

Dignity for the frail old –
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Dignity Center
FOR THE FRAIL OLD

The dying old, death as a fact of life

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Main topics of this lecture

Illness trajectories in elderly patients

Attention to detail

- Assessment and treatment of pain in patients with dementia
- Delirium
- Symptom management at the end-of-life

Research and implementation in nursing home (NH) medicine

Elsa is dying in a nursing home a late Saturday night

With or without access to:

Palliative care?

Pain and symptom management

Relatives?

Staff?

Ethical decision?

Admission to hospital?

A "good" death?

Dementia

Heart failure

Severe dyspnoea

Pain and anxiety

Cancer trajectory

Better treatment of pain, dyspnoea, constipation ($p < 0.001$)

Communication, decision making

Not restricted in activities until final stages, then rapid decline

Heart and lung failure

More emergency hospital admission;
Dyspnoea, anxiety, pain, fatigue

More sudden death

Long-term trajectory

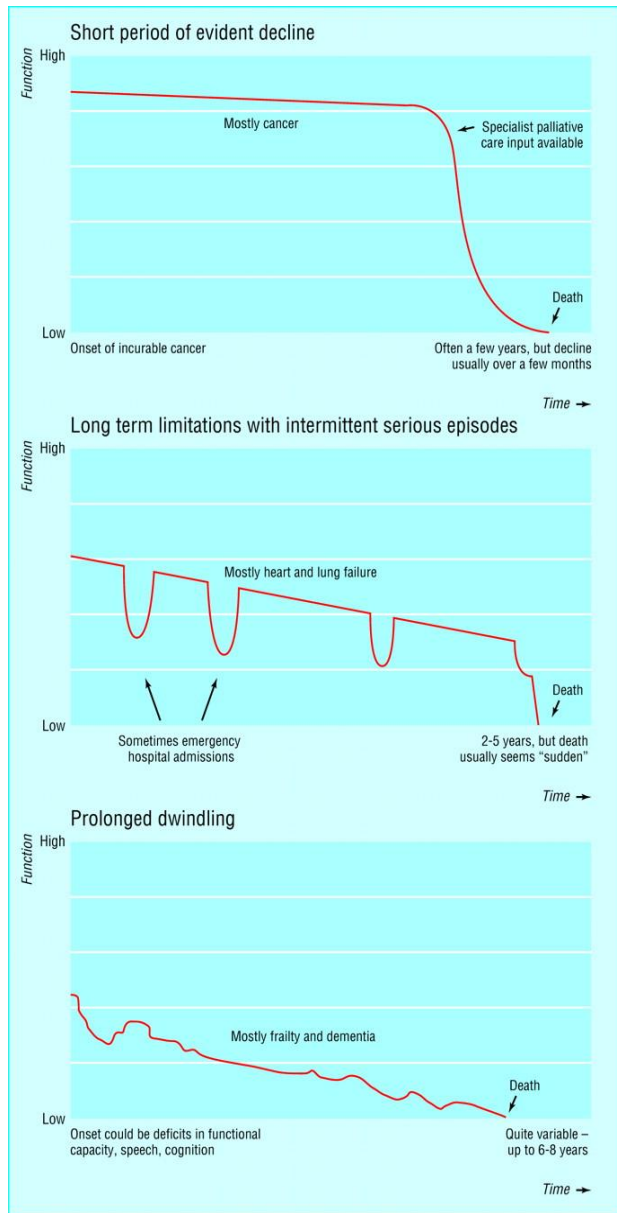
More pressure ulcer, pneumonia, fever, feeding tubes ($p < 0.001$)

Less advance directives: Do not resuscitate”,
”Do not hospitalise”

Less standing orders for analgesics

More burdensome procedures

Low level of baseline function



Which Cancer Patients Die in Nursing Homes (NH)?

