Norwegian Congress of Geriatrics 2005
Ageing and Health

Care for Patients with Chronic Severe Brain Damage

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Content

- Approach to the problem
- Medical issues
- Who decides
- End of life decisions
- Ethical issues
- Conclusions

Approach to the problem

- Definition of chronic severe brain damage
  - Patients with severe brain damage are people in whom brain damage, due to illness or injury, has led to a persistent state of unconsciousness or extreme impairment of consciousness; almost invariably, there is irreversible loss of the ability to communicate. In such patients, a return to consciousness or the ability to express free will cannot be expected
  - patients have largely lost their autonomy and are dependent on others.
  - Other people have to make decisions for them
  - their personal rights have to be respected
  - When does chronic severe brain damage begin?
    - Relevance of advanced directives
  - Chronic severely brain-damaged patients cannot be equated with terminally-ill patients. The former are still in a stable but seemingly irreversible state.

PVS and Neurodegeneration

- (PVS): a comatose state, or a "vegetative state", i.e. a "state of consciousness without any detectable awareness"
  - < 1month →"persistent vegetative state"
  - one speaks of a "permanent vegetative state" when it is in all probability irreversible
- Severe advanced degenerative brain disease (e.g. Alzheimer's disease):
  - severe cognitive breakdown (i.e. vocabulary reduced to a few words, verbal communication no longer possible, loss of motor capability, totally dependent on others for care Functional Assessment Stages (FAST) by Reisberg et al., Stage 7

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Medical issues

- Ambroise Paré (16th century) as doctor you can
  - always console
  - often alleviate suffering
  - rarely heal
- Do no harm
  - Decubitus prevention / treatment
  - Pain relieve
  - Treatment of acute exacerbation or concomitant illnesses
  - Prevention of contractions
  - Nutrition

What are the duties of medicine

- is the sole retarding of stepping over the doorstep to death a real duty of medicine?
  - Today the „service to live“ is extended over the ancient task of relieve of suffering and healing to the role of a general body engineering for many diverse reasons of personal or social choice
  - Medicine deals with life in its totality.. Also with its „still-desirability“. To keep the flame burning, not the ashes glowing, even if we have to take care of the glowing.
  - The right to live is the source of all our rights. A correct and full understanding includes also the right to die.

