Palliative Care in Dementia

Nordic Specialist Course in Palliative Medicine
26th of April 2017
Stockholms Sjukhem, Stockholm, Sweden

Johan Sundelöf, MD, PhD
Nordic Specialist Course in Palliative Medicine
Senior Physician, Project Manager of Betaniastiftelsen
Johan.sundelof@betaniastiftelsen.nu
www.palliationsakademin.se

What if there was a toolbox for palliative care in dementia?

Yeah, toolbox would be great!

Congratulations, there is a toolbox!!!!!

So, expectations?

What would you like to know?

What would you expect to find in the toolbox?

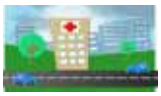
The toolbox for palliative care in dementia

KNOWLEDGE

ADVANCED CARE PLANNING

Behavioural and psychiatric symptoms in dementia (BPSD)

ETHICAL ISSUES



PERSON CENTERED CARE

SYMPTOM CONTROL

Knowledge - Epidemiology

Definition of dementia

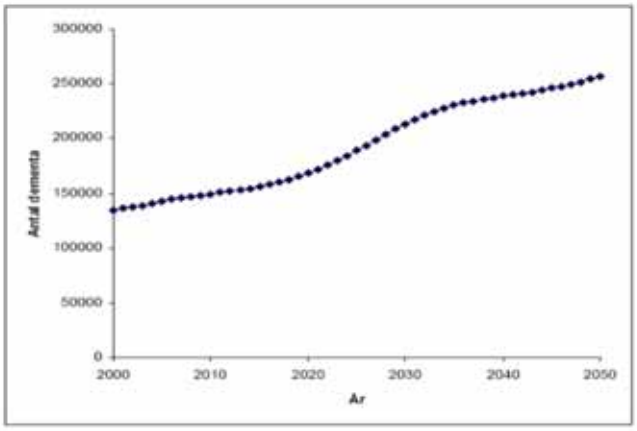
A sustainable (>6 months) cognitive impairment caused by any neurodegenerative disease, severe enough to cause difficulties to manage the daily living

(ICD-10; World Health Organization's 10th International Classification of Diseases
DSM-IV; Diagnostic and Statistical Manual of Mental Disorders IV)

Alzheimer´s disease most common cause of dementia

- Alzheimer´s disease 60%
- Vascular dementia 25%
- Lewy body dementia 10%
- Frontotemporal dementia 5%

The number of persons with dementia increases in Sweden



Figur 2. Prognos för antalet demenita 2000–2050.

(SBU 2005)

Dementia increases in the world

- **Rare before age 60**
- **1% prevalence at age 65 year**
- **Prevalence doubles every 5 year**

Sweden:
2005: 140 000
2050: 250 000

Denmark	Norway	Finland	Iceland
2011: 85 000	66 000	95000	4000
2050: 150 000	135 000	160 000	9000

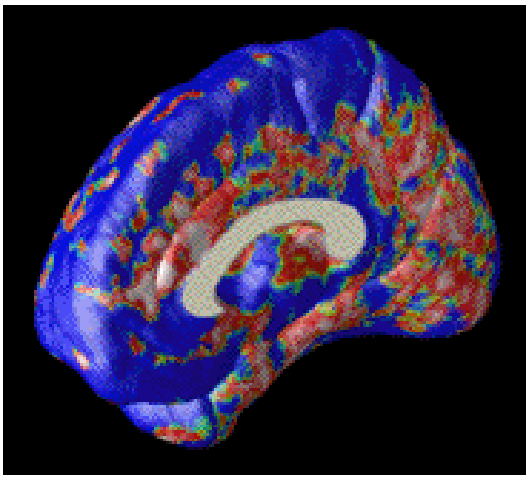
Worldwide:
2005: 24 millions
2040: 80 millions

(Socialstyrelsen 2005)
(Ferri et al, Lancet, 2005)

Dementia is the most expensive disease group

- Dementia 63 billion SEK/yr
- Hjärt-kärlsjukdomar 61 billion SEK/yr
- Cancer ca 37 billion SEK/yr
- 78% of costs in the county

