PALLIATIVE CARE IN BELGIUM

De Bosschere Christine

Artevelde University College Ghent
Concept

When it is no longer possible to cure, it is your duty to care! (C. Saunders, 1978)

**Definition WHO** : ‘Palliative care is an *active total* care for the incurable patiënt and his family where every curative treatment isn’t usefull for the quality of life.’

‘*total pain concept*’:
attention to the *physical* complaints
psychosocial, *emotional* and *spiritual* support
(Cicely Saunders)

**Purpose**:  
comfort and quality of life!  
Living until the end...!
CURRENT ULTIMATE QUESTION

What makes your life, as a palliative sick person, difficult to unbearable?

→ guideline to the path to offer help!

(Burvenich, 2009)

Attitude : journey in truth...
17 years law on palliative care

- Because of this law and by the funds of government
- Quality in end-of-life!
Organised palliative care is no more a dream but a real fact! *(receiving government funding)*

- 15 networks
- as many home care teams
- dozens of teams in hospitals and rest homes
- 5 day care centers
- more than 30 palliative units
Increasing professionalisation

- research ensure continuous evaluation of care and refinement
- universities to ensure a strong scientific basis
  - care path palliative care (in hospital/home care)
  - directives f.e. for ‘palliative sedation’, ‘dyspnea’, ‘death rattle’...
  - working groups for specific target groups: children, people with dementia, persons with non-Western background, psychiatry, people with intellectual disabilities...

- spacious and high quality training offer
  - f.e. postgraduate for doctors, banaba for nurses...

Also for population ‘palliative care’ is natural!

(clear positive evolution)
In Belgium: change of the definition of palliative care since 2016!

New model www.fliece.be (2016) after 4 years of intensive research

Palliative care should be started from the diagnosis of an incurable illness.
PICT SCALE: new scientific validated instrument to identify palliative patients and to determine the level of their care needs.

Based on the international SPICT + 3 stages of care needs:
1° single statute (incl. ACP !)
2° increased statute
3° fully statute (last 3 months)
Another important fact: ageing / increasing dementia...

Document for advanced care planning!
(not only for cancer patients!)

It’s good to know what one may or not may want to...

So: renewal of the definition in Belgium is very good news for persons with dementia too because the government is funding now the ACP consultations!
PALLIATIVE CARE / PAIN MANAGEMENT FOR PEOPLE WITH DEMENTIA

‘The overturning moment to palliative care for people with dementia’

De Bosschere Christine

Artevelde University College Ghent
Dementia is a progressive and irreversible chronic disease, which goes to a final stage.

Discussing the current and future desired care, leads to a better alignment between the wishes of the patient and help given.


https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6010277/

Euthanasia is not allowed for persons with dementia in Belgium

17% Vascular dementia

62% Alzheimer's disease

10% mixed: Alzheimer's disease and vascular dementia

4% Lewy bodies

3% Other

2% Fronto-temporal

2% Parkinson's disease dementia

Dementia = a progressive degenerative disease

https://www.youtube.com/watch?v=dcVIx0OujU

Adelin has Alzheimer disease – palliative care 42.17-46.45

Euthanasia is not allowed for persons with dementia in Belgium
The major disease pathways
Huge increase! *(by aging)*

- **1999**: ± 81,000 patients with Alzheimer's disease (all age groups) = 0.8% in the total population.
- **2010**: 215,000 patients with dementia and 102,000 patients with Alzheimer's disease.
- ...
- + Research shows that 30% also suffers from other chronic diseases
Natural evolution of the disease

Not just memory loss!
The course of any type of dementia has separate characteristics.

*But strong similarities in the last stages of palliative needs.*
Persons with dementia: need for palliative care?  
_Some wrong views_

- Palliative care is only for cancer patients
- Old age and pain go together
- Older people feel less pain
- Elderly treaties no pain medication
- Pain medication gives risk of habituation
- Pain medication only "if necessary"
Persons with dementia: need for palliative care? *Facts!*

- confusion: 83%
- urine incontinence: 72%
- pain: 64%
- depression: 61%
- constipation: 59%
- anorexia: 53%

The experience of dying with dementia: a retrospective study.

