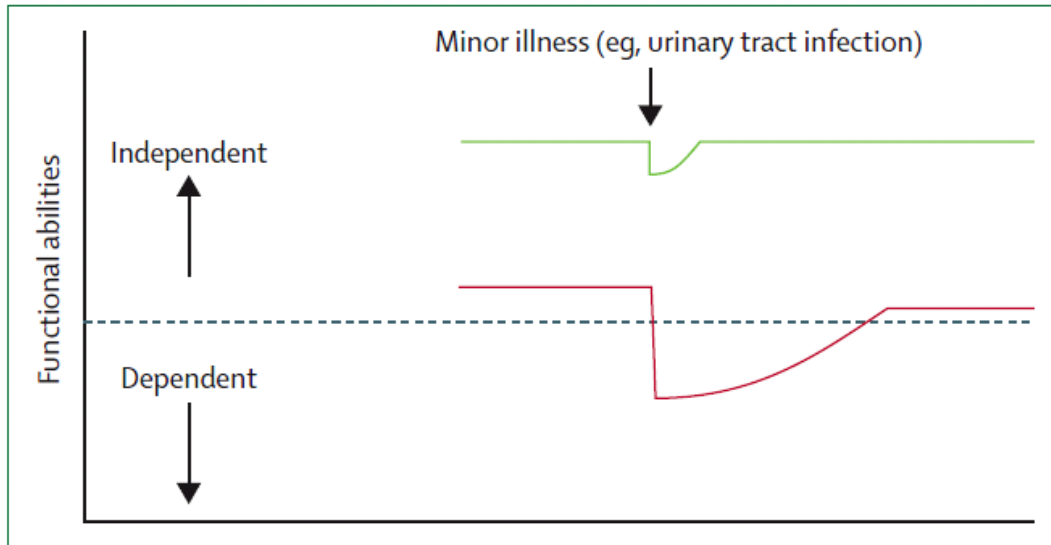
Figure 1: Number of chronic disorders by age-group