Neurodegeneration in Alzheimer patient´s brain



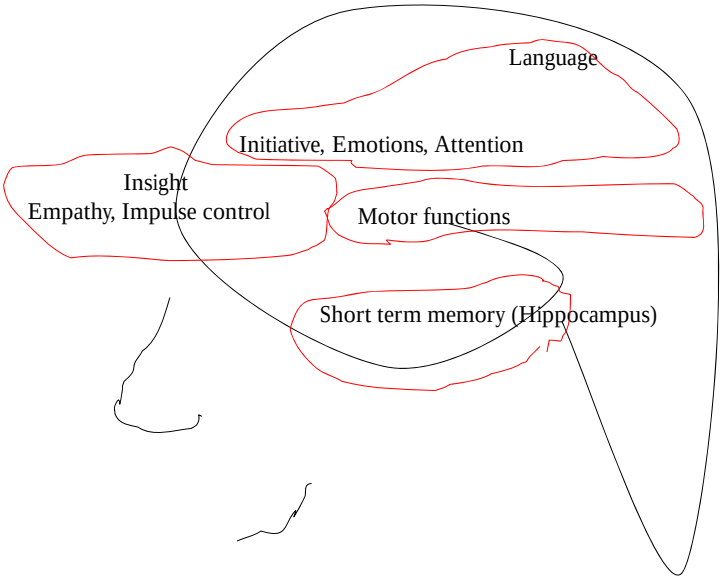
Thomson et al., J. Neurol. Science, January, 2011

What increases the risk to develop dementia?

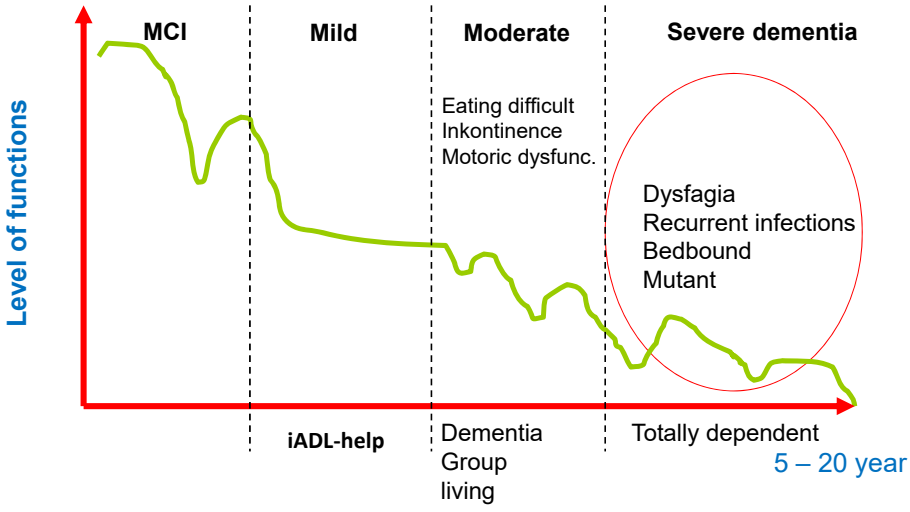
Risk factors

Dementia in general	Alzheimer
High age	High age
Diabetes	Genetic changes
Hypertension	APOE ε4 gene
Hyperlipidemia	Female gender
Obesitas	Head trauma
Smoking	

Symptoms depend on where neurodegeneration is located



Knowledge of the disease course is the key for consensus about the goals of care



Dementia will lead to death

Summary

- Dementia not one disease - defines severity of cognitive impairment
- Several diseases lead to dementia
- Dementia will lead to death – symptomatic treatment
- Disease course 4 phases
- Cardinal signs of end stage dementia

BPSD

Behavioural and psyciatric disturbances in dementia (BPSD)

a. Behavioural disturbances (=main problem for surrounding)
- Aggressions
- Irritability
- Obstruction
- Screaming
- Restlessness
- Walking
- Sleeping disturbances
- Inactivity

b. PSYCOTIC SYMPTOMS (=main problem for patient)
- Depression
- Anxiety
- Rigidity