Persons with dementia: need for palliative care? *more facts!*

- less visits of family practice
- quality of visit less well
- more need for homecare
- more need for social assistance

The experience of dying with dementia: a retrospective study.
Symptoms in last year of life cancer / dementia

Fig. 1. Symptoms reported to have been experienced for at least 6 months by cancer and dementia patients in the last year of life.
Influence of an acute event

*an acute event shortens considerably the life in dementia* Each ‘acute’ medical condition in dementia: risk of dying ↑↑↑

Morrison et al.: JAMA 2010; 284: 47-52
dementia has poor prognosis

→ focus on

↑ comfort - QUALITY OF LIFE

↓ invasive investigations

↓ invasive treatments f.e. tube feeding, infusion with antibiotics, surgery, ... Because no benefits for those persons (more discomfort) and it prolongs their illness...

→ timely starting up palliative approach!!
Barriers to good care

- Dementia was not recognised as a terminal illness.
- Discussions about symptom control were difficult.
- Providers of dementia care often found complex decision making and future care planning difficult, with staff giving conflicting and confusing information using poor communication skills.
- Patients and relatives were often thinking that active intervention was the best or only option of care.

When start palliative care?

Reality

- perception as terminal illness is missing
- ignorance about clinical prognosis
- lack of knowledge about impact acute events
- lack of prognostic tools

RESULT

overestimating life span and too late starting-up palliative care!
When start with fully palliative care?

- Incurable condition is terminally (3 to 6 months)
- Approach is evolving from cure to care
- Total care need is intense

Important: all concerned are in agreement!

Legal representative needed for person with dementia! (partner, parent, child...)

Importance of ACP as soon as possible after diagnosis!
This table illustrates how during the course of Alzheimer's the Mini Mental state is evolving and the capabilities of the patient. In the course of this process will always increase the appropriateness of palliative care, at the expense of the curative efforts.
AD: a progressive CNS disorder impairing patients’ ability to function

Definitions from the Global Deterioration Scale
Reisberg B et al., 1982
In the last stage: situation becomes ‘terminally’

- 7A. The **voice capability** is diminished to **six easy-to-understand words** in the course of an average day or during an intensive interview.
- 7B. The **speech ability** is limited to the use of a **single intelligible word** in the course of an average day or during an intensive interview.
- 7C. The **ability to steps** has been **lost** (the person can no longer steps without help).
- 7D. The **ability to sit** has been **lost** (the person cannot be without armrest).
- 7E. The **ability to laugh** (smile) has been **lost**.
- 7F. The **ability to set up independently of the head** is **lost**.

Reisberg B. "Functional assessment staging (FAST)"
GDS 7c-f

Functionality determines the palliative stage:

- seat, bedridden
- incontinence (urinary and faecal)
- limited or no communications
- nutritional problems: food intake limited; swallowing...
- complications: pneumonia, pressure ulcers, contractures, primitive reflexes...
- severe comorbidity: stroke, epilepsy, Parkinsonism...

## Palliative Performance Scale (PPSv2) version 2

<table>
<thead>
<tr>
<th>PPS Level</th>
<th>Ambulation</th>
<th>Activity &amp; Evidence of Disease</th>
<th>Self-Care</th>
<th>Intake</th>
<th>Conscious Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>100%</td>
<td>Full</td>
<td>Normal activity &amp; work</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No evidence of disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>90%</td>
<td>Full</td>
<td>Normal activity &amp; work</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some evidence of disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>80%</td>
<td>Full</td>
<td>Normal activity with Effort</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some evidence of disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>70%</td>
<td>Reduced</td>
<td>Unable Normal Job/Work</td>
<td>Occasional assistance necessary</td>
<td>Normal or reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Significant disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>60%</td>
<td>Reduced</td>
<td>Unable hobby/house work</td>
<td>Considerable assistance required</td>
<td>Normal or reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Significant disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50%</td>
<td>Mainly Sit/Lie</td>
<td>Unable to do any work</td>
<td>Mainly assistance</td>
<td>Normal or reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Extensive disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>40%</td>
<td>Mainly Sit/Lie</td>
<td>Unable to do most activity</td>
<td>Normal or reduced</td>
<td>Full or Drowsy +/- Confusion</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Extensive disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30%</td>
<td>Reduced</td>
<td>Unable to do any activity</td>
<td>Total Care</td>
<td>Normal or reduced</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Extensive disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20%</td>
<td>Reduced</td>
<td>Unable to do any activity</td>
<td>Total Care</td>
<td>Minimal to sips</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Extensive disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10%</td>
<td>Totally Bed</td>
<td>Unable to do any activity</td>
<td>Total Care</td>
<td>Mouth care only</td>
<td>Drowsy or Coma +/- Confusion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Extensive disease</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>0%</td>
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</tr>
</tbody>
</table>

- **3 months**
- **1 month**
- **1 week**

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Surprise question

You wouldn't be surprised if that person will die within 6 – 12 months?

Family member or colleague notes that resident is quickly going backwards

Reason can be:
- treatment target change: from function maintenance to comfort care
- evolution to stage GDS 7d (Reisberg)
- weight loss > 5%
- more problems with swallowing
- recurrent infections
- new serious pathology
- refusing care and food

...
Conclusion: *Palliative file necessary?*

- **goal**: extra attention for the needs of the resident

- **more intensive care** than comfort care! PAIN – and SYMPTOM CONTROL !! *re-evaluate medication!*

- **physical, psychological, emotional, social, spiritual**

- **quality of the time that's left!** f.e. complementary care...(massage, aromatherapy, haptonomy, music therapy, ...)

- **clarity**: maximum attention for resident and family (journey of truth)

- **administration**: palliative status requests

- **tools**: present pain scales, spiritual checklists, medication Syringe Pump, guidelines
  ‘dying phase’...

**Better too early than too late!**

In **Belgium**: 3 stages of palliative statute

*11/3/2016 International Conference - Tallinn*
The importance of Advance Care Planning: Do.... !!
(DNR = do not...)
transfer of information = very important!

Figure 1. Advance care planning process

- Advance directive (AD)
- Advance care planning (ACP)
- End-of-life care
- Discussions of preferences
- Treatment decisions
- Life-prolonging treatments
- Palliative care
- Diagnosis of progressive and incurable illness
- Progression of illness

LW = living will
DPAHC = durable power of attorney for health care
DNR = Do Not Resuscitate

Shared decision making!
**Goals of ACP**

- **ACP A:** do anything *to sustain life* except resuscitation (DNR1)?
- **ACP B:** do anything *to assure function maintenance*  
  - function maintenance  
  - optimize functions  
  - preservation of independence  
  - maintaining or improving quality of life  
- **ACP C:** do everything to give comfort  
  - comfort care  
  - *psychosocial and existential*  
  - *palliative care*  
- **ACP Ct:** do anything to support dying process  
  - *pain- and symptomcontrol* *(incl. palliative sedation)*  
  - *non-renewal dying process*

White paper on palliative care in dementia – recommendations from the EAPC (2013)
“Before I forget”

Use of I-pad : project 2016
for communication about ACP

Because it mostly never happened and because the resident (and certainly in the case of dementia) was not involved...
Palliative care for people with dementia: *attention for ‘pain’!*

- Prevalence of pain: 50% are experiencing pain regularly
  

- Prevalence rises to 80% increase in dementia (WZC)

- Growing evidence of inadequate treatment
  
Interesting research...

Vergelijking van pijnbehandeling t.g.v. heupfractuur bij gevorderd dementerend en cognitief valide ouderen
Journal of Pain and Symptom Management vol. 19 No. 4  April 2000

<table>
<thead>
<tr>
<th></th>
<th>niet-dementerend</th>
<th>dementerend</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>95</td>
<td>38</td>
</tr>
<tr>
<td>pijnschaal</td>
<td>0 tot 4</td>
<td>niet te testen</td>
</tr>
<tr>
<td>N = 4</td>
<td>40%</td>
<td>niet te testen</td>
</tr>
<tr>
<td>Opiaten</td>
<td>100</td>
<td>33</td>
</tr>
<tr>
<td>Routine analgesie</td>
<td>17%</td>
<td>24%</td>
</tr>
</tbody>
</table>
Objective

- Before we can treat pain, we need to recognize pain ...

- more accurate estimating discomfort (physical/affective)
- more accurate treatment of physical /affective pain
Effects of un (-der) treated pain

- depression
- social deprivation
- sleeping disorders
- mobility ↓
- health care ↑
- rehabilitation ↑
- impact on health care providers

- functionality ↓
- Quality of life ↓
- Psychological stress ↑
Pain sensation in dementia

1. sensory-motor component
   - Central nervous system damage > identical pain sensation as cognitive intact older person
     Scherder, Herr, Pickering, Gibson, Benedetti & Lautenbacher, 2009

2. affective component
   - Alzheimer's: reduced affective experience
   - Fronto-temporal: greatly reduced affective component
   - Vascular dementia: increased affective component

3. cognitive component
   - atypical pain presentation
   - memory disorders
   - language apraxia

4. behavioural component
   - Behavioral disorders indicate discomfort.
   - Behavioral disorders on the basis of discomfort by pain are similar to this on the basis of other disturbed needs as overstimulation, toilet care, psychosis, ....
Diagnosis

1. think of common causes

- degenerative joint pains
- rheumatoid arthritis
- low back problems
- neuropathic pain (diabetes, zona, ..)
- headache
- mouth – and toothaches
- calf cramps
- peripheral artery disease
- post-- CVA problems
- fixation
- immobilisation sitting position
- contractures
- pressure ulcers
- amputation
- ...

14/3/2019 International Conference - Tartu / Estonia
Diagnosis

2. self reporting

“Pain is whatever the experiencing person says it is, existing whenever the experiencing person says it does”


- Novice dementia: Person is able to report pain!
- Complaints about pain are sincere.
- Dementia patients will deny no pain when they are explicit about queried.
- The further advanced the dementia is, the less pain is reported.

(Parmelee P., 2009)
Diagnosis

3. Observations

➢ observing behavioral parameters
  - face
  - body
  - sleep pattern
...

➢ aspecific signs of discomfort behavioral disorders
  - frowns, grimaces, fearful facial expression, teeth grinding
  - cramping, repelling reactions, rubbing against handrail
  - fidgeting, restlessness, aggression, agitation
  - reduced food, bad sleep
  - sighs, moaning, panting
  - decrease level of activity and ADL
  - resistance to care
  - gang disorders
  - behavioural change
...

14/3/2019
International Conference - Tartu / Estonia
Diagnosis

3. Observations
use of observation scales


Results

Twenty-nine publications reporting on behavioural pain assessment instruments were selected for this review. Twelve observational pain assessment scales (DOLOPLUS2; ECPA; ECS; Observational Pain Behavior Tool; CNPI; PACSLAC; PAINAD; PADE; RaPID; Abbey Pain Scale; NOPPAIN; Pain assessment scale for use with cognitively impaired adults, REPOS) were identified. Findings indicate that most observational scales are under development and show moderate psychometric qualities.

Conclusion

Based on the psychometric qualities and criteria regarding sensitivity and clinical utility, we conclude that PACSLAC, PAINAD and REPOS are the most appropriate scales currently available. Further research should focus on improving these scales by further testing their validity, reliability and clinical utility.
Self-report is the gold standard!

Reflection: not so good because it gives more the question: ‘How do you feel?’ instead of ‘Do you have pain?’
PACSLAC Pain Assessment Checklist for Seniors with Limited Ability to Communicate