Jordhøy MS, Saltvedt I, Fayers P, et al. Palliative Medicine 2003,17:433-444

OBJECTIVES Explore cancer patients characteristics dying in NHs

METHODS 434 cancer patients included in RCT study

RESULTS 66% patients died in hospital, 20% at home, 14% in NHs
NH patients were older, female, without spouse
Lower level of education, poorer performance status
Worst in terms of fatigue, nausea/vomiting, pain
Less appetite, lower cognitive and social functioning

CONCLUSION Those dying in NHs suffered from severe functioning impairments with higher symptom burden compared to patients dying elsewhere

Palliative Care for Patients With Heart Failure

Pantilat SZ, Steimle AE. JAMA. 2004;291:247682.

BACKGROUND Leading cause of death in US
Heart failure accounts for more hospitalizations
50% die within 5 years, sudden death
60% dyspnoea , 41% pain, fatigue, depression, poor sleep,
Decreased appetite, oedema, low QoL

CASE CONTROL STUDY

74-year-old man with heart failure to illustrate
ways physicians can address to improve care and
treatment of these patients

CONCLUSION Only 10% of patients with heart failure enrolled in hospice
High needs for realistic understanding of prognosis, advance
directives, sudden death, palliative care

Symptom Experience of Dying Long-Term Care Residents.

Hanson LC, Eckert JK, Dobbs D, et al. JAGS 2008, 56; 1: 91-98

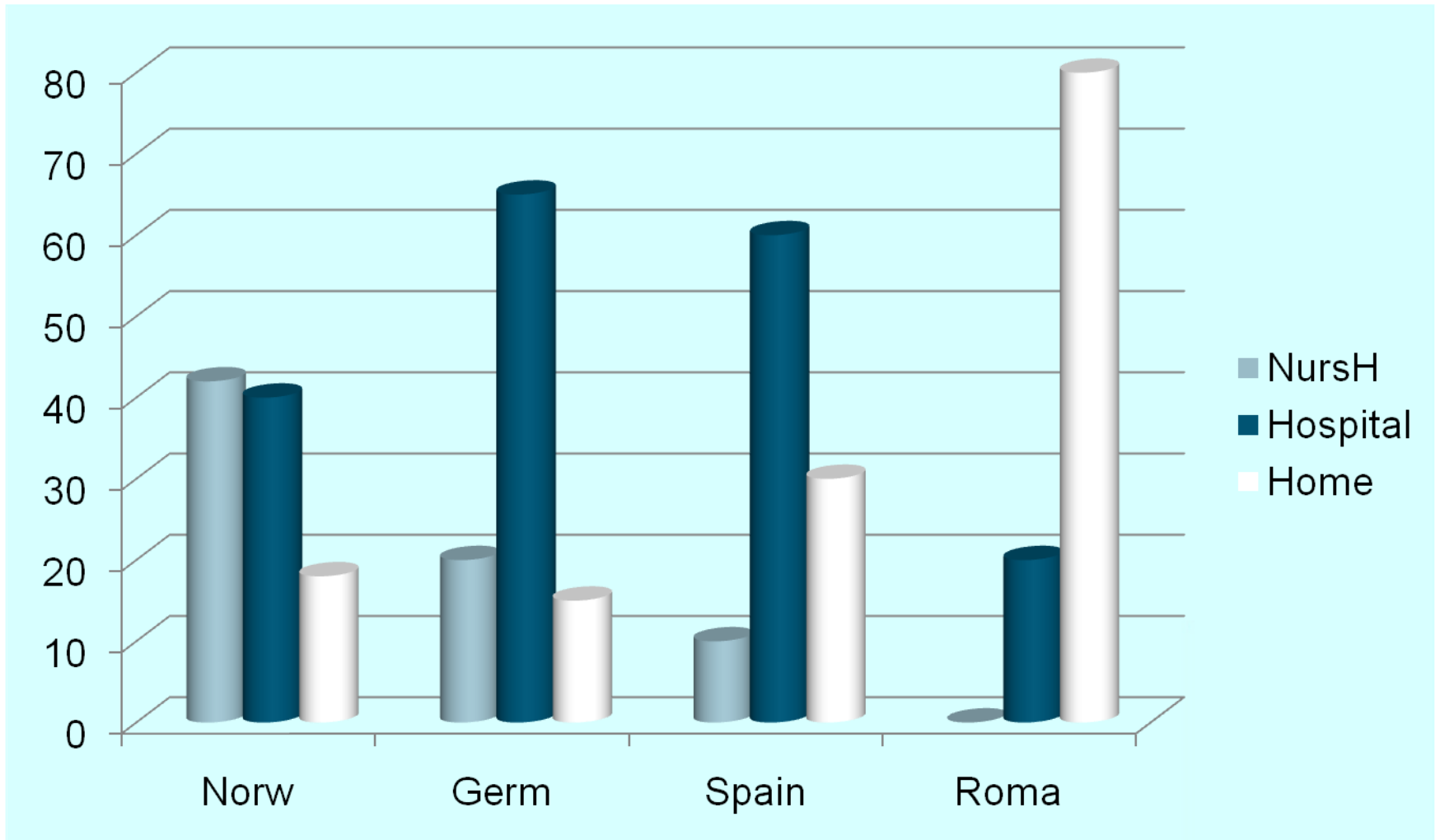
OBJECTIVES Describe the end-of-life symptoms of NH patients
Compare staff and family symptom ratings