Neurodegeneration in crucial areas causes BPSD

Lack of perception ability

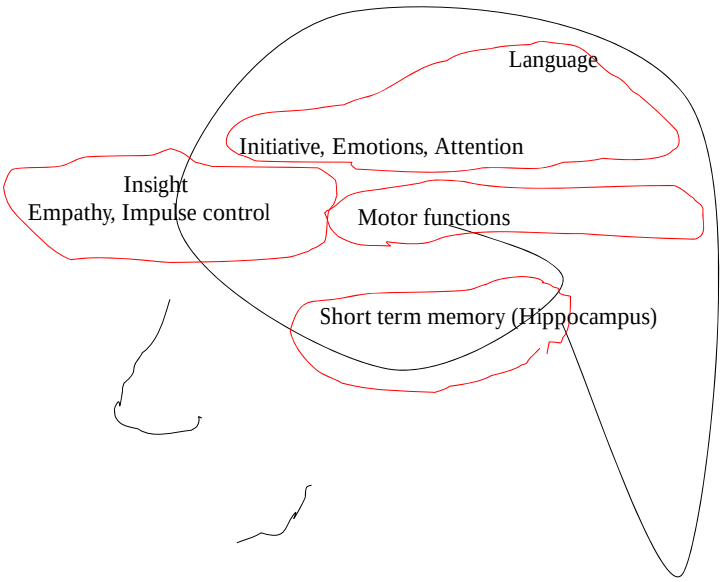
Lack of ability to interpret perceptions

Lack of emotional control

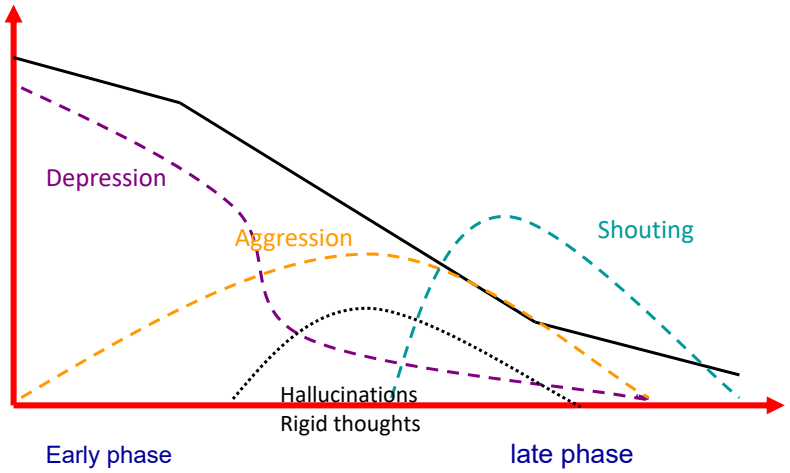
Lack of impulse control

Lack of insight

Symptoms depend on where neurodegeneration is located



BPSD over time in Alzheimer´s disease



Communication difficulties causes BPSD

External stimuli, symptom or care plan (dressing, bathing, go to bed)

↓

Staff try to help

↓

Patient misperception situation (because of neurodegeneration cortex)

↓

Patient misunderstands situation – danger?

↓

Lack of ability to adjust resistence (amygdala+frontal cortex)

↓

Strong resistence is interpreted by staff as aggression

Desire for drugs against aggression at the medical round

Symptom assessment of BPSD

1. What symptoms are observed?
   - BPSD and other symptoms
2. When did it start?
3. What caused the symptoms to occur?
4. Variations througout the day (surroundings, milieu, staff approach)?
   When calm? When BPSD?
5. Previous medical history?
6. Medical examination, somatic and psychiatric status
   examine whole body; mouth, abdomen, articular examination, feet
7. Basic human needs addressed, physical and existential needs?
   human contact, activity, nutrition, elimination, sleep
8. Inventory of drugs? Adequate pain control?
9. Interpretation of the situation
10. Action depends on the cause
11. Evaluation
12. Don´t treat difficulties in communication with drugs!!!