*Lancet 2012 380: 37-43*

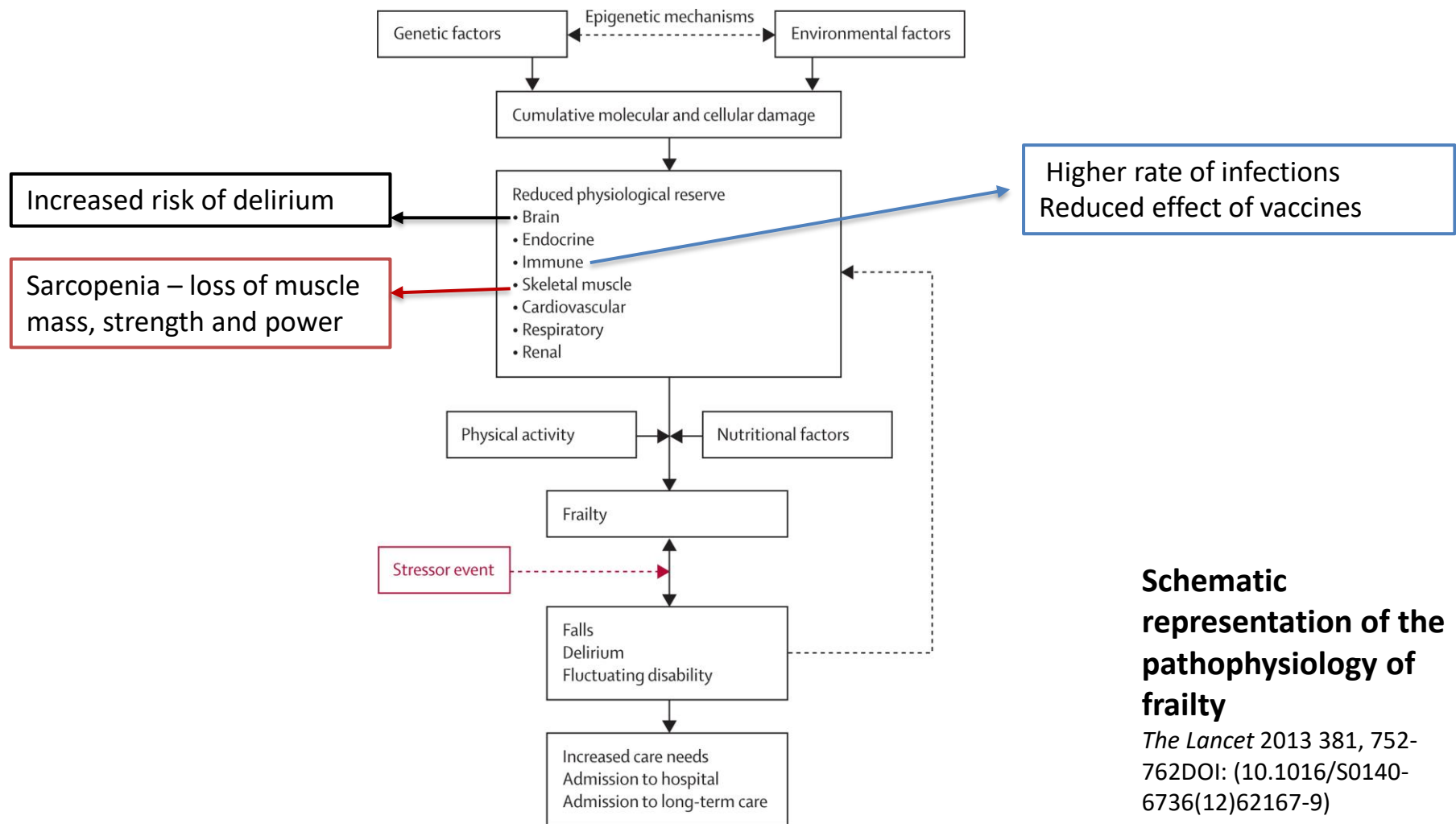


# Frailty

**“(…) increased vulnerability, resulting from age-associated declines in physiologic reserve and function across multiple organ systems, such that the ability to cope with everyday or acute stressors is compromised.”**



Vulnerability of frail elderly people  
to a sudden change in health  
status after a minor illness  
Clegg, Lancet, Febr 2013



# Clinical presentations of frailty

- Unspecific
  - Fatigue
  - Weight loss
  - Infections
- Falls
  - Related to intercurrent illness
  - Spontaneous
- Delirium
- Functional decline



# Atypical symptom presentation

- Lack of classical symptoms
- Falls
- Delirium
- Urinary incontinence
- Acute/subacute functional decline
- Dehydration

# Cognitive impairment

	Delirium	Dementia
<b>Onset</b>	Rapid (hours/ days). Triggering factor	Slow (months/ years)
<b>Course</b>	Fluctuating	Gradual deterioration
<b>Duration</b>	Days- weeks	Chronic
<b>Consciousness</b>	Fluctuates	Generally intact
<b>Attention</b>	Disturbed	Usually normal, except in severe dementia
<b>Perceptions</b>	Hallucinations/ illusions	Usually intact early
<b>Cure</b>	Often possible	Not possible

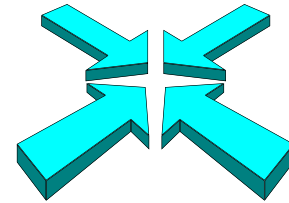
# Dementia – prevalence in Norway

Tabell 6 Antall og prevalens av personer med MCI og demens (95 % konfidensintervall, KI)

Alder	Antall respondenter	Antall personer med demens	Standardisert prevalens av demens*	95 % KI	Antall personer med MCI	Standardisert prevalens av MCI*	95 % KI
Totalt							
70–74 år	4014	234	5,6 %	(4,9–6,3)	1451	36,0 %	(34,5–37,6)
75–79 år	2575	263	9,5 %	(8,4–10,7)	938	36,6 %	(34,7–38,6)
80–84 år	1564	303	17,9 %	(16,0–20,0)	513	32,9 %	(30,4–35,5)
85–89 år	901	333	33,0 %	(29,7–36,5)	293	33,2 %	(29,8–36,8)
90+ år	609	337	48,1 %	(43,0–53,3)	187	35,7 %	(30,7–41,1)
Sum	9663	1470	14,6 %	(13,9–15,4)	3382	35,3 %	(34,3–36,4)

# Cognitive impairment - nonspecific

- Acute incidents (e.g.: stroke)
- Frailty/ poor health condition
- Depression
- Sensory impairment
- Medication
  - Opioids, benzodiazepines...
- Loneliness (lack of stimuli)



Many possible contributors  
- Often a combination

# Comprehensive geriatric assessment (CGA)

- An **interdisciplinary, systematic, multidimensional** diagnostic process focusing on frail elderly patients' capabilities and limitations
- Purpose
  - Diagnostic
  - Develop an integrated and coordinated plan for treatment and follow-up included rehabilitation.

