



PALLIATIVE CARE IN BELGIUM

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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 patient and his family where every curative treatment isn't useful 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...



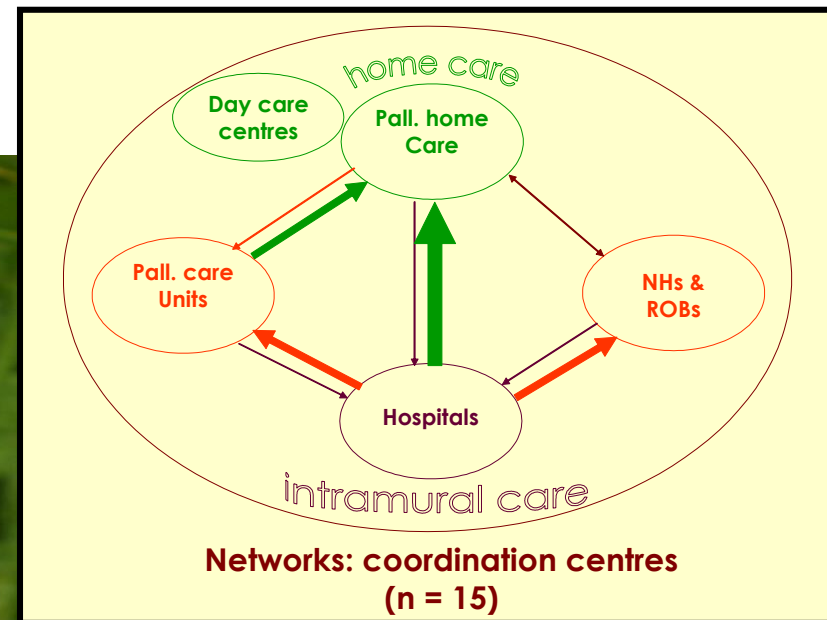
17 years law on palliative care

- 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!

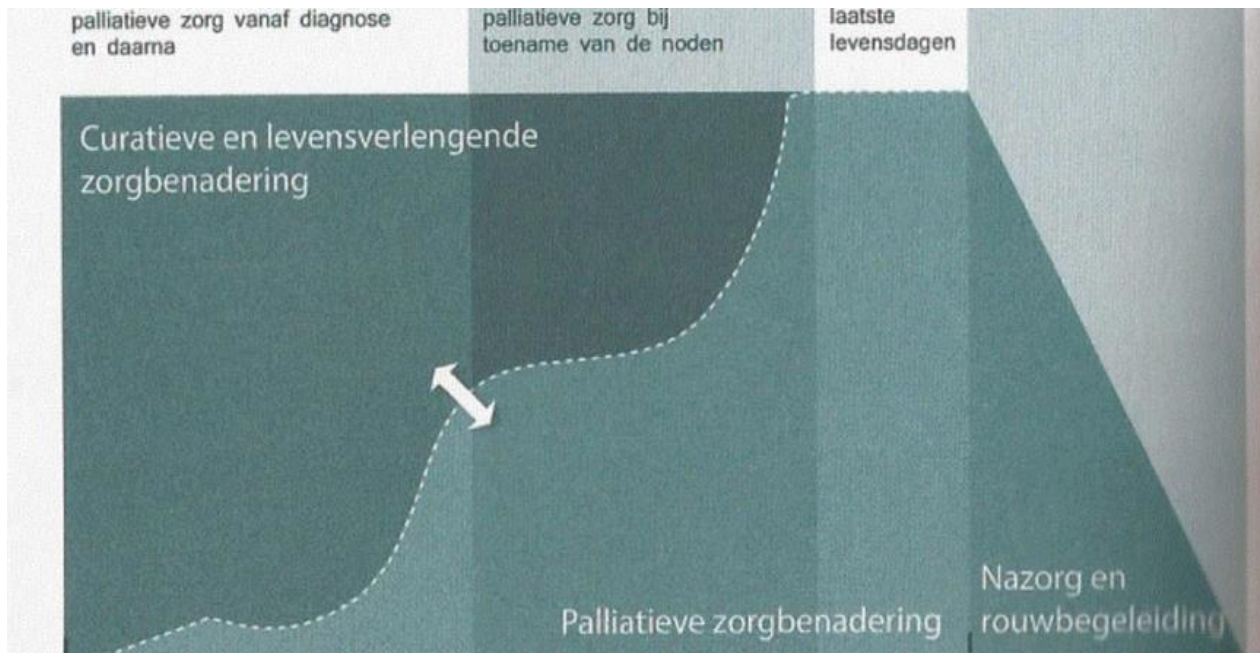
(clear positive evolution)



Palliative care should be started from the diagnosis of an incurable illness

In Belgium : change of the definition of palliative care since 2016!

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



(Cohen, Smets, Pardon & Deliens, 2016)

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)



Supportive and Palliative Care Indicators Tool (SPICt™)



The SPICt™ is a guide to identifying people at risk of deteriorating health and dying. Assess these people for unmet supportive and palliative care needs.

Look for two or more general indicators of deteriorating health.

- Performance status is poor or deteriorating (the person is in bed or a chair for 50% or more of the day); reversibility is limited.
- Dependent on others for most care needs due to physical and/or mental health problems.
- Two or more unplanned hospital admissions in the past 6 months.
- Significant weight loss (5-10%) over the past 3-6 months, and/ or a low body mass index.
- Persistent, troublesome symptoms despite optimal treatment of underlying condition(s).
- Patient asks for supportive and palliative care, or treatment withdrawal.

Look for any clinical indicators of one or more advanced conditions

Cancer

Functional ability deteriorating due to progressive metastatic cancer.

Too frail for oncology treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; swallowing difficulties.

Urinary and faecal incontinence.

No longer able to communicate using verbal language; little social interaction.

Fractured femur; multiple falls.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/ or progressive swallowing difficulties.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Heart/ vascular disease

NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:

- breathlessness or chest pain at rest or on minimal exertion.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe chronic lung disease with:

- breathlessness at rest or on minimal exertion between exacerbations.

Needs long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping dialysis.

Liver disease

Advanced cirrhosis with one or more complications in past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is contraindicated.

Review supportive and palliative care and care planning

- Review current treatment and medication so the patient receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals, and a care plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Record, communicate and coordinate the care plan.