Treatment of BPSD?
What drugs and what are the doses?

The doses are non-pharmacological treatment

Haloperidol

- 3 studies
- Some effect on aggression in doses >1,5mg/day
- Insufficient data for effect with doses below 1,5mg/day
- Marked extrapyramidal side effects
- No studies on dementia
- **Not recommended in dementia**

Risperidone

- 6 studies - 30-60% improvement - difference vs placebo non significant!
- One study; Risperidone 1,2mg/dag effect on psycotic symptom in severe dementia but small effect compared with placebo
- ≥MMSE 13-15p, no difference between Risperidone vs placebo
- Side effects
- previous indication: unspecific states of anxiety/aggression in dementia
- Changed indication after metaanalys 2004 increased risk of intracerebral lesions (stroke eller TIA) in patients with Risperidone treatment
- **Current indication: Severe psychotic symptoms like aggressions in persons with dementia for whom such symptoms may lead to suffering, danger for the patient or risk of selfdestructive acts**

Bensodiazepines

- One study on Temesta:
  - more effective than placebo
  - remarkable risk of falling, impaired cognition och paradoxal reactions
- Clinical experience:
  - short acting BDZ like Sobril (Oxazepam) may be tested for anxiety
- No evidence of effect in long term use
- Risk of side effects, addiction or side effects after stopping medication
- Think ”In and out dates”, in similarity with antibiotic treatment

Hemineurin (Klometiazol)

- Accepted for sleeping disturbances and agitation in elderly
- No studies on persons with dementia
- Side effects
- Clinical experience:
  In hospitals and under careful observation Hemineuvrin may be used in acute situations

Pharmacological treatment BPSD

1. **SSRI:s.** Citalopram, lowest effective dose. Start with 10mg, if effect stop, increase if needed. If no effect of 20mg, reconsider indication.
2. **SSRI no/moderate effect**; try addition of or change to **Remeron, or Mianserin**.
3. **Sobril (Oxazepam)** in lowest possible dose if **unspecific anxiety**, start with test dose 5mg, then 5mg x 2, 5mg x 3, 10mg x 2. Reconsider indication. No evidence for long term use!
4. **Neuroleptics, Risperidone**, 0.5-1.5mg/24h divided into 2 doses.
   Restrictive use. Second line treatment. Hallucinations, compulsions, or unsatisfying effect of SSRI on aggressions and behavioural disorders. Recurrent reconsideration!
5. **Ebixa** can be tested on BPSD as well, start with 5 mg, increase dose slow, like initiation procedure, halt increase if effect.
6. **Aricept** can be tested against *optic hallucinations*.
7. S**leeping disorder** if **non-pharmacological treatment** insufficient; 1. **Zopiklon 5**-**7.5mg**, second **Heminevrin 300mg** (short duration).

”First aid meeting persons with dementia”

- " Show **patience and tolerance**. Wait up (1-2 minutes if necessary) and have tolerance when the dementia sufferer makes it a little mad sometimes .
- **Confirm feelings**.
- **Pass away attention** from what worries or arouses anger.
- **Delay** if wants to leave the ward or do something inappropriate.
- **Return later** if the person does not want or ask someone else to take over.
- **Do not argue**
- **Tell what to do step by step**. Don´t tell what not to do but instead step by step what to do .
- Use the " intuition " . How may the person react?
- Imagination, creativity, empathy

(M. Skoog, Silviahemmet)

Summary BPSD

- Correlates to neuroanatomical changes
- Miscommunication common reason
- Pharmacological treatment no/little effect vs placebo
- Non-pharmacological treatment 1:st choice
- Pharmacological treatment, in&outdate, reconsider indication!
- Don´t treat miscommunication with drugs!!

Person-centered care

Person-centered care (cont)

The difference between high quality and less successful palliative care

Why?

Gustaf

Gustaf is suffering from dementia. It is morning. The care giver enters the room och Gustaf recently woke up.

What should we do first?

What is most important?

Strategy, plans and decisions define what the day will be like for Gustaf.