*LZ Rubenstein in Geriatric Assessment Technology 1995*

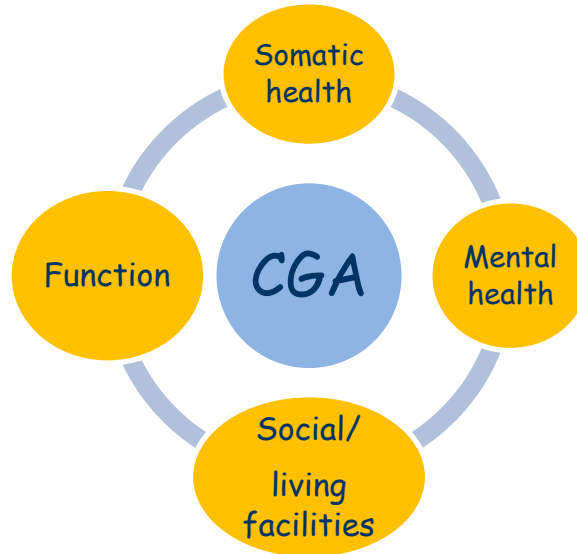
# CGA – dimensions usually assessed

## Physical health

- Somatic assessment
- Drugs
- Nutrition
- Skin
- Pain

## Function

- ADL /IADL \*
- Mobility
- Elimination (urine/feces)
- Hearing
- Vision



## Mental health

- Cognition
  - Delirium
  - Dementia
- Depression
- Anxiety

## Social situation

- Caregivers/ network
- Residence
- Need of assistance at home
- Driving

**ADL – Activities of daily living:** Eating, bowel-/ bladder continence, personal toilet, dressing, transfer, walking on level surface and stairs, bathing.

**IADL – Instrumental ADL:** use telephone, shopping, food preparation, housekeeping, laundry, transportation, ability to handle medication and finances

# An update on a systematic review of the use of geriatric assessment for older adults in oncology

M. T. E. Puts<sup>1\*</sup>, B. Santos<sup>1</sup>, J. Hardt<sup>1</sup>, J. Monette<sup>2</sup>, V. Girre<sup>3</sup>, E. G. Atenafu<sup>4</sup>, E. Springall<sup>5</sup> & S. M. H. Alibhai<sup>6</sup>

<sup>1</sup>Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Toronto; <sup>2</sup>Division of Geriatric Medicine, and McGill University/Université de Montreal Solidage Research Group on Frailty and Aging, Jewish General Hospital, Montreal, Canada; <sup>3</sup>Department of Oncology-Hematology, Centre Hospitalier Departemental, La Roche sur Yon, France; <sup>4</sup>Department of Biostatistics, Princess Margaret Cancer Centre, Toronto; <sup>5</sup>Gerstein Science Information Centre, University of Toronto Libraries, Toronto;

<sup>6</sup>Department of Medicine and Institute of Health Policy, Management, and Evaluation, University Health Network and University of Toronto, Toronto, Canada

**Conclusion:** Consistent with our previous review, several domains of GA are associated with adverse outcomes. However, further research examining effectiveness of GA on treatment decisions and oncologic outcomes is needed.

# Assessment of the cognitively impaired

## - *some challenges*

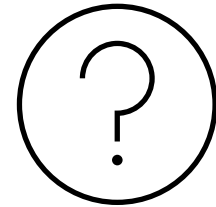
- **Memory** - ability to remember symptoms
  - **Speech** - ability to understand and express
  - **Abstraction** - ability to translate symptoms into rating instruments
  - **Judgement**, intellectual function
- 
- Behavior may be changed due to dementia
  - Neuropsychiatric symptoms in dementia (hallucinations etc) may be triggered or aggravated by somatic illness
  - Atypical symptoms





# Perception of pain in people with dementia

- Unchanged?
- Changed?
- Depends on
  - Degree of cognitive impairment
  - Neurodegenerative changes



# Assessment methods

- **History**

- Patient
- Relatives
- Primary health care

- **Physical examination**

- Routine somatic assessment
- Blood samples
- ECG
- Imaging
- Screening for common conditions

- **Observation**

- Rating instruments
  - Patient
  - Relatives
  - Medical personell

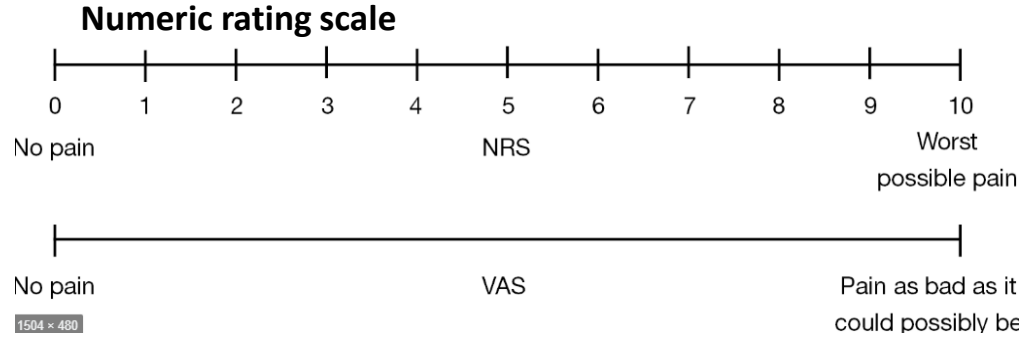
# Assessment of pain in people with dementia

## 1 – Self report

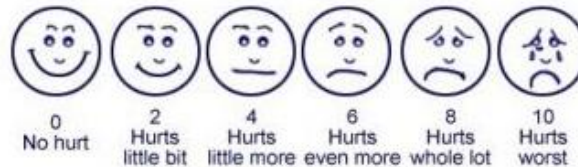
- Self-report
    - Mild and moderate dementia
    - Often unobtainable in severe dementia (observational instrument recommended)
  - Verbal rating scales
  - Numeric rating scales
- Generally reliable and valid  
- Unidimensional (indicator of pain intensity alone, not location, effect on function etc.)
- VAS (Visual Analogue Scale) – not recommended in this group

Pain assessment	
5	Worst possible pain
4	Severe pain
3	Moderate pain
2	Mild pain
1	No pain

### Verbal rating scale 1-5



### Visual Analogue Scale



FACES Pain Rating Scale. Image courtesy of the US Department of Veterans Affairs.



## Edmonton Symptom Assessment System (revidert versjon) (ESAS-r)

Vennligst sett ring rundt det tallet som best beskriver hvordan du har det NÅ:

Ingen smerte 0 1 2 3 4 5 6 7 8 9 10 Verst tenkelig smerte

Ingen slapphet 0 1 2 3 4 5 6 7 8 9 10 Verst tenkelig slapphet  
(slapphet = mangel på krefter)

Ingen døsighet 0 1 2 3 4 5 6 7 8 9 10 Verst tenkelig døsighet  
(døsighet = å føle seg søvnig)

Ingen kvalme 0 1 2 3 4 5 6 7 8 9 10 Verst tenkelig kvalme

Ikke nedsatt matlyst 0 1 2 3 4 5 6 7 8 9 10 Verst tenkelig nedsatt matlyst

Ingen tung pust 0 1 2 3 4 5 6 7 8 9 10 Verst tenkelig tung pust

Ingen depresjon 0 1 2 3 4 5 6 7 8 9 10 Verst tenkelig depresjon  
(depresjon = å føle seg nedstemt)

Ingen angst 0 1 2 3 4 5 6 7 8 9 10 Verst tenkelig angst  
(angst = å føle seg urolig)

Best tenkelig velvære 0 1 2 3 4 5 6 7 8 9 10 Verst tenkelig velvære  
(velvære = hvordan du har det, alt tatt i betraktning)

Ingen \_\_\_\_\_ 0 1 2 3 4 5 6 7 8 9 10 Verst tenkelig \_\_\_\_\_  
Annet problem (f.eks. forstoppeelse) \_\_\_\_\_

# Assessment of pain in people with dementia

## 2 – Search for potential causes of pain/ discomfort

- Chronic disorders
- Neurological, musculoskeletal
- Recent falls etc.

# Assessment of pain in people with dementia

## 3 – Common pain behaviors (non-verbal pain communication)

### Facial expressions

- Slight frown; sad, frightened face
- Grimacing, wrinkled forehead, closed or tightened eyes
- Any distorted expression
- Rapid blinking

### Verbalizations, vocalizations

- Sighing, moaning, groaning
- Grunting, chanting, calling out
- Noisy breathing
- Asking for help
- Verbally abusive

### Body movements

- Rigid, tense body posture, guarding
- Fidgeting
- Increased pacing, rocking
- Restricted movement
- Gait or mobility changes

### Changes in interpersonal interactions

- Aggressive, combative, resisting care
- Decreased social interactions
- Socially inappropriate, disruptive
- Withdrawn

### Changes in activity patterns or routines

- Refusing food, appetite changes
- Increase in rest periods
- Sleep, rest pattern changes
- Sudden cessation of common routines
- Increased wandering

### Mental status changes

- Crying or tears
- Increased confusion
- Irritability or distress

# Assessment tools

## Review



## Pain assessment in elderly adults with dementia

Thomas Hadjistavropoulos, Keela Herr, Kenneth M Prkachin, Kenneth D Craig, Stephen J Gibson, Albert Lukas, Jonathan H Smith

Lancet Neurol 2014; 13: 1216-27

See Online for podcast

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SK, Canada  
(Prof T Hadjistavropoulos PhD);  
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Chronic pain is highly prevalent in the ageing population. Individuals with neurological disorders such as dementia are susceptible patient groups in which pain is frequently under-recognised, underestimated, and undertreated. Results from neurophysiological and neuroimaging studies showing that elderly adults are particularly susceptible to the negative effects of pain are of additional concern. The inability to successfully communicate pain in severe dementia is a major barrier to effective treatment. The systematic study of facial expressions through a computerised system has identified core features that are highly specific to the experience of pain, with potential future effects on assessment practices in people with dementia. Various observational-behavioural pain assessment instruments have been reported to be both reliable and valid in individuals with dementia. These techniques need to be interpreted in the context of observer bias, contextual variables, and the overall state of the individual's health and wellbeing.

«Across these reviews, there is still no one instrument that meets all purposes, and clinicians should consider the evidence and clinical usefulness of a recommended instrument for their specific population and setting.»

## Panel 1: Instruments suitable for the assessment of pain in the elderly adult with dementia

- Abbey Pain Scale<sup>77,82-84</sup>
- Checklist of Non-Verbal Pain Indicators (CNPI)<sup>78,84,85</sup>
- Certified Nursing Assistant Pain Assessment Tool (CPAT)<sup>75,86</sup>
- DOLOPLUS-2<sup>87,88-90</sup>
- Discomfort Scale in Dementia of the Alzheimer's Type (DS-DAT/DS-DAT modified)<sup>91-95</sup>
- EPCA-2<sup>96</sup>
- Mahoney Pain Scale<sup>97</sup>
- Mobilization-Observation-Behaviour-Intensity-Dementia (MOBID and MOBID-2) Pain Scale<sup>74,98,99</sup>
- Non-Communicative Patient's Pain Assessment Instrument (NOPPAIN)<sup>57,72,85,100</sup>
- Pain Assessment in the Communicatively Impaired (PACI)<sup>101-103</sup>
- Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC and PACSLAC-II)<sup>2,73,85,104-107</sup>
- Pain Assessment for the Dementing Elderly (PADE)<sup>85,108</sup>

«(...) different guidelines have recommended different instruments, which often relate to the country of origin.»



# 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

YOU MAY TICK SEVERAL BOXES FOR EACH ACTIVITY

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

☐
☐
☐

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

☐
☐
☐

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

☐
☐
☐

4. Guide to turn in bed to both sides

☐
☐
☐

5. Guide to sit at the bedside

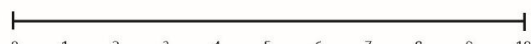
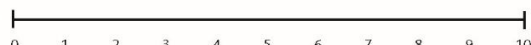
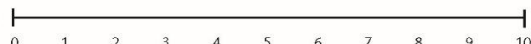
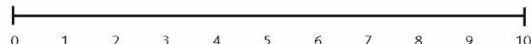
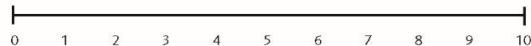
☐
☐
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## Pain Intensity

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

HOW INTENSE DO YOU REGARD THE PAIN TO BE?