<table>
<thead>
<tr>
<th>Facial Expression</th>
<th>Present</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grimacing</td>
<td></td>
</tr>
<tr>
<td>Sad look</td>
<td></td>
</tr>
<tr>
<td>Tighter Face</td>
<td></td>
</tr>
<tr>
<td>Dirty Look</td>
<td></td>
</tr>
<tr>
<td>Change in Eyes</td>
<td>(Squinting, dull, bright, increased eye movements)</td>
</tr>
<tr>
<td>Frowning</td>
<td></td>
</tr>
<tr>
<td>Pain Expression</td>
<td></td>
</tr>
<tr>
<td>Grim Face</td>
<td></td>
</tr>
<tr>
<td>Clenching Teeth</td>
<td></td>
</tr>
<tr>
<td>Wincing</td>
<td></td>
</tr>
<tr>
<td>Open Mouth</td>
<td></td>
</tr>
<tr>
<td>Creasing Forehead</td>
<td></td>
</tr>
<tr>
<td>Screwing Up Nose</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Activity/Body Movement</th>
<th>Present</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fidgeting</td>
<td></td>
</tr>
<tr>
<td>Pulling Away</td>
<td></td>
</tr>
<tr>
<td>Flinching</td>
<td></td>
</tr>
<tr>
<td>Restless</td>
<td></td>
</tr>
<tr>
<td>Pacing</td>
<td></td>
</tr>
<tr>
<td>Wandering</td>
<td></td>
</tr>
<tr>
<td>Trying to Leave</td>
<td></td>
</tr>
<tr>
<td>Refusing to Move</td>
<td></td>
</tr>
<tr>
<td>Thrashing</td>
<td></td>
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<tr>
<td>Decreased Activity</td>
<td></td>
</tr>
<tr>
<td>Refusing Medications</td>
<td></td>
</tr>
<tr>
<td>Moving Slow</td>
<td></td>
</tr>
<tr>
<td>Impulsive Behaviours</td>
<td></td>
</tr>
<tr>
<td>(Repeat Movements)</td>
<td></td>
</tr>
<tr>
<td>Uncoperative/Resistance to care</td>
<td></td>
</tr>
<tr>
<td>Guarding Sore Area</td>
<td></td>
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<tr>
<td>Touching/Holding Sore Area</td>
<td></td>
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<tr>
<td>Limping</td>
<td></td>
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<tr>
<td>Clenching Fist</td>
<td></td>
</tr>
<tr>
<td>Going into Fetal Position</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Social/Personality/Mood</th>
<th>Present</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Aggression</td>
<td></td>
</tr>
<tr>
<td>(e.g., pushing people and/or objects, scratching others, hitting others, striking, kicking).</td>
<td></td>
</tr>
<tr>
<td>Verbal Aggression</td>
<td></td>
</tr>
<tr>
<td>Not Wanting to be Touched</td>
<td></td>
</tr>
<tr>
<td>Not Allowing People Near</td>
<td></td>
</tr>
<tr>
<td>Angry/Mad</td>
<td></td>
</tr>
<tr>
<td>Throwing Things</td>
<td></td>
</tr>
<tr>
<td>Increased Confusion</td>
<td></td>
</tr>
<tr>
<td>Anxious</td>
<td></td>
</tr>
<tr>
<td>Upset</td>
<td></td>
</tr>
<tr>
<td>Agitated</td>
<td></td>
</tr>
<tr>
<td>Cranky/Irritable</td>
<td></td>
</tr>
<tr>
<td>Frustrated</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other (Physiological changes/Eating Sleeping Changes/Vocal Behaviors)</th>
<th>Present</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pale Face</td>
<td></td>
</tr>
<tr>
<td>Flushed, Red Face</td>
<td></td>
</tr>
<tr>
<td>Teary Eyed</td>
<td></td>
</tr>
<tr>
<td>Sweating</td>
<td></td>
</tr>
<tr>
<td>Shaking/Trembling</td>
<td></td>
</tr>
<tr>
<td>Cold Clammy</td>
<td></td>
</tr>
<tr>
<td>Changes in Sleep Routine (Please circle 1 or 2)</td>
<td></td>
</tr>
<tr>
<td>1) Decreased Sleep</td>
<td></td>
</tr>
<tr>
<td>2) Increased Sleep During the Day</td>
<td></td>
</tr>
<tr>
<td>Changes in Appetite (Please circle 1 or 2)</td>
<td></td>
</tr>
<tr>
<td>1) Decreased Appetite</td>
<td></td>
</tr>
<tr>
<td>2) Increased Appetite</td>
<td></td>
</tr>
<tr>
<td>Screaming/Yelling</td>
<td></td>
</tr>
<tr>
<td>Calling Out (i.e., for help)</td>
<td></td>
</tr>
<tr>
<td>Crying</td>
<td></td>
</tr>
<tr>
<td>A Specific Sound of Vocalization</td>
<td></td>
</tr>
<tr>
<td>For pain &quot;ow,&quot; &quot;ouch&quot;</td>
<td></td>
</tr>
<tr>
<td>Moaning and groaning</td>
<td></td>
</tr>
<tr>
<td>Mumbling</td>
<td></td>
</tr>
<tr>
<td>Grunting</td>
<td></td>
</tr>
</tbody>
</table>

**Total Checklist Score**

Good in stages 3, 4, 5 of dementia – says only if there is pain but nothing about the severity of the pain!
**PAINAD** Pain Assessment in Advanced Dementia Scale  
(Warden et al., 2003)

<table>
<thead>
<tr>
<th>Behavior</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathing</td>
<td>Normal</td>
<td>Occasional labored breathing</td>
<td>Noisy labored breathing</td>
<td></td>
</tr>
<tr>
<td>Independent of vocalization</td>
<td></td>
<td>Short period of hyperventilation</td>
<td>Long period of hyperventilation</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Cheyne-Stokes respirations</td>
<td></td>
</tr>
<tr>
<td>Negative vocalization</td>
<td>None</td>
<td>Occasional moan or groan</td>
<td>Repeated troubled calling out</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Low-level speech with a negative or disapproving quality</td>
<td>Loud moaning or groaning</td>
<td></td>
</tr>
<tr>
<td>Facial expression</td>
<td>Smiling or inexpressive</td>
<td>Sad</td>
<td>Facial grimacing</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Frightened</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Body language</td>
<td>Relaxed</td>
<td>Tense</td>
<td>Rigid</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Distressed pacing</td>
<td>Fists clenched</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Fidgeting</td>
<td>Knees pulled up</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Pulling or pushing away</td>
<td></td>
</tr>
<tr>
<td>Consolability</td>
<td>No need to console</td>
<td>Distressed or reassured by voice or touch</td>
<td>Unable to console, distract, or reassure</td>
<td></td>
</tr>
</tbody>
</table>

**Scoring:** The total score ranges from 0-10 points. A possible interpretation of the scores is: 1-3=mild pain; 4-6=moderate pain; 7-10=severe pain. These ranges are based on a standard 0-10 scale of pain.
**REPOS** Rotterdam Elderly Pain Observation Scale

for elderly with complete limitation of expression - last stage of dementia
REPOS corresponding decision tree –
Training by E-learning in Belgium/Netherlands
Tips: using a pain scale for dementia patients

- Learn to work with it: test them out first (referent nurse)
- Multi-disciplinary: everyone must work with
- Score only what you see, not what you think
- You score only behavioural change with possible pain as a cause; This is often difficult to interpret!
- 2 x daily for the improvement, then with wider interval = part of the care file
- When in doubt about pain: try treatment
- Anyway if still verbal possibilities: ask about pain (VAS??)
presumption of pain behavior

- **Manipulation pain**
  - **Yes**: premedication, anti-anxiety approach
  - **No**: = spontaneous pain behavior

- **Basic needs fulfilled?**
  - **No**: R/comfort care

- **Pathology?**
  - **Yes**: R/causal treatment
  - **No**: R/empirical trial!
At the transition from ‘curative care’ to ‘palliative care’ for people with dementia, there is usually involve a rollover process instead of a roll-over time. For this the communication between caregiver and patient, the patient and his family, and the interdisciplinary team, is very important! Only then, the final 'overturning moment' will not be unexpected. Tools can support this process!
Comfort care – Quality of life

Complementary care as support in palliative stage for people with dementia some evidence

- The results of multi-sensory stimulation in 24-hour Dementia Care: reduction of stress, anxiety, pain... (Van Weert J., 2009)
- Positive outcomes reported following massage therapy include pain reduction, better quality of life, improve sleep and function as well as reduced depressive symptoms. This growing evidence base should aid clinicians in recommending massage as evidence-based therapeutic modality. (Kenny & Cohen, 2011)
- Research proves: aromatherapy supports dementia patients.
- People with dementia respond very well on scents, that remind them of times gone by. It gives them peace. On the other hand, it is also proved that different oils – aromatherapy - have an analgesic effect through gentle massage. (Alzheimer's Research Center, 2013)
- Haptonomy is a treatment in which touch between the therapist and the patient is an important entrance. Via the touch you can get in touch with the feelings that are stored in the body. Blockages can freely come. (Devreese K., 2014)
Please, touch me...if I am your aged father or mother, please, touch me...when I was young, I’ve been touched so many times. Hold my hand, sit close to me, give me some power and warm my tired body with your presence. I know my skin is wrinkled but it loves to be touched, don’t be afraid...just touch me... (Devreese K., 2016)
Working with dying people is certainly not easy, but it also helps you to see a lot of things in your life in perspective: It might sound odd, but by working with death I feel like living my life to the fullest and I live a lot more intensive...


Thank you for your attention!