Person-centered care

- Many tasks
- Morning routines
- Toilet routines
- Adult diapers – change
- Washing
- Dressing
- Medications
- Breakfast

Person-centered care works best

- Task-centered care
- Research and clinical experience:
  - person-centered care works better in dementia

Person-centered care

- How plan this day according to mood&temper?
- Respect the situation today
- Adjust plans
- Not ”a to do list” or ”objects” to handle

Person-centered care

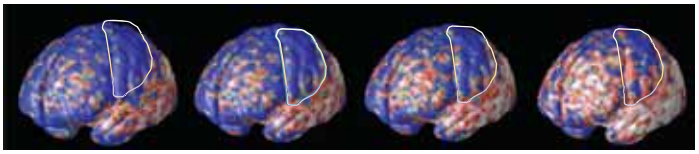
- Personal needs decide
- Needs not diagnosis in focus
- Goal - a meaningful comfortable situation

Examples

- Ebba needs a shower
- Ebba wants to leave the ward
- Gustaf is not in the mood today

Impression centres works - bypass neurodegeneration

art, music, make persons feel good



MCI Mild dementia Severe dementia End-stage dementia

Person-centered care (cont)

The difference between high quality and less successful palliative care

Symptom control

- Symptom prevention
- Symptom assessment
- Symptom treatment

Symptom prevention

- **Common complications**
  - obstipation
  - urinary retention/incontinence
  - cronical illnesses
  - infections
  - aspiration
  - falling – risk for fractures
  - polypharmaci
- **Fiber rich meals** – prevent obstipation
- **Frequent position changes** – prevent pressure ulcers and pneumonia
- **Ambitious mouth care** – prevent swallowing difficulties
- **Prevention of falling**
- **Review of pharmacological treatment**
- **Rescue doses** for pain, nausea, anxiety and secret stagnation

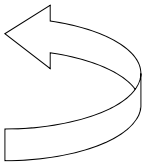
Symptom assessment

- Lack of optimal assessment tools (**Abbey Pain Scale** for pain is ok)
- **Changed behaviour** (body language) may indicate bad symptom control
- Identify the cause of changed behaviour or BPSD
- **Signs of pain? Body language?**
- **Earlier pathology?** – medical record!
- **Examine the patient**!

  mouth, abdomen, articular examination, feet
- **Exclude:** obstipation, urinary retention, fracture, infection
- **Liberal use of analgetics**
- **Evaluate**

Symptom assessment – teamwork

- Medical journal
- Family, relatives, staff
- Abbey Pain Scale
- Documentation
- Interpretation
- Treatment - plan
- Evaluation



Symptom control in end stage dementia

- Optimize enviroment
- Pain control
- Mouth care
- Prevent pressure ulcers
- Plan for miction/defecation

Symptom control in end stage dementia

- Rescue doses prescribed for pain, nausea, anxiety and secret stagnation – no difference
- Advanced care planning
- Documentation updated

Dementia– palliative philosophy is the solution

- Symptom control
- Team work
- Support of relatives
- Communication

ETHICAL ISSUES

Kasper is a 86 year old gentlemen suffering from Alzheimer´s disease, living in a dementia group living. His two sons want to talk to you and make sure that you will; rescusitate if Kasper´s heart stops, refer Kasper to hospital if he gets an infection, they would also like to ask you to put in a nasogastric tube because of his swallowing difficulties. What would you say to the sons?

ETHICAL ISSUES

- Cardiopulmonary resuscitation
- Hospital referral
- Nutrition
- Antibiotics

CPR in dementia

- Dementia in group living: less than 1% survival
- Applebaum et al; 115 persons with heart arrests; 102 dead at arrival to hospital, 13 died in hospital first 24h, dementia worse diagnosis
- Complications; fractures, sequele, cognitive impairment
- 41% of relatives positive in dementia group livings

  5% positive after information of bad prognosis in dementia
  (Murphy et al NEJM, 1994)