DESIGN After-death interview
230 patients, 674 caregivers, 446 family members

RESULTS Median age 85 years, 77% dementia, 47% pain
48% dyspnoea, 90% problems with cleanliness
Staff relied on nonverbal expressions to assess dyspnoea,
but not pain

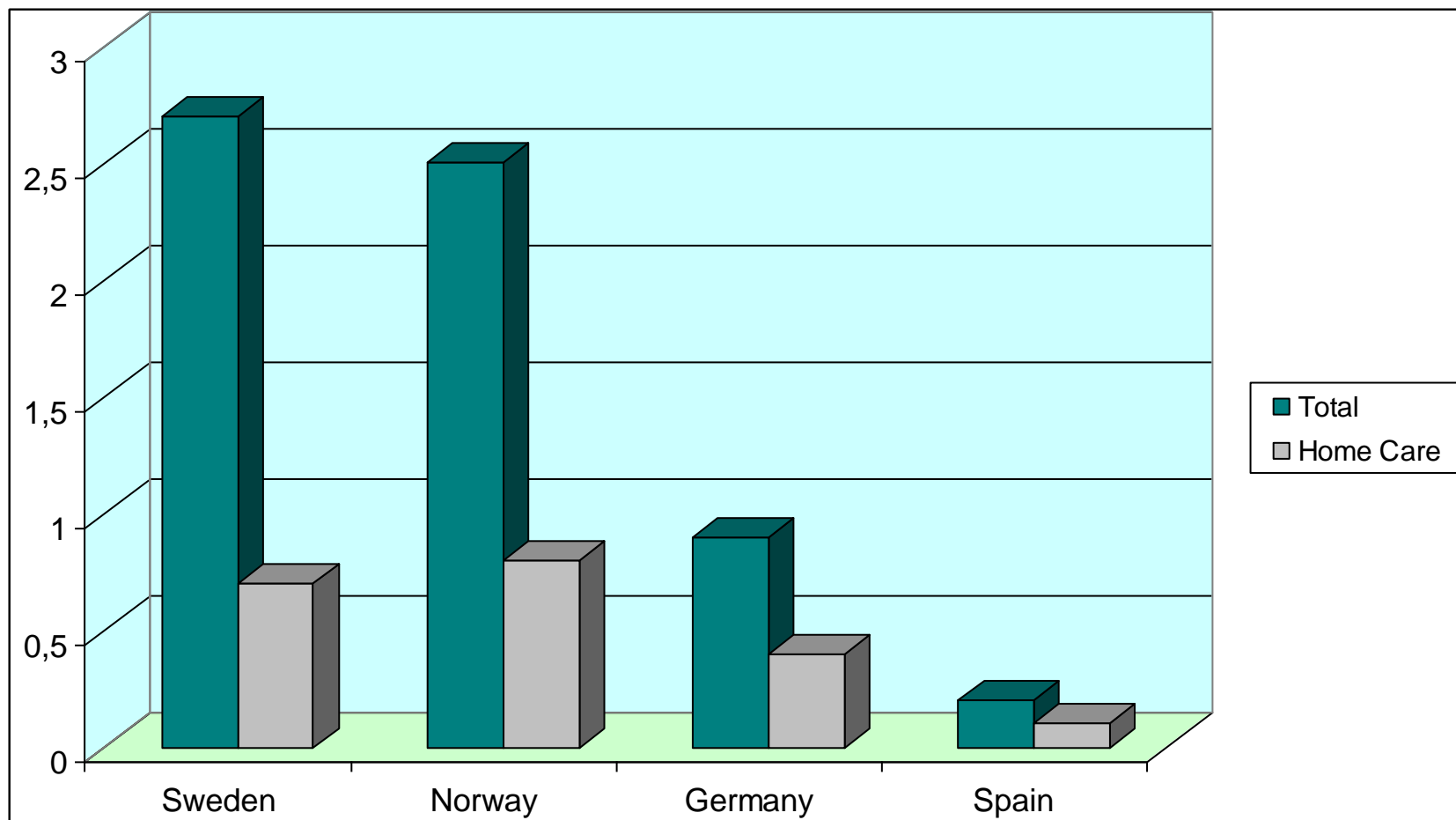
CONCLUSION NH patients have high rates of physical symptoms, need for more-effective palliative care. Both groups recommended improved application of treatment and increased staffing

Site of death (%)



Societies expenditure in % of BNP

Long-term care for elder persons



Dementia - prevalence

Worldwide

- 2009: 25 mill. patients
- 2040: 75 million patients
- Every year: 4.6 mill. new cases

Europe

- 10 mill. patients
- 2009: 2% of population
- 2040: 4% of population

China, Asia, Latin-American

- Ca. 350% increase into 2040

Pain – dementia – prevalence

NH patients suffer by **undiagnosed** and **untreated** pain (AGS Panel 1998)

83% of NH patients suffer from pain, leading to inactivity, depression and reduced quality of life (Ferrell B 1995)

Patients without cognitive impairment receive significant more **analgesics** than patients with dementia (Cohen-Mansfield J 2002)

Assessment as prerequisite for treatment

Procedures to assess the of pain components

1. Pain intensity
2. Pain affect
3. Pain quality
4. Pain location
5. Patient's history
6. Pain duration (diaries)
7. Physiological changes
8. Pain behaviour and interpretation

Why a new pain assessment instrument?

Established instruments have **limited clinical usability** in patients with severe dementia (Hadjistavropoulos 2007)

Assess patient **in rest**

Do not differ between

different pain **localizations**

pain behaviour and inferred **pain intensity**

pain behaviour and behaviour caused by **dementia**

MOBID-2 Pain Scale

Mobilization

Observation

Behaviour

Intensity

Dementia

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)

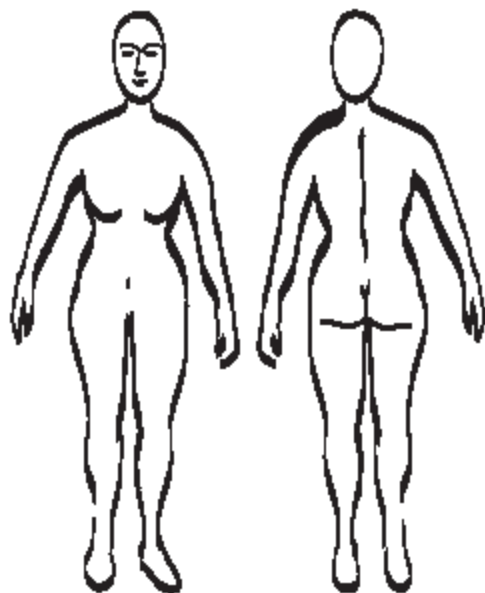
| | YOU MAY TICK SEVERAL BOXES FOR EACH ACTIVITY | | | HOW INTENSE DO YOU REGARD THE PAIN TO BE? 0 is no pain and 10 is as bad as it possibly could be |
|---|--|--------------------------|--------------------------|--|
| 1. Guide to open both hands, one hand at a time | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 0 1 2 3 4 5 6 7 8 9 10 |
| 2. Guide to stretch both arms towards head, one arm at a time | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 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 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 0 1 2 3 4 5 6 7 8 9 10 |
| 4. Guide to turn in bed to both sides | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 0 1 2 3 4 5 6 7 8 9 10 |
| 5. Guide to sit at the bedside | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 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)

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 | → | _____ | |
| | | 0 1 2 3 4 5 6 7 8 9 10 | |
| 7. Heart, lung, chest wall | → | _____ | |
| | | 0 1 2 3 4 5 6 7 8 9 10 | |
| 8. Abdomen | → | _____ | |
| | | 0 1 2 3 4 5 6 7 8 9 10 | |
| 9. Pelvis, genital organs | → | _____ | |
| | | 0 1 2 3 4 5 6 7 8 9 10 | |
| 10. Skin | → | _____ | |
| | | 0 1 2 3 4 5 6 7 8 9 10 | |

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

0 1 2 3 4 5 6 7 8 9 10

Who Suffers Most? Dementia and Pain in Nursing Home Patients: A Cross-sectional Study

Bettina Sandgathe Husebo, MD, Liv Inger Strand, PhD, Rolf Moe-Nilssen, PhD, Stein BorgeHusebo, MD, Dag Aarsland, PhD, and Anne Elisabeth Ljunggren, PhD

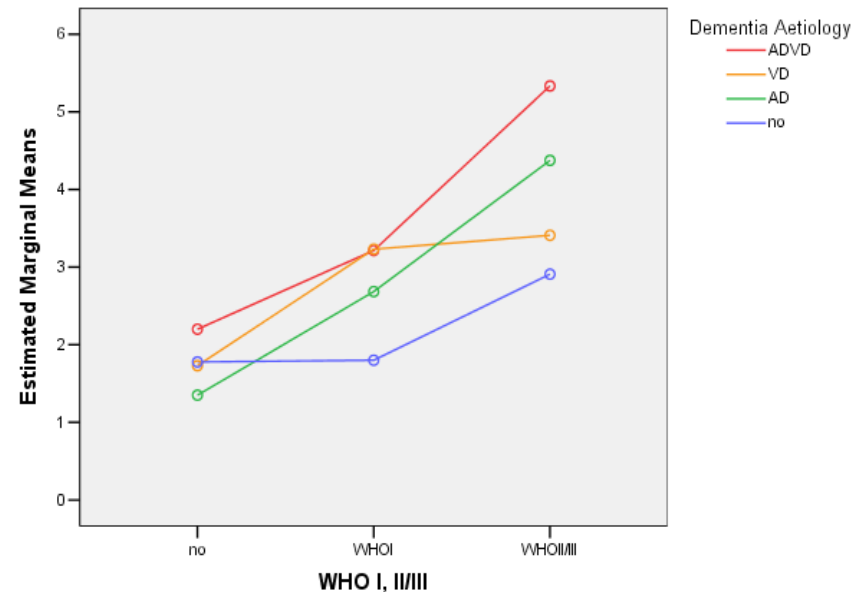
Objectives

Explore relationship between NH patients with different stages and diagnoses of dementia, and use of medication according to pain intensity

Results

Patients with severe dementia and mixed dementia are at high risk to suffer from severe pain.

Estimated Marginal Means of nurse pain score (MOBID)



Pain treatment in the elderly – balance between effect and side effect

They need the same drugs compared to adults,
but first

- **Observe and rate** pain, be obvious about delirium and BPSD
- **Stop** useless treatment
CAVE: Interactions and poly-pharmacy
- Try analgesics, no placebo!
 - Start **low** – increase **slow**
 - Non-invasive administration
- **Communication** with relatives and staff – they have to observe the effect

Delirium

Is one of the **most frequent** (30-88%) and serious complication in patients with advanced illness with **acute onset** and **fluctuating** course

A **complex organic brain** syndrome based on **reduced cholinergic** activity and **increased dopaminergic** transmission

Delirium is not a disease and about **50%** is reversible

| | Delirium | Dementia | Depression | Psychosis |
|-------------------------------|---|----------------------------|----------------------------|---------------------------------|
| Onset | Acute: confusion agitation, anxiety sleep disturbance restlessness irritability | Slow | Variable | Variable |
| Course | Short period, quick fluctuating | Slow | Variable | Variable |
| Reversibility | 50% | Non | Reversible | Variable |
| Consciousness | Disordered attention (arousal) | Lucid until last stages | Intact | Intact |
| Attention & memory | Inattention, short- term | Impairment | Intact | Poor attention Intact memory |
| Cognition | Memory deficit language disturb. | Cognitive failure | Intact | Variable |
| Psychotic symptoms | Frequent, brief | Less | Rare | Frequent, complex, paranoid |
| Treatment | Causes? Medical attention | Chronic follow-up | Psych.therap. treatment | Psych. evaluation treatment |

Multifactorial risk model of delirium

Drugs (opioids, anticholinergics, TCA, neuroleptics, hypnotics, steroids, H2 blockers, NSAIDs etc.)

Dementia

Pain

Terminal illness

Postoperative

Sepsis, infections

Alcohol- drug abuse

Median number of probable factors is 3/pas

Elsa - Advance directives

Suffers by **severe dementia**,
heart failure, and is totally
bed-ridden

In case of impending death
she and her family do

not wish resuscitation

not wish hospital admission

In case of emergency contact
her **daughter** and her
responsible **physician**

Pain, dyspnoea

Morphine 2.5-10mg/sc/4-6/h

Death rattle

Scopolamin 0.3-0.6mg/sc

Panic, restlessness

Midazolam 2.5-5mg/sc

Delirium, nausea,

Haloperidol 0.5-2.5mg/x2/d

Our Standard for Sufficient Palliative Care

Within 24 hours excellent

Review and relief of pain and symptoms

- Withdrawal of unnecessary treatment (diuretics, antidepressants, antibiotics)
- No suction in case of death rattle, but scopolamine s.c.
- No oxygen in case of dyspnoea, but morphine s.c.
- No i.v. fluids or feeding, but mouth care

Only apply drugs which contribute to improved QoL

Communication to patient, relatives, staff

Total care - day and night

Planning and documentation

Symptom relief – the last hours and days of life

All drugs can be given subcutaneous – also in a syringe driver

| Drug | Indication | Dose Daily dose |
|-------------------------------|---------------------------------|--|
| Morphine | Pain, dyspnoe | 5-? mg every 4.th hour (30 – 60 - ? mg) |
| Scopolamine | Death rattle, bowel obstruction | 0.3-0.6 mg up to x 4 (0.6 – 2.5 mg) |
| Haloperidol Haldol | Nausea, delirium | 0.5 – 2.5 mg x 1-2 (1 – 5 mg) |
| Midazolam Dormicum | Panic, anxiety, delirium | 2.5 – 5 mg up to x 4-6 (5 – 10 - ? mg) |
| Metamizol Novalgine | Periphery pain, fever | 3-6 g / day |

Nursing home research

Prerequisite for **change**

Increases **competence** and **focus**

Recruiting competent staff and resources

NHs are the optimal site for long-term **research**

And...

Financial compensation to NHs

Implementation of results and knowledge

Research Centre of NH medicine, University of Bergen

3 PhD projects (2004 – 2008): medication, sleep, pain

Post-doc and PhD projects

Pain-dementia-BPSD

Lewy-body dementia

Poly-pharmacy

Depression

Quality of life

Documentation

Narrative medicine

Music therapy

In planning

Illness trajectories in NHs

Hip fractures

Volunteers

Pain free NH

MOBID-2 PC version

How people die remains in the memories of those who live on, and for them (as for the patient) we need to be aware of the nature and management of terminal pain and distress.

What happens in the last hours may heal some earlier memories or remain as disturbing recollections that hinder the resolution of bereavement.

Cicely Saunders