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

<https://www.youtube.com/watch?v=dcVlx0QujIU>

Adelin has Alzheimer disease – palliative care 42.17-46.45

Euthanasia is not allowed for persons with dementia in Belgium

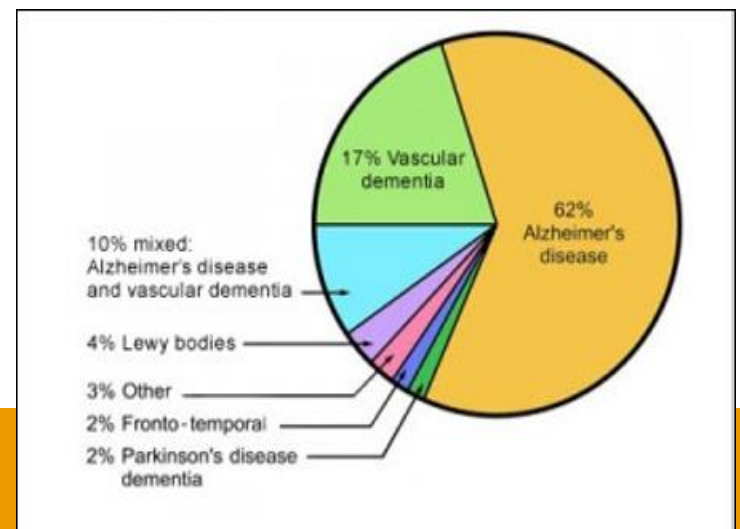
Dementia = a progressive degenerative disease

Dementia is a progressive and irreversible chronic disease, which goes to a final stage.

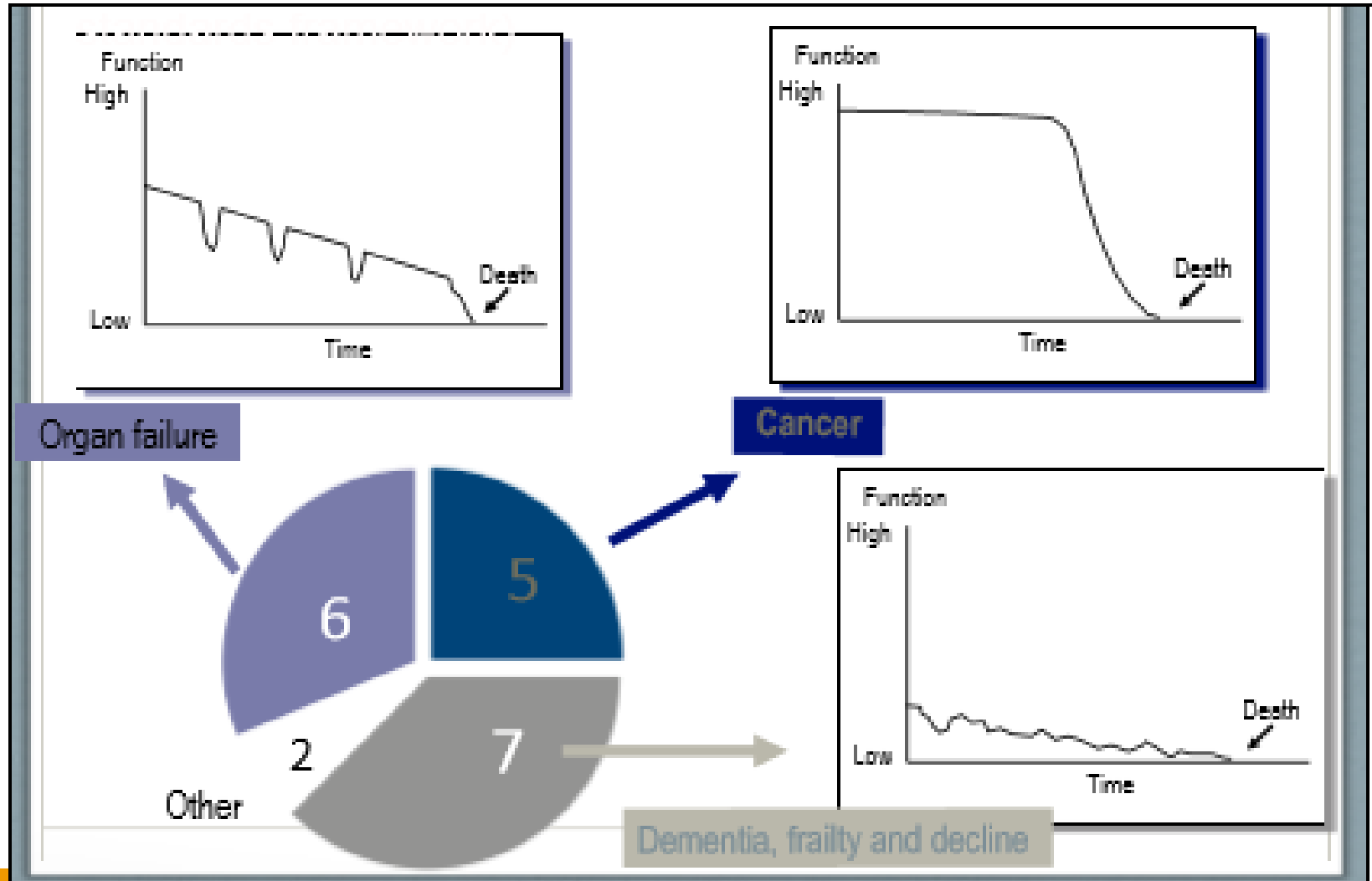
Discussing the current and future desired care, leads to a better alignment between the wishes of the patient and help given.

Tilburgs B., Vernooij-Dassen M., Koopmans R., et al. (2018) Barriers and facilitators for GP's in dementia advance care planning: A systematic integrative review. PLoS ONE 13(6).