Referral to Hospital- evidence

- 18,7% mortality (6 week) in group livings
  39.5% mortality if referred to hospital
  Comparable groups
  (Thompson et al 1997)
- Confusion, falls, eating refusal, incontinence
- Psychometrics, restrictions, nasogastric tubes, urinary catheter
- Complication risk high
- Prolonged time in hospital
- Worse functional status 2 months after hospital admittance

Antibiotic treatment

- Motivated in isolated infections
- ★ Oral treatment equally effective compared to intravenous administration
- Patients - why needles? Why blood samples? Restrictions? Psykotropics?
- ★ No effect on survival time in severe dementia
  (Luchins et al 1997)
- Analgetics och Antipyretics effective for symptom control
- Complication risks – GI side effects, allergies, clostridium difficile infections
- ★ Recurrent infections limit the effect on survuval time
- ★ Which infection is ”ok” to be the last?

Nutrition

- **Severe dementia – cannot eat themselves, difficulties to swallow**
- **Refusal to eat is common**
- **Adjust consistence of food**

- **Eating refusal – symptom control, anti-depressants eller apetite stimulants**
  (Morris et al 2000)

- **Nasogastric tube does not affect survival**
  (Gillick et al NEJM 2000)(ESPEN guidelines)

- **Nasogastric tube does not prevent aspiration pneumonia**
- Risk of complications
- Risk of infections
- Inconventient
- Restrictions necessary?
- Mortality associated with PEG
- Malnutrition vs kakexi – malnutrition/hunger/reversible,
  cachexia/no hunger/irreversible

Clinical Nutrition

ESPEN Guideline

ESPEN guidelines on nutrition in dementia

Dorothee Volkert [a, *], Michael Chourdakis [b], Gerd Faxen-Irving [c], Thomas Frühwald [d], Francesco Landi [e], Merja H. Suominen [f], Maarits Vandewoude [g], Rainer Wirth [a, h], Stéphane M. Schneider [i]

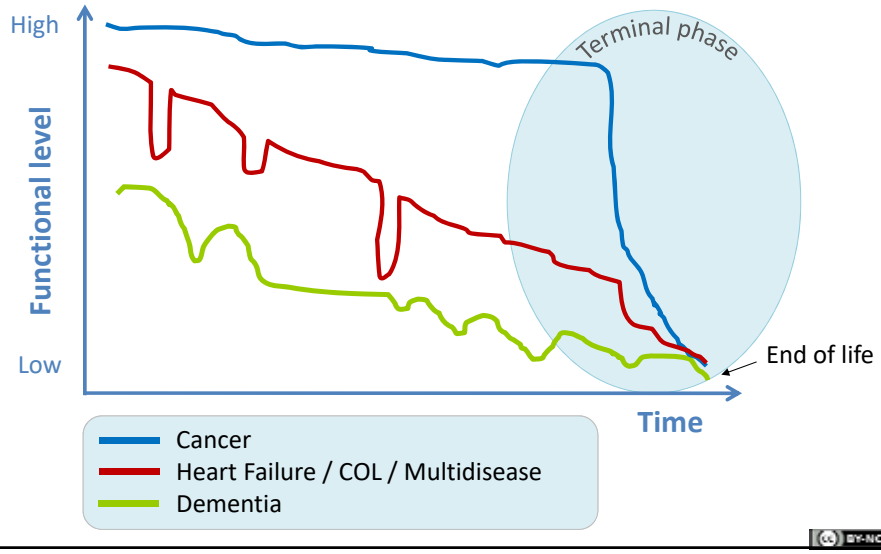
Conclusion: Nutritional care and support should be an integral part of dementia management. In all stages of the disease, the decision for or against nutritional interventions should be made on an individual basis after carefully balancing expected benefit and potential burden, taking the (assumed) patient will and general prognosis into account.