Hans Jonas: Technik, Medizin und Ethik Suhrkamp Taschenbuch 1514

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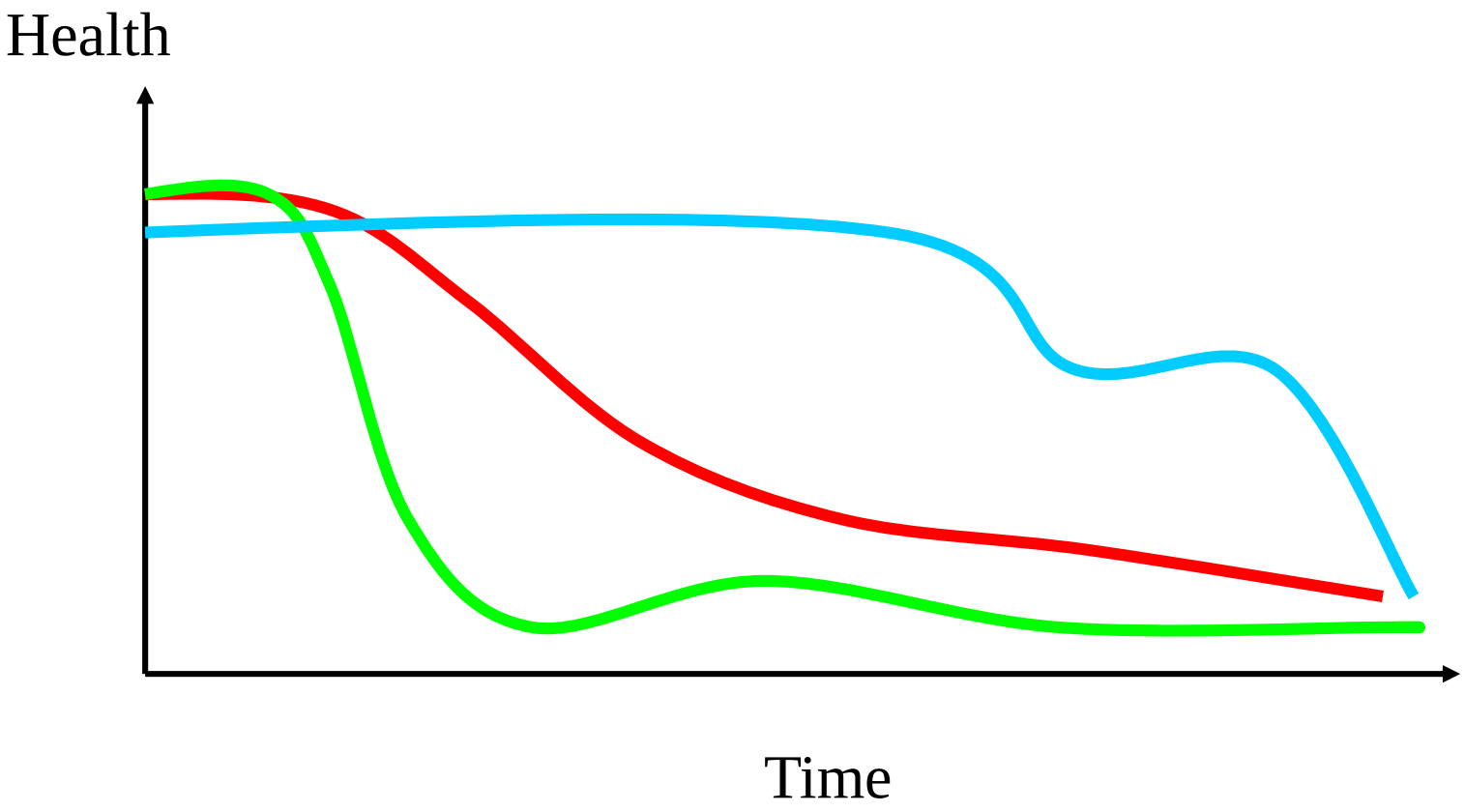
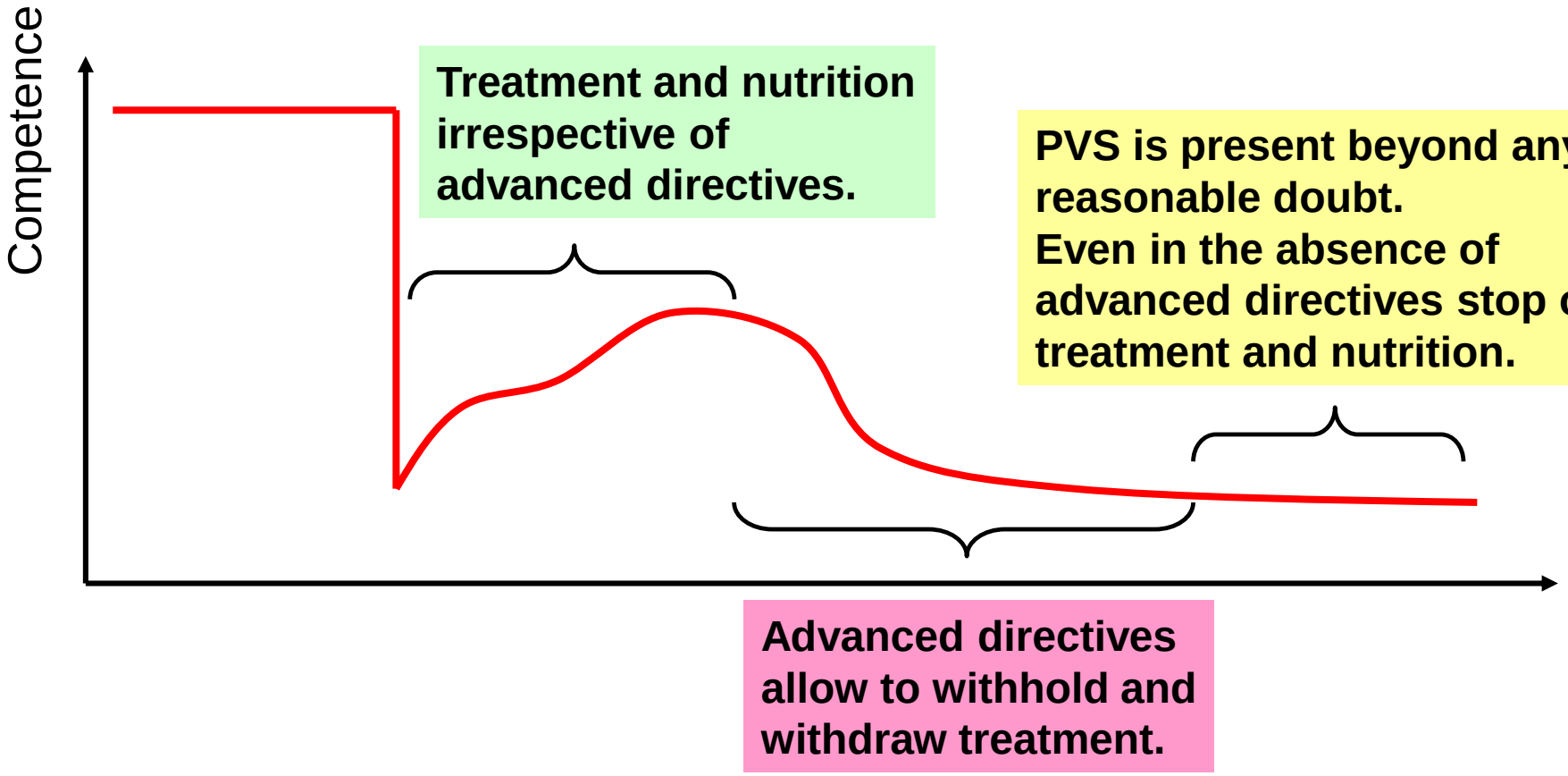
Who decides?