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

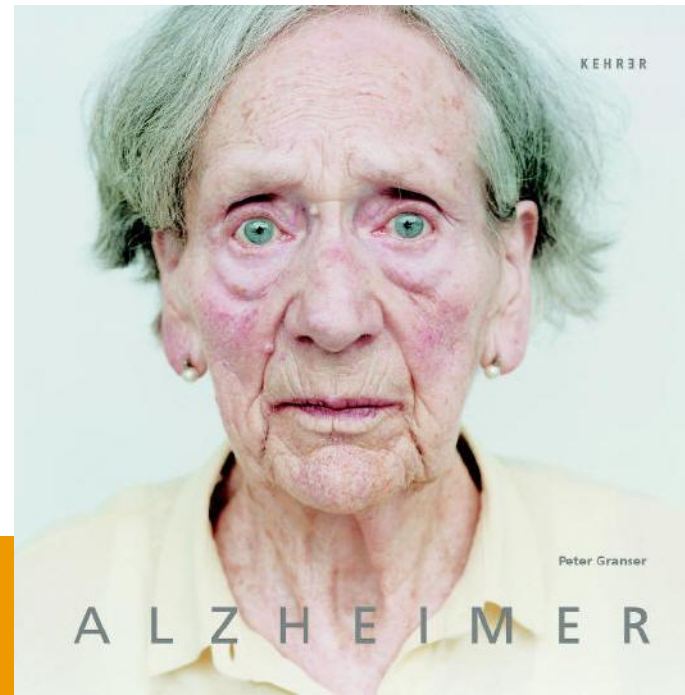


The major disease pathways

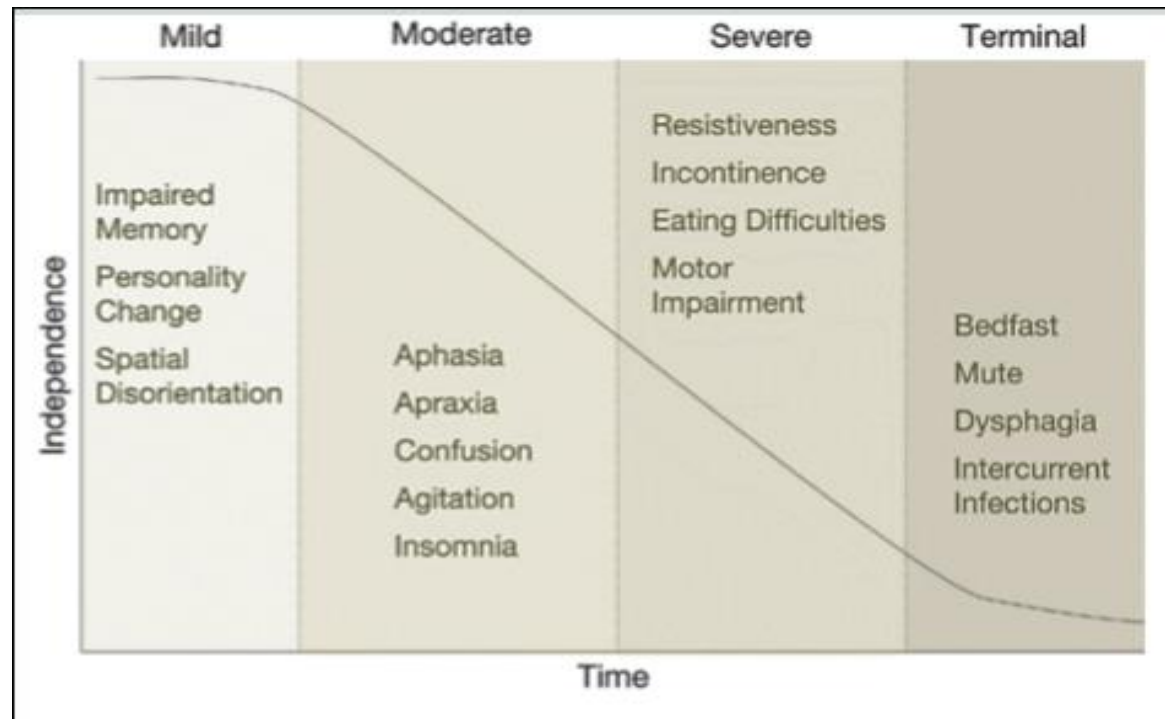


Huge increase! *(by aging)*

- 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.

Int J Geriatr Psychiatry. 2010 Mar;12(3):404-9.



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

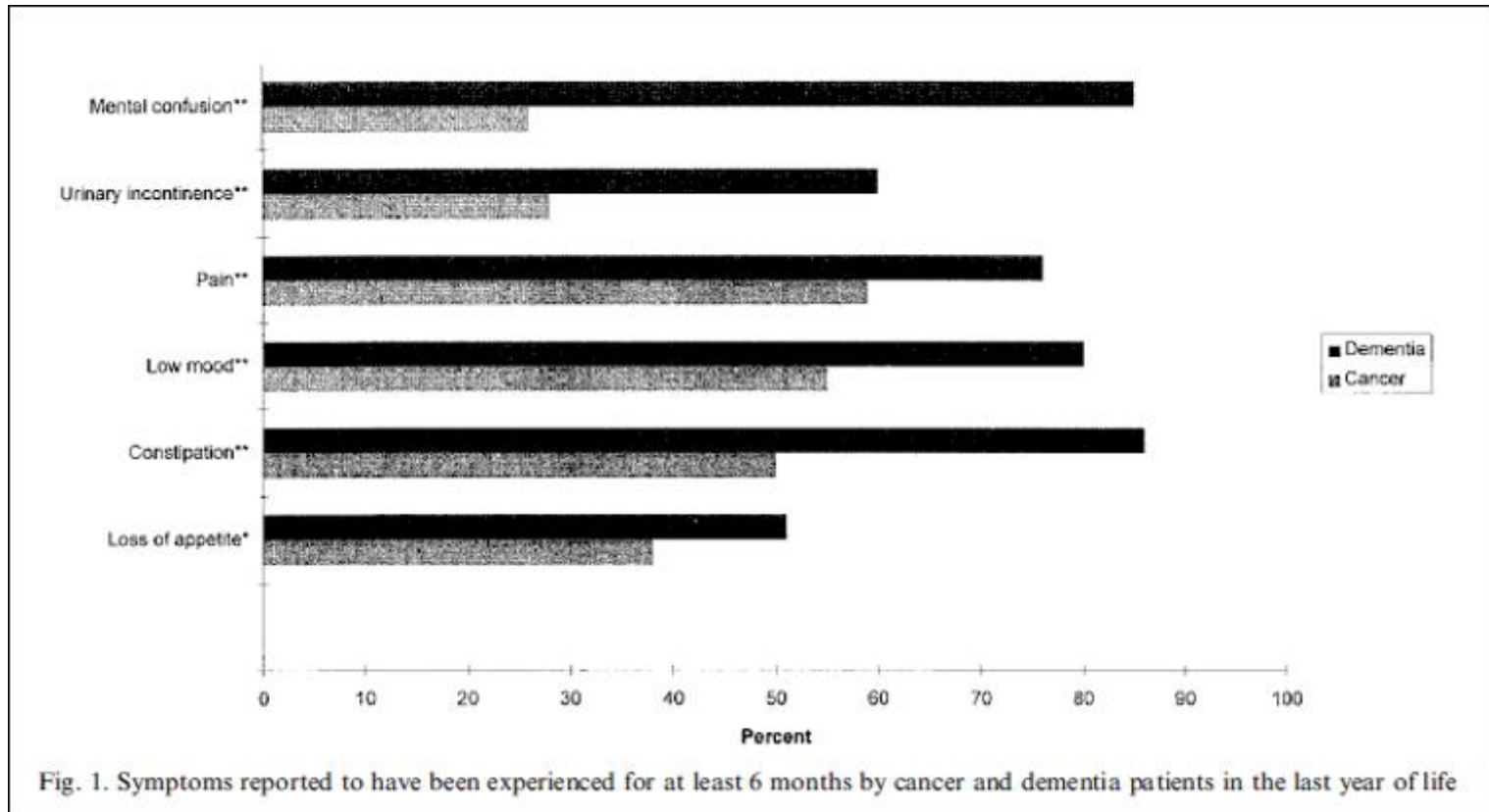
- less visits of family practice
- quality of visit less well
- more need for homecare
- more need for social assistance

The experience of dying with dementia: a retrospective study.

Int J Geriatr Psychiatry. 2010 Mar;12(3):404-9.

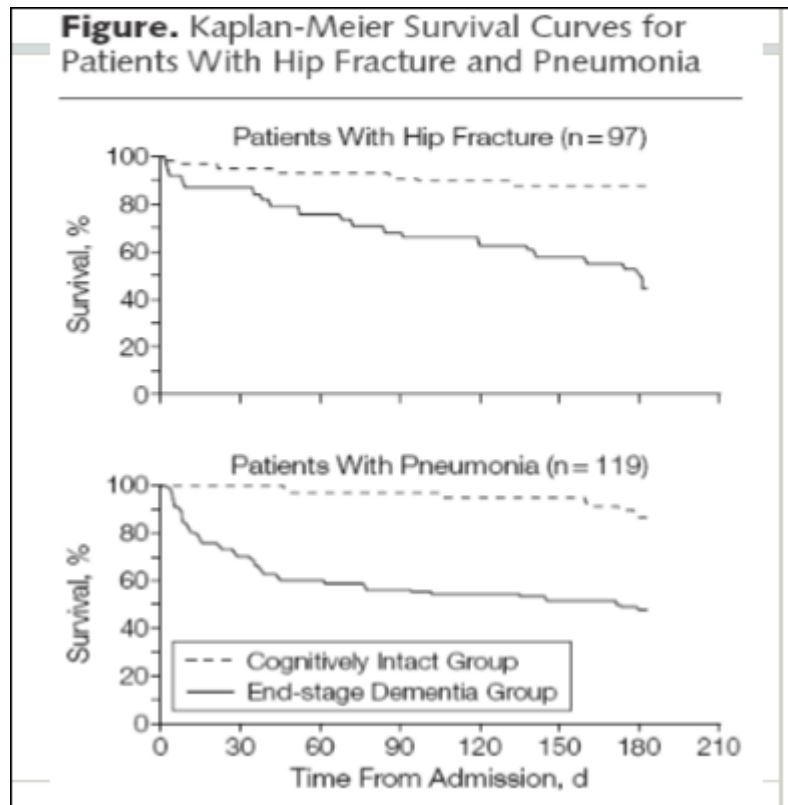


Symptoms in last year of life cancer / dementia



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 prolonges 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.

Johnson A, Chang E, Daly J et al (2009) The communication challenges faced in adopting a palliative care approach in advanced dementia. *International Journal of Nursing Practice*. 15, 1, 467-474.



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!

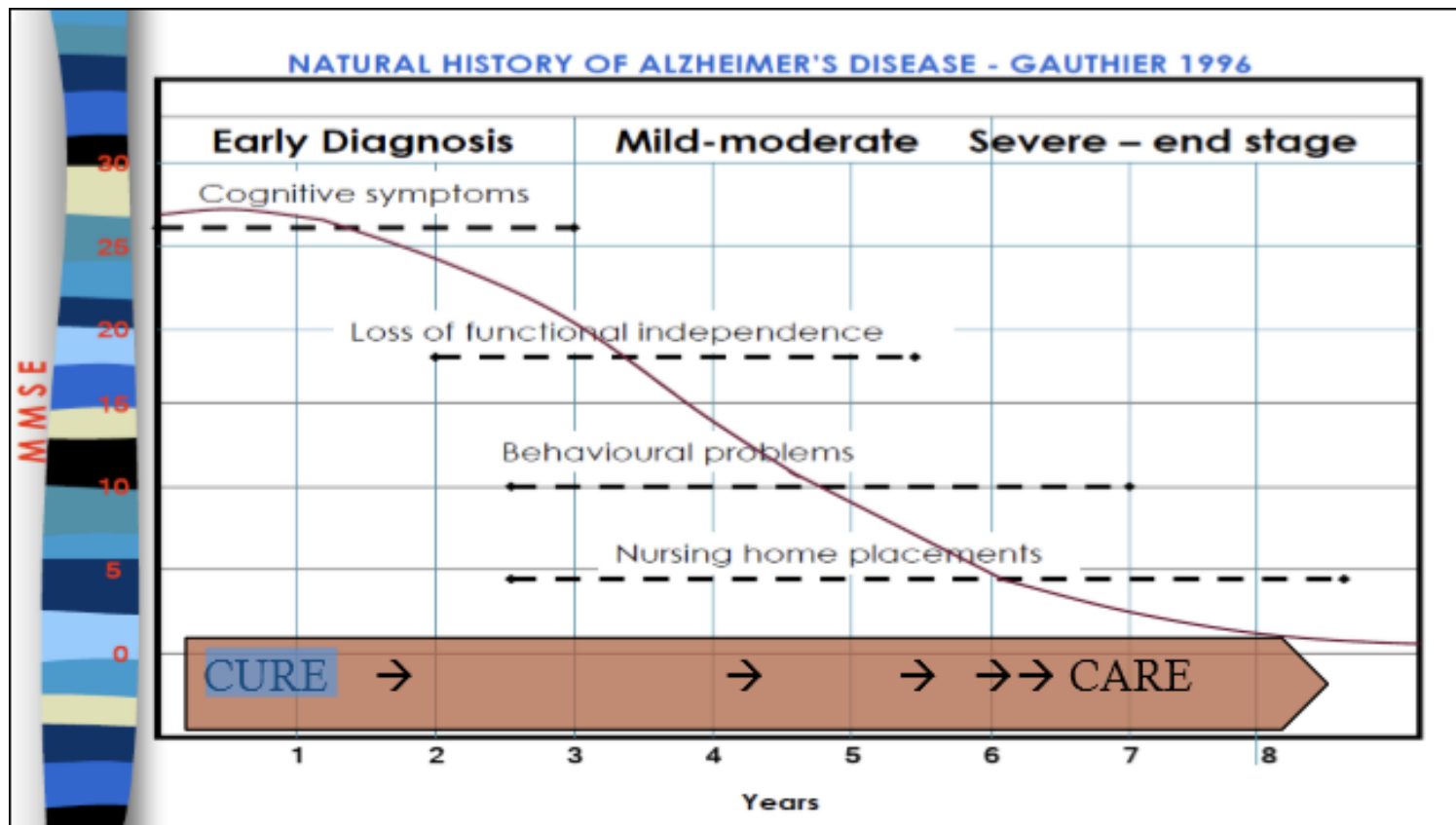
When start with fully palliative care?

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

Importance of ACP as soon as possible after diagnosis!

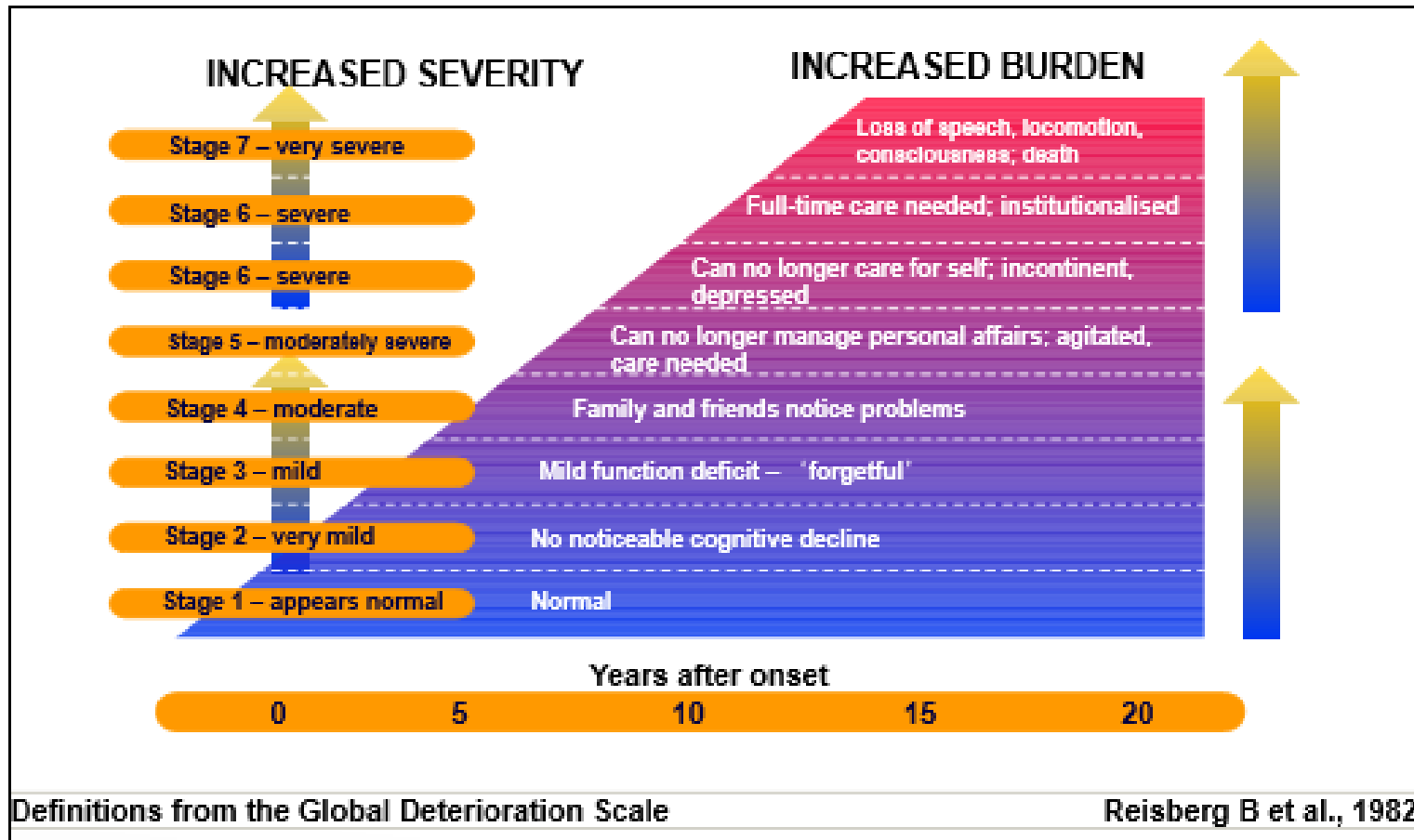
Important : *all concerned are in agreement!*

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



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



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)

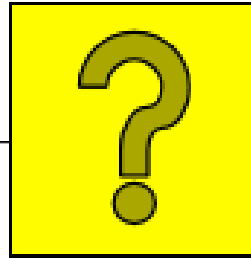


GDS 7c-f

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...

Guidelines for prognosis in chronic diseases – National Hospice Organization – Clin Geriatr Med 2000; 878



Palliative Performance Scale (PPSv2) version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity <i>with</i> Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	3 months	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%		Round	Unable to do any activity Extensive disease	Total Care	Normal or reduced
20%	1 month	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	1 week	-	-	-	-

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the flasher

➤ Surprise question

You wouldn't be surprised if that person will dy 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

...

➤ PPS schaal : evolution to 40-30%

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'...

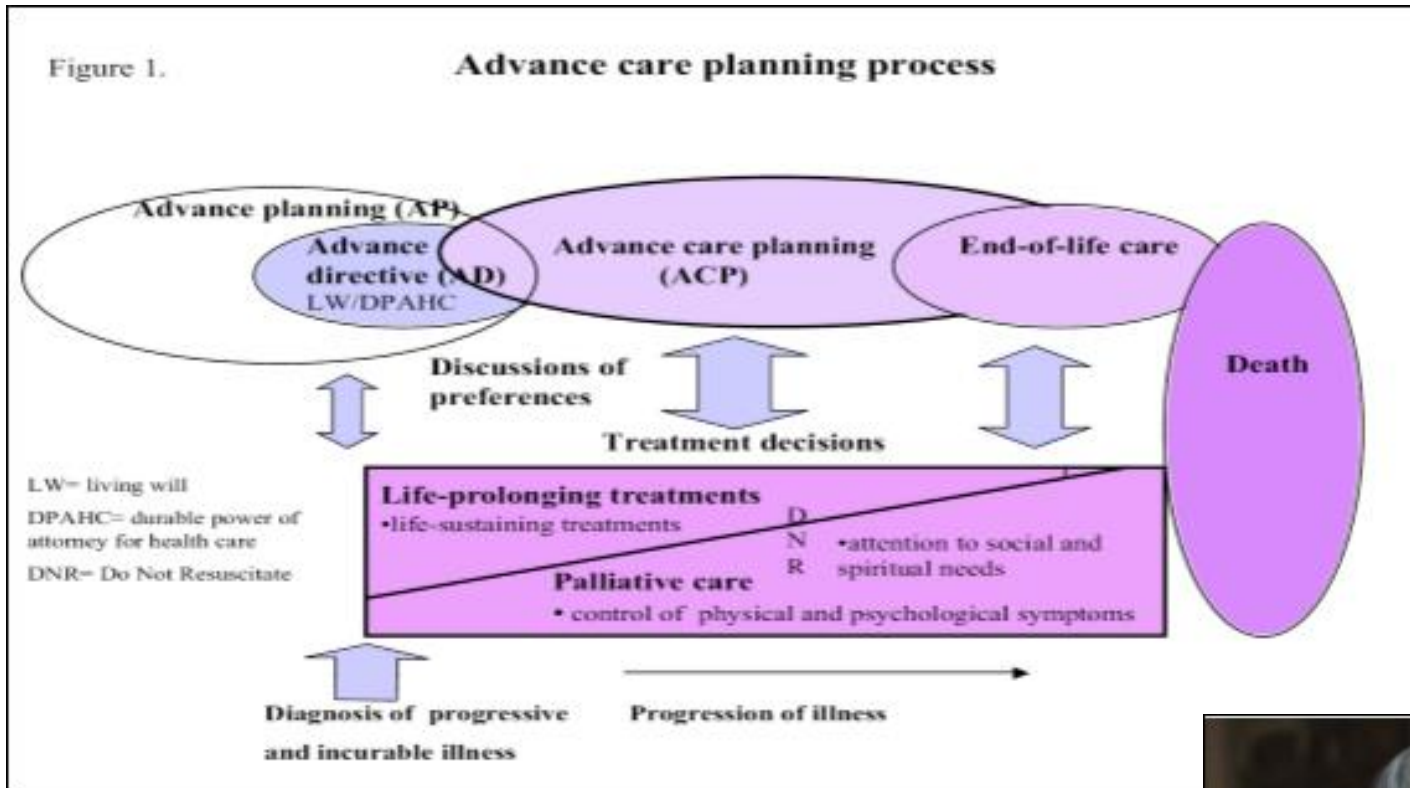
Better too early than too late!

In Belgium : 3 stages of palliative statute

The importance of Advance Care Planning : Do.... !!

(DNR = do not...)

transfer of information = very important!



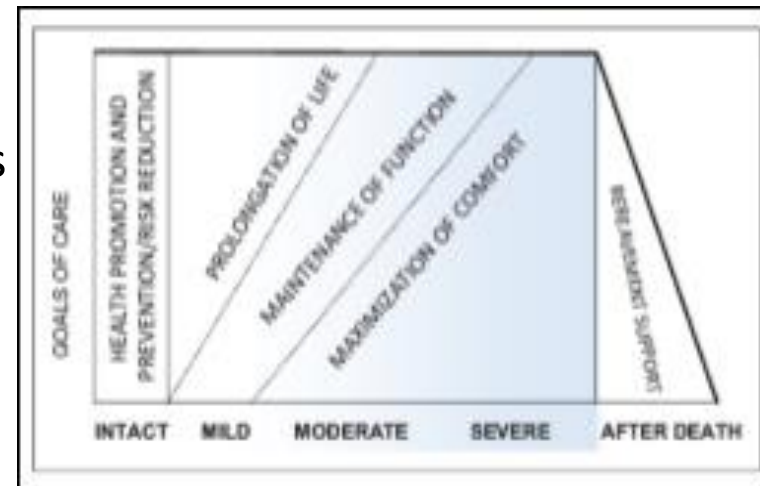
Shared decision making!



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

Corbett, a. et al. Assessment and treatment of pain in people with dementia NAT. Rev. Neurol. 8, 264-274 (2012).

- prevalence rises to 80% increase in dementia (WZC)
- growing evidence of inadequate treatment

Achterberg, w. p. et al. Pain management in patients with dementia. Clin. Interv. Aging 8, 1471-1482 (2013).

Interesting research...

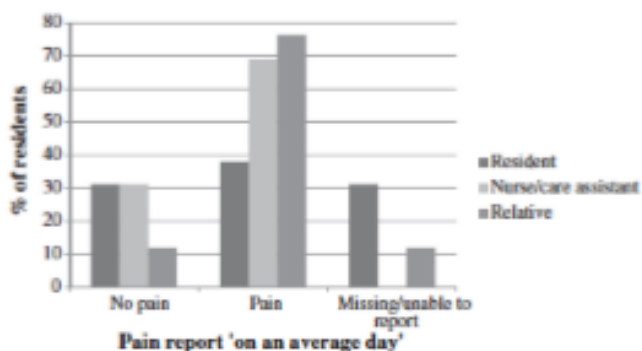


Figure 2 Comparison of pain reports provided by residents, nurses/ care assistants and relatives, using the verbal descriptor scale.

Int J Geriatr Psychiatry 2015; 30: 55-63

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

niet-dementerend dementerend

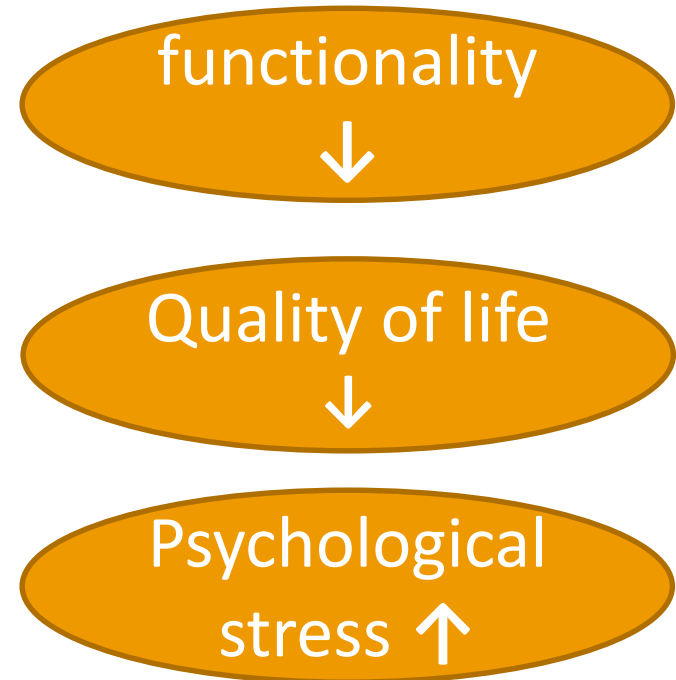
	95	38
N		
pijnschaal	0 tot 4	niet te testen
N = 4	40%	niet te testen
Opiaten	100	33
Routine analgesie	17%	24%

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



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
- ...



Diagnosis

2. *self reporting*

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

McCaffery, M., Beebe, A., 1989. Pain : clinical manual for nursing practice

- 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

....



Diagnosis

3. Observations

use of observation scales



BMC Geriatr. 2010; 6: 3. Pain in elderly people with severe dementia: A systematic review of behavioural pain assessment tools Sandra MG Zwakhalen, Jan PH Hamers, Huda Huijer Abu-Saad and Martijn PF Berger

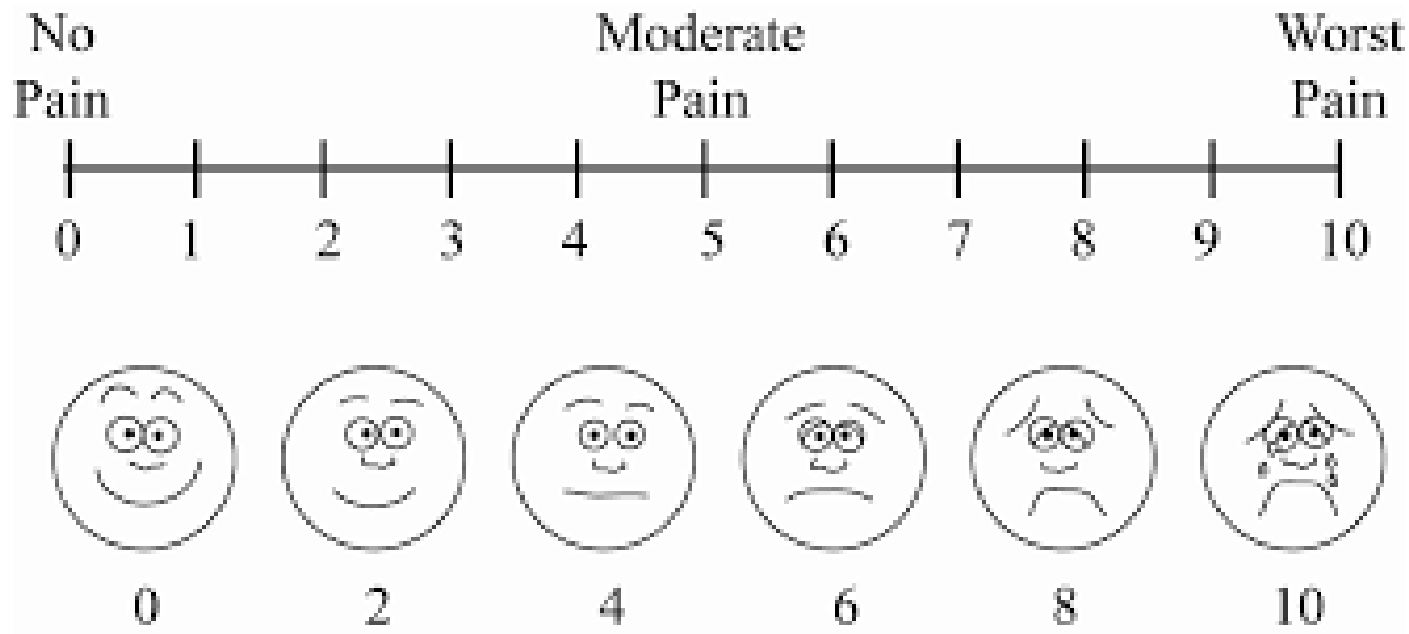
Results

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

Fuchs-Lacelle, S. & Hadjistavropoulos, T. (2004). Development and preliminary validation of the pain assessment checklist for seniors with limited ability to communicate (PACSLAC). *Pain Management Nursing*, 5(1), 37-49.

Facial Expression	Present	Activity/Body Movement	Present	Social/Personality/Mood	Present
Grimacing		Fidgeting		Physical Aggression (e.g. pushing people and/or objects, scratching others, hitting others, striking, kicking). Verbal Aggression Not Wanting to be Touched Not Allowing People Near Angry/Mad Throwing Things Increased Confusion Anxious Upset Agitated Cranky/Irritable Frustrated	
Sad look		Pulling Away			
Tighter Face		Flinching			
Dirty Look		Restless			
Change in Eyes (Squinting, dull, bright, increased eye movements)		Pacing			
Frowning		Wandering			
Pain Expression		Trying to Leave			
Grim Face		Refusing to Move			
Clenching Teeth		Thrashing			
Wincing		Decreased Activity			
Open Mouth		Refusing Medications			
Creasing Forehead		Moving Slow			
Screwing Up Nose		Impulsive Behaviours (Repeat Movements)			
		Uncooperative/Resistance to care			
		Guarding Sore Area			
		Touching/Holding Sore Area			
		Limping			
		Clenching Fist			
		Going into Fetal Position			
		Stiff/Rigid			
Other (Physiological changes/Eating Sleeping Changes/Vocal Behaviors)	Present	Changes in Appetite (Please circle 1 or 2)			
Pale Face		1) Decreased Appetite -----			
Flushed, Red Face		2) Increased Appetite			
Teary Eyed		Screaming/Yelling			
Sweating		Calling Out (i.e. for help)			
Shaking/Trembling		Crying			
Cold Clammy		A Specific Sound of Vocalization For pain "ow," "ouch"			
Changes in Sleep Routine (Please circle 1 or 2)		Moaning and groaning			
1) Decreased Sleep -----		Mumbling			
2) Increased Sleep During the Day		Grunting			
		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)

Behavior	0	1	2	Score
Breathing Independent of vocalization	<ul style="list-style-type: none"> Normal 	<ul style="list-style-type: none"> Occasional labored breathing Short period of hyperventilation 	<ul style="list-style-type: none"> Noisy labored breathing Long period of hyperventilation Cheyne-Stokes respirations 	
Negative vocalization	<ul style="list-style-type: none"> None 	<ul style="list-style-type: none"> Occasional moan or groan Low-level speech with a negative or disapproving quality 	<ul style="list-style-type: none"> Repeated troubled calling out Loud moaning or groaning Crying 	
Facial expression	<ul style="list-style-type: none"> Smiling or inexpressive 	<ul style="list-style-type: none"> Sad Frightened Frown 	<ul style="list-style-type: none"> Facial grimacing 	
Body language	<ul style="list-style-type: none"> Relaxed 	<ul style="list-style-type: none"> Tense Distressed pacing Fidgeting 	<ul style="list-style-type: none"> Rigid Fists clenched Knees pulled up Pulling or pushing away Striking out 	
Consolability	<ul style="list-style-type: none"> No need to console 	<ul style="list-style-type: none"> Distracted or reassured by voice or touch 	<ul style="list-style-type: none"> Unable to console, distract, or reassure 	
TOTAL SCORE				


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**



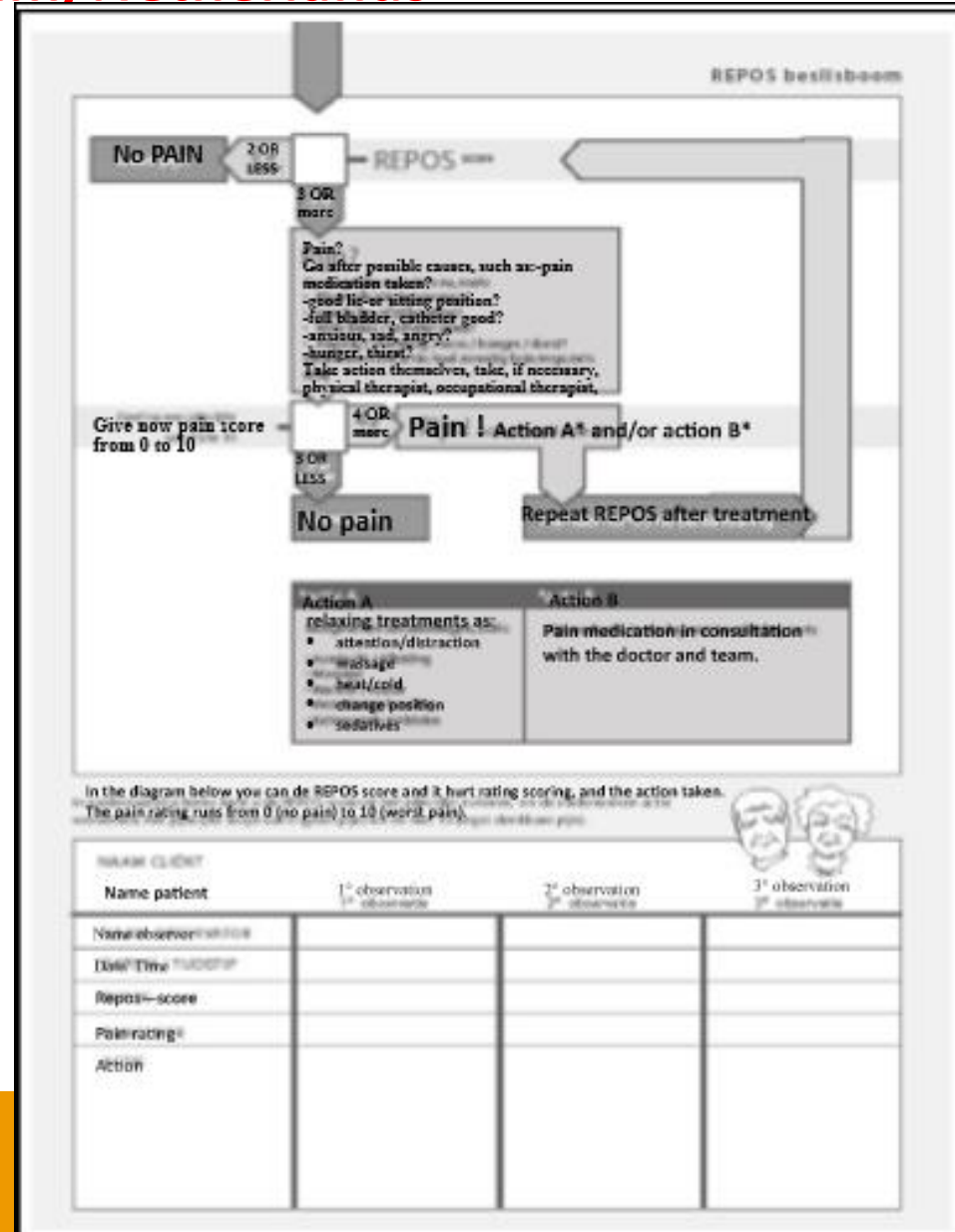
Rotterdam Elderly Pain Observation Scale (REPOS)
 First 2 minutes observing and then tick as behavior was present during the observation.
 Count then all the behaviors for the ticked REPOS total score.



NAME CLIENT Name patient	1 st observation 1 st observe	2 nd observation 2 nd observe	3 rd observation 3 rd observe
Name observer			
Date/ Time			
Situation (fall, running, wound care, rest, physiotherapy ...)			
Pain medication (?, dose, last gift)			
tense face Gezopenen gezicht	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
eyes (almost) Ogen (bijna) afkeuringen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
pull up upper lip Opheffen bovenlip	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
grimace Grimas	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
anxious look	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
move body part	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
panicky, panic reaction Paniekachtig, paniekaanval	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
moaning, whining	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
unrest sounds, verbal expression Onrustgekluisden / verbaal uitingen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
involve breath, faltering respiration	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
REPOS TOTAL SCORE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

REPOS® versie 1.2. Van Nieuw, Beelding, Wet. Pijk, Erasmus MC 2008

REPOS corresponding decision tree – Training by E-learning in Belgium/Netherlands

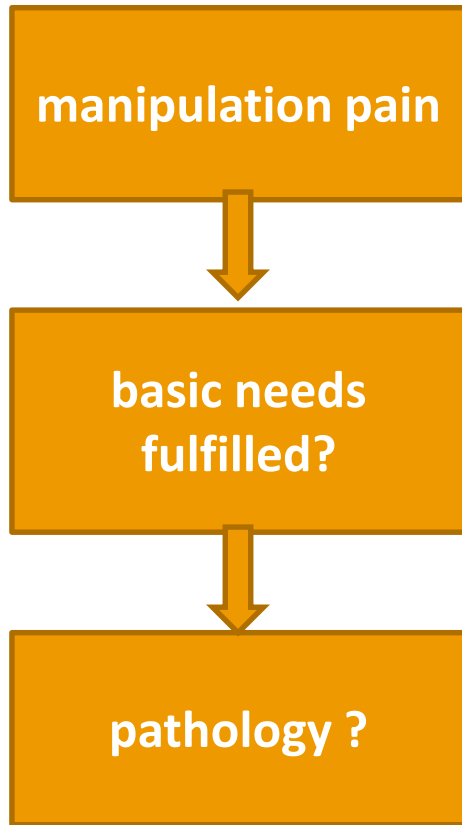


Tips: using a pain scale for dementia patients

- 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



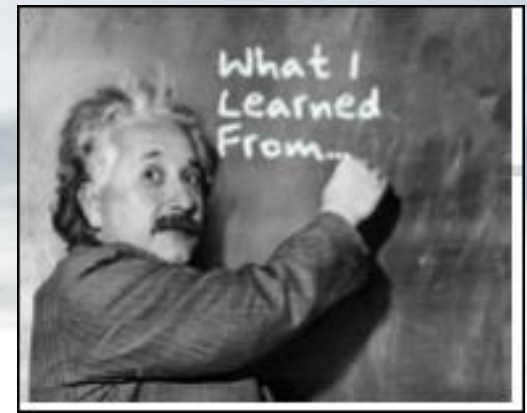
Yes: premedication, anti-anxiety approach
No: = spontaneous pain behavior

No: R/comfort care

Yes: R/causal treatment
No: R/empirical trial!

TAKE HOME MESSAGES!

- dementia is deadly
- people with dementia **have** palliative needs
- palliative stage is not recognized or too late
- pain is undertreated
- nursing team must organize themselves not to miss palliative phase!



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)
- **Music therapy** for dementia. The effects of music therapy in reducing behavioural problems in elderly people with dementia.(Erkelens H., 2013)
- 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 time. 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...

<http://www.upworthy.com/youll-be-amazed-how-just-a-song-could-break-through-to-this-woman-with-alzheimers>

Thank you for your attention!