ESPEN GUIDELINES OM NUTRITION

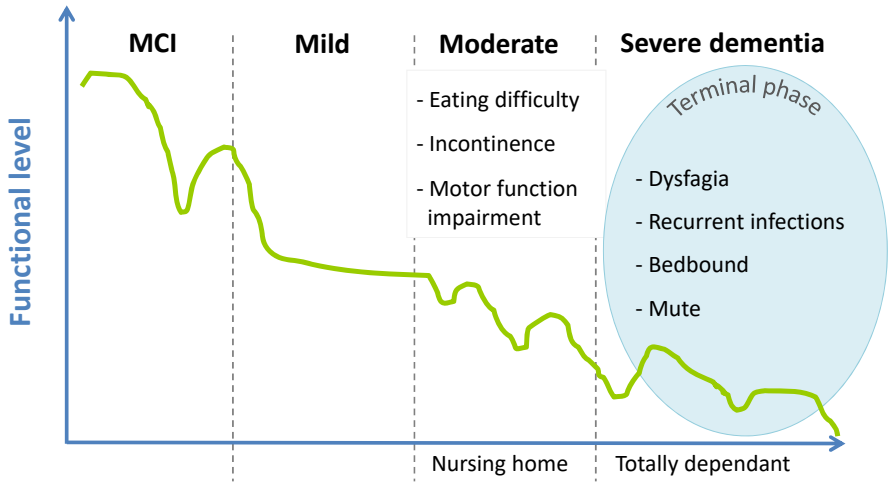
- Optimize nutrition along disease course
- Individual plan
- Reflection and plan based on pros&cons
- Nasogastric tube not indicated in palliative care of persons with dementia

Advance care planning

What can we expect?



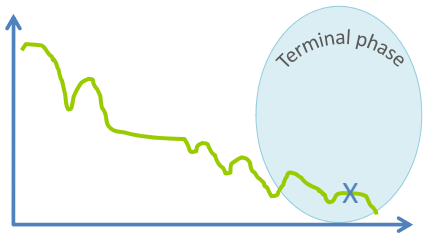
Knowledge of the disease course is the key for consensus about the goals of care



Advance planning is the key - goals of care

Ethical issues:

- Cardiopulmonary resuscitation?
- Antibiotics?
- External nutritional support?
- Hospital referral?
- Worries?
- Preferences? What matters?



”Sundelöf´s Checklist for dialogue with relatives”

- Describe disease course within 1 month after referral to dementia group living
- Describe in advance the “signs” of end stage dementia
- Mark in what phase of the disease the patient is
- Talk about external nutrition/fluids in terminally ill patients
  – risk of nausea and fluid retention
- Describe cachexia vs malnutrition
- Evidence
  Cardiopulmonary rescusitation
  Referral to hospital
  Antibiotics
  External nutritional support
- Common causes of death in dementia – “recurrent infections”
- Post mortem dialogue with relatives 4-6 weeks after death – feed back for free!

European Association of Palliativ Care (EPAC)

White paper – ”State of the art”
Recommendations palliative care in dementia


White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care

Content – EAPC white paper

- Person-centered care
- Plan and establish insights in advance
- Pharmacotherapy
- Symptom relief and assessment
- Psychosocial and existential support
- Support of relatives
- Teamwork
- Social ethical aspects
- Palliative care philosophy the solution

Key messanges EAPC ”white paper”

- Dementia will lead to death – key insight
- Palliative care philosophy natural approach – along disease course – goals change
- Improve and focus on quality of life
- Support functions
- Maximize comfort
- Stay in home settings as long as possible
- Continuity central

Key points (cont)

- Patient´s needs in focus
- Shared decision making – patient and relatives
- Information along disease course
- Respect wishes&priorities
- Consideration of relative´s needs

ETHICS - EAPC

- Restrictions should be avoided
- External fluids:
  - not indicated in end-of life care in dementia
  - Worsen dyspnea
- Nasogastric tube does not prolong life – not indicated
- Early and close dialogue with relatives
- Antibiotics:
  - Sometimes indicated as symptom relief BUT…
  - not always motivated if life prolonging treatment only goal without any concern of QoL or symptom relief.

DEFINE GOALS AND ADVANCE CARE PLANNING

- Define goals of care
- Goals define plans
- Information to patient and relatives
- Avoid referral to hospital
- Arrangement/planning
  - What are the goals?
  - Based on the needs of whom?
- Pros and cons?
- Risks?

EAPC - organisation

- Cooperate palliative and dementia competence
- Adjust resources, organisation, staff enabling high quality palliative care for persons with dementia
- Education important
- Palliative care plan applicable on persons with dementia

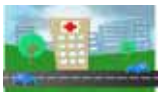
Summary palliative care in dementia

KNOWLEDGE

ADVANCED CARE PLANNING

Behavioural and psychiatric symptoms in dementia (BPSD)

ETHICAL ISSUES



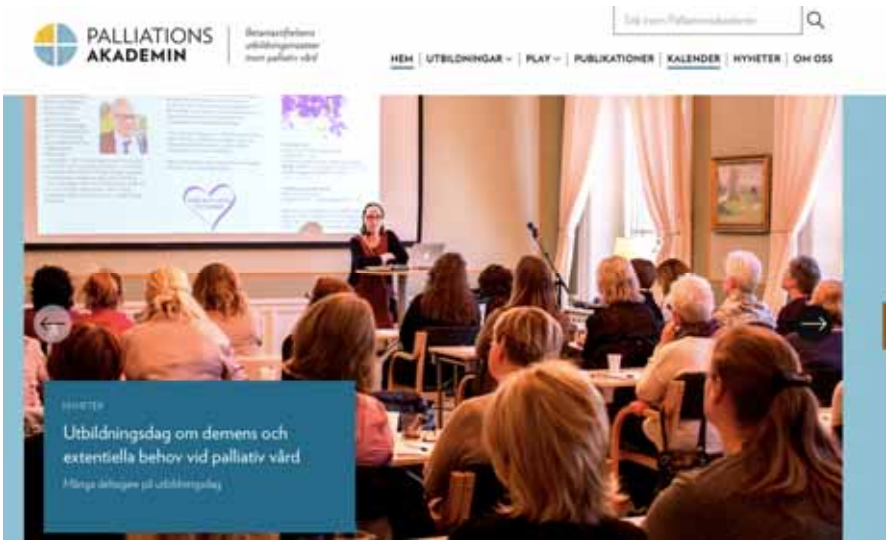
PERSON CENTERED CARE

SYMPTOM CONTROL

Summary

- Dementia will lead to death
- Clinical signs of end stage dementia
- BPSD – non pharmacological treatment
- Symptom assessment and relief
- Person-centered care works best
- Ethics
- Advanced care plan
- EAPC
- ESPEN guidelines

Are you happy?



Palliationsakademins utbildningsinsatser

Palliation ABC (E-utbildning)

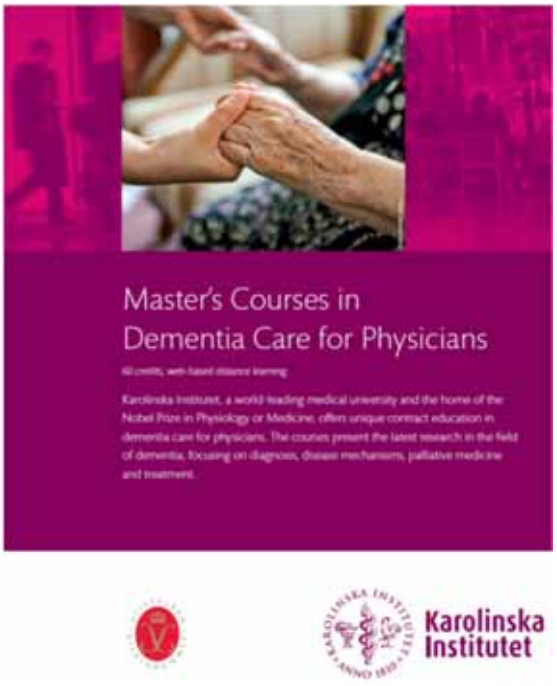
Palliationspraktikan

Palliationplay

Livesändningar

Utbildningsdagar

Palliationspodden



Let´s remember…

”A person who leaves life should recieve just as much attention and loving care, regardless of the diagnosis, as the care given to a person who just entered life,”

Thank you!