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

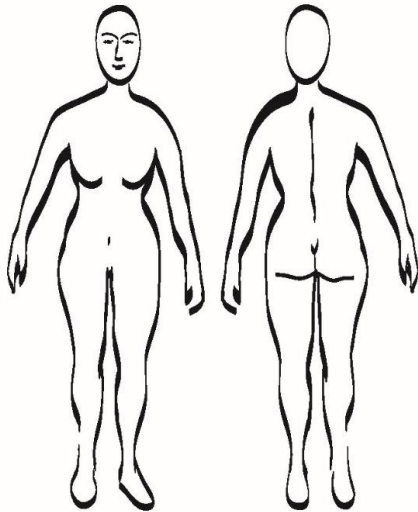


## APPENDIX

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)

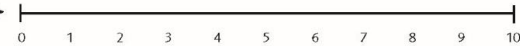


### Pain Intensity

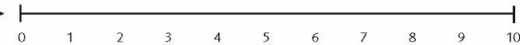
Based on pain behaviour, rate the pain intensity with a cross on the lines (0–10)

HOW INTENSE DO YOU REGARD THE PAIN TO BE?  
0 is no pain and 10 is as bad as it possibly could be

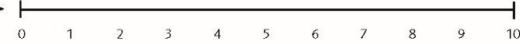
6. Head, mouth, neck



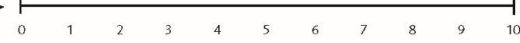
7. Heart, lung, chest wall



8. Abdomen



9. Pelvis, genital organs



10. Skin



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



# DOLOPLUS -2

SOMATIC REACTIONS		
1 • Somatic complaints	<ul style="list-style-type: none"> <li>• no complaints</li> <li>• complaints expressed upon inquiry only</li> <li>• occasional involuntary complaints</li> <li>• continuous involuntary complaints</li> </ul>	0 1 2 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 positions</li> <li>• protective postures continuously and effectively sought</li> <li>• protective postures continuously sought, without success</li> </ul>	0 1 2 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 investigation or nursing</li> <li>• protective actions against any investigation or nursing</li> <li>• protective actions taken at rest, even when not approached</li> </ul>	0 1 2 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 and unusually blank look (voiceless, staring, looking blank)</li> </ul>	0 1 2 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>• insomnia affecting waking times</li> </ul>	0 1 2 3
PSYCHOMOTOR REACTIONS		
6 • washing &/or dressing	<ul style="list-style-type: none"> <li>• usual abilities unaffected</li> <li>• usual abilities slightly affected (careful but thorough)</li> <li>• usual abilities highly impaired, washing &amp;/or dressing is laborious and incomplete</li> <li>• washing &amp;/or dressing rendered impossible as the patient resists any attempt</li> </ul>	0 1 2 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 cuts down on his/her movements)</li> <li>• any movement is impossible, the patient resists all persuasion</li> </ul>	0 1 2 3
PSYCHOSOCIAL REACTIONS		
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 refusal of any form of communication</li> </ul>	0 1 2 3
9 • Social life	<ul style="list-style-type: none"> <li>• participates normally in every activity (meals, entertainment, therapy workshop)</li> <li>• participates in activities when asked to do so only</li> <li>• sometimes refuses to participate in any activity</li> <li>• refuses to participate in anything</li> </ul>	0 1 2 3
10 • Problems of behaviour	<ul style="list-style-type: none"> <li>• normal behaviour</li> <li>• problems of repetitive reactive behaviour</li> <li>• problems of permanent reactive behaviour</li> <li>• permanent behaviour problems (without any external stimulus)</li> </ul>	0 1 2 3

## Checklist of Nonverbal Pain Indicators (CNPI)

**Instructions:** Observe the patient for the following behaviors both at rest and during movement.

### Checklist of Nonverbal Pain Indicators (CNPI)

Behavior	With Movement	At Rest
1. Vocal complaints: nonverbal (Sighs, gasps, moans, groans, cries)		
2. Facial Grimaces/Winces (Furrowed brow, narrowed eyes, clenched teeth, tightened lips, jaw drop, distorted expressions)		
3. Bracing (Clutching or holding onto furniture, equipment, or affected area during movement)		
4. Restlessness (Constant or intermittent shifting of position, rocking, intermittent or constant hand motions, inability to keep still)		
5. Rubbing (Massaging affected area)		
6. Vocal complaints: verbal (Words expressing discomfort or pain [e.g., "ouch," "that hurts"]; cursing during movement; exclamations of protest [e.g., "stop," "that's enough"] )		
Subtotal Scores		
Total Score		

## Kompetansesenter i lindrande behandling Helseregion Vest

### ESAS sekundærobservasjonsskjema: Registrering av problem

Dette skjemaet fylles ut to ganger daglig for å sikre best mulig oppfølging og behandling av pasienten. Det settes et kryss på hver linje. Den venstre enden av linjen beskriver uproblematisk situasjon og høyre enden av linjen beskriver verst tenkelig tilstand.

<https://helse-bergen.no/kompetansesenter-i-lindrande-behandling/palliasjon-verktoy-for-helsepersonell/esas-symptomregistrering>

#### Pustebesvær

Ubesværet

0 1 2 3 4 5 6 7 8 9 10

Tungpust

#### Matinntak

Normalt

0 1 2 3 4 5 6 7 8 9 10

Ikke noe

#### Bevissthetsnivå (våkenhet)

Normalt  
bevisst

0 1 2 3 4 5 6 7 8 9 10

Bevisstløs

#### Orientering (kognitiv evne)

Helt  
adekvat

0 1 2 3 4 5 6 7 8 9 10

Forvirret/tapt  
kognitiv evne

#### Motorisk ro/uro

Motorisk  
rolig

0 1 2 3 4 5 6 7 8 9 10

Svært urolig

#### Ansiktsuttrykk

Fredfylt

0 1 2 3 4 5 6 7 8 9 10

Ikke fredfylt

#### Årsak til sekundærobservasjon

- Bevissthetsnivå ☐
- Allmenntilstand ☐
- Kognitiv evne ☐
- Generelt stress ☐
- Annet ☐

Hva?

# Assessment of pain in people with dementia

## 4 – Surrogate reporting – family, caregiver

- Familiar with the patient
- Knowledge of pain behavior
- Training in assessment of pain

# Assessment of pain in people with dementia

## 5 – Attempt analgesic treatment

...and reevaluate the patient

### Efficacy of treating pain to reduce behavioural disturbances in residents of nursing homes with dementia: cluster randomised clinical trial

Bettina S Husebo *postdoctoral fellow*<sup>1</sup>, Clive Ballard *professor*<sup>2</sup>, Reidun Sandvik *registered nurse*<sup>1</sup>, Odd Bjarte Nilsen *statistician*<sup>3</sup>, Dag Aarsland *professor*<sup>4</sup>

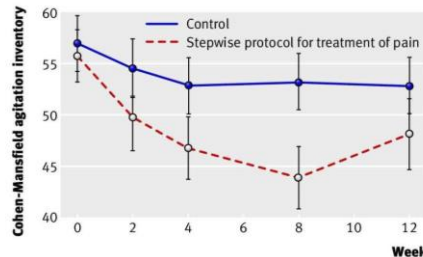


Fig 2 Cohen-Mansfield agitation inventory scores, with 95% confidence intervals, over study period

**Intervention** Participants in the intervention group received individual daily treatment of pain for eight weeks according to the stepwise protocol, with paracetamol (acetaminophen), morphine, buprenorphine transdermal patch, or pregabalin. The control group received usual treatment and care.

**Results:** Agitation was significantly reduced in the intervention group compared with control group after eight weeks (...)

# Take home message

- Cognitive impairment is very frequent among sick elderly patients
- A comprehensive, interdisciplinary assessment is recommended
- Assessment should be based on
  - Medical assessment of the patient
  - History of patient and caregivers
  - Use of assessment tools
- Pain assessment in persons with dementia
  1. Self report
  2. Search for potential causes
  3. Behavioral pain indicators
  4. Surrogate reports
  5. Analgesic trial
- Need of more research to find pain assessment tools in patients with severe dementia