

# PALLIATION, TERMINATION

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# 4 important principles

The Appleton Concensus 1988

- Non-maleficence
- Beneficence
- Autonomy
- Justice

# beneficence

- Non-maleficence --- do no harm
- Beneficence ---- do good !
- => if a treatment is of benefit to the patient (in the widest sense) it should be initiated
- => only harmful treatment should be stopped
- => no obligation to continue a non-benefi-cent treatment

# DECISION MAKING

# Typical challenges

- VAI/VDI's choice should be made based on an informed consent (when possible)
- It should in advance be emphasized that treatment can be terminated -- the VDI is not trapped
- Decision on when, and on what conditions the treatment will terminate should be made

# autonomy

The opportunity to make one's own choices and to implement these without interference by others

# Autonomy ↔ dignity

”Dignity has been defined as having a sense of personal worth. The dignity of one person is not absolute, but depends on the way that people behave towards that person....

Finlay 1996

# Autonomi ↔ dignity

“The role of professional carers must be to enhance a person’s sense of dignity at all times”

Finlay 1996

Dementia and impaired cognition  
"So what?"

# Tema: Dømt til autonomi

Doomed to autonomy



# autonomy

- The human factor is instrumentalized
- Life as a permanent state of emergency
- Survival strategies replace a natural presence in life

# Dementia and impaired cognition

A DIFFICULT GREY ZONE with respect to:

- Ethics and moral
- Legal issues
- Psychology
- Practicality/implementation

# What do we do ? - directions ??

- Is it LIFE we prolong or is it the DEATH-PROCESS ??
- If it is the life we prolong, is it a LIFE WITH QUALITY ??

# Initiating and terminating treatment

- Society increasingly focused on the individual and on patient autonomy
- Termination of (ventilator) treatment allowed in Denmark (on patient's request)
- sedation is allowed in conjunction with that
- BUT: no doctor should engage in any action that will lead to a patient's death

# Decision about terminating treatment

## LEGAL FRAME WORK

- Law concerning patients' rights
  - Chapter 2
    - § 6, section 1:
      - no treatment can be initiated or continued without the informed consent of the patient
      - The patient can at any time withdraw the consent
    - § 16: permits palliative treatment
  - National Board of Health has specified the legal frame work

# Termination of treatment

- Termination of treatment is different from euthanasia
- Termination of treatment can occur on demand from the ventilator user, or if incompetent by initiative of others
- Termination of treatment may **not** mean termination of life ---- important to explain clearly to ventilator user



# Pt. with ALS

- 40 yrs. with ALS
- vice-president of local IBM, 80 kg
- April 01:  $SaO_2/PtcCO_2 = 92\%/8$  kPa and  $PaO_2/CO_2 = 11.5/7.2$  kPa,  $FEV_1/FVC = 0.8L$ , dyspnea, secretions, weight loss 30 kg
- April 01: discussion of future trach and termination of treatment. Attendants informed

# Pt. with ALS

BiPAP(<sub>TM</sub>) via full face mask initiated  
(IPAP/EPAP = 10/4  $\Rightarrow$  14/4)  $\Rightarrow$  SaO<sub>2</sub>/PtcCO<sub>2</sub> =  
94.2%/6.5 kPa, and PaO<sub>2</sub>/CO<sub>2</sub> = 14.5/5.8 kPa,  
and improved sleep and daytime function

# Pt. with ALS

- Rapid deterioration
- July 7th: tracheostomy --- conditions for termination of treatment discussed --- Pt: "when I approach inability to communicate I want the treatment terminated !"
- recurrent pneumonias and periods of problems with tracheostomy
- regularly seen at the out-patient clinic

# Pt. with ALS

- Stesolid and morphine injected and pt. is disconnected from ventilator  $\Rightarrow$  death
- follow-up talk with wife a couple of weeks later

# Criteria ?

- No formal criteria, but
- Well prepared and early in the course of the disease
- Almost a requirement before initiating HMMV, and certainly before a state of locked in
- Scenario is repeated and discussed several times
- Try to include family (but not necessarily)

# GOAL OF TERMINATION

- RESPECT VENTILATOR USERS CHOICE
- COMFORT AND EASE
  - THE FINAL PART OF VENTILATOR USERS LIFE
  - THE DEATH PROCESS
- SECURE A TOLERABLE MEMORY FOR THE RELATIVES

# WHAT REALLY HAPPENS ?

## THE STRONGEST DETERMINANT FOR WITHDRAWAL IS

- Physician's impression of patient's desire for life support
- Physician's prediction of likelihood of survival
- Poor cognitive function

Cook, N Engl Med J 2003

# What really happens ?

- Legislation and national guide lines influence decision making
- Less than 40 % participate in end-of-life decision making

Nava, Eur Respir J 2007



# Problems

- Principles are in conflict with each other:
- limited resources put a limit to when 1) beneficence (“.. When a treatment is of any benefit it should be started ..”), and 2) autonomy (“acceptance of patient’s choice”) can be granted