- The patient
- The doctor
- The family
- The caregiver
- The state / public

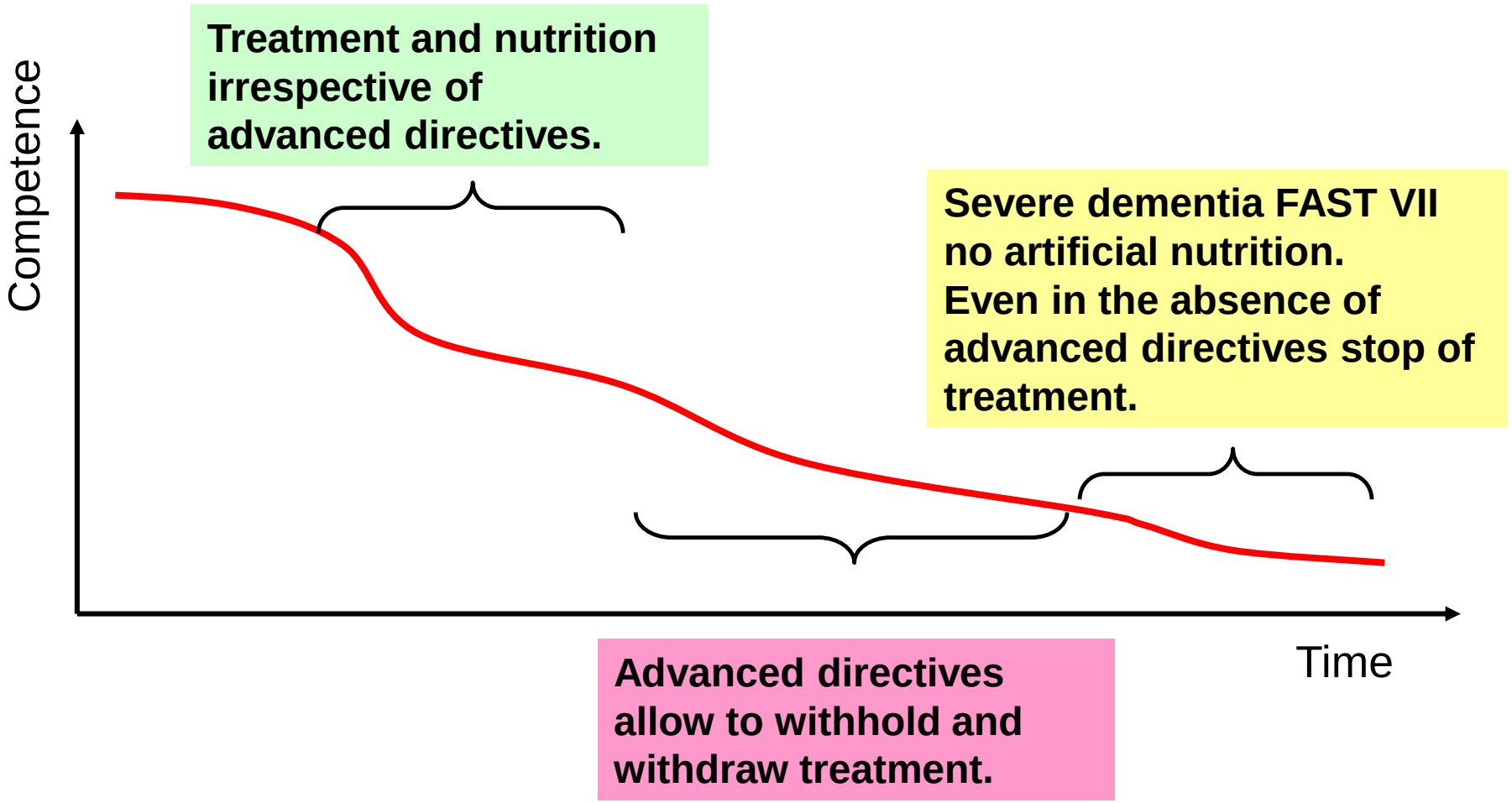
Courses of illnesses



Sudden event with loss of competence



Progressive neurodegenerative illness



Feeding?:

- Rejection of nutrient and fluid intake
- Rejection of life-sustaining therapies
- Explicit wish to die
- Is tube feeding a treatment or a basic right

Nutrient requirements change…

- Patient is often immobilized
  - → energy requirements reduced
  - → sarcopenia
  - → osteopenia
- ➢ Change in body composition
- ➢ Decreased energy requirements
- ➢ Disease mediated changes
  - Immune system
  - Difficult to be aware of pain, stress, hunger, thirst

When becomes feeding artificial and a treatment?

- Competent persons have a right to refuse life-sustaining treatment. This right is not lost when a person becomes incompetent
  - The case of Karen Quinlan
- Six of the nine justices explicitly found that no legal distinction could be made between artificially delivered fluids and nutrition and other medical interventions
  - The case of Nanzy Cruzan

Annas GJ NEJM 2005

Fluid

- 1.5-2 Liter per day
  - Depending on temperature and nutrition the requirements may differ
    - In Summer e.g. reduce diuretics
    - In acute deterioration, confusion event. 1l saline s.c.
- Never over longer periods solely fluid without nutrients
  - Pressure soars, PEM. Micronutrient deficiency
- Some patients suffer from dehydration (without feeling thirsty) because they wish to avoid nycturia
  - In the old from 8pm-8am twice the urine volume than through daytime!!
    - Event. ADH 10-20 mcg as nasal spray at night

Tube Feeding / PEG

- What is the goal
  - Event. preparation for surgery, rehabilitation etc.
- Whose indication
  - Define the process
  - Evaluate alternative solutions
- Difficulties in swallowing (ALS, SNP, Stroke, Cancer, Dementia?)
  - Determine a priori the duration and re-evaluate regularly
- Unconsciousness
  - Cause, Prognosis

How and when to feed?

- As long as patient accepts and swallows food and liquid one may not stop
  - Challenge to the care
- If access via tube (artificial nutrition) removal and event. stopping possible in certain countries
- Never solely adequate fluid without nutrients
  - Event. terminal maximal 2-300ml 0.9% NaCl i.v, per infusionem

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Problems

- Legal issues
  - Advanced directives, dignity
- Prognosis is open
- Patient can not decide
- The will of the patient is not known
- External influence
- Stress
- Attitude of caregivers

Advanced directives

- The right to die builds upon the right to know the truth
- Dignity of knowledge (Human dignity implies a right to contemplate one owns death)
- The patient in a hospital or nursing home is in the public domain and under normative control

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Who chooses life supporting treatment?

- What wants the old patient?:
  - A study in 218 old persons living at home, 50% said that , in case of an Alzheimer`s disease, they wish to receive tube feeding and artificial ventilation, almost 75% wish to receive antibiotics in case of a severe infection (Reilly et al. 1994)
  - A study in the general population found only 10% wishing tube feeding and ventilation in if suffering from dementia (Emanuel et al. 1991)

The conscious, incurable terminal patient

- ..the essence of the medical profession (does not allow), may not assign the physician to deliver death, even if asked by the patient. „Euthanasia" may be discussed only in cases of an unconscious artificially over a lengthy period supported rest of life in which the person of the patient is already extinguished.
- There is a difference between killing and allowing to die.
- Helplessness of the patient should not lead to dependence from the physician… The illness is the killer… do not force to continue to live

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The patient in irreversible comatose state

- No longer a subject and lacking the possibility to choose…there is not a right to die
- The subject is no longer existing that could claim a right.. Therefore it is not hurt if the its „will" is not followed.
- Whose right is respected or hurt? That of the former person or that of the depersonalized present rest?
- The question is ..the obligation or the right of others, to perpetuate the present condition, and alternatively their right or duty by withdrawing the artificial support to end… Let the poor shadow die of what was formerly a person, as the body is ready and end the degradation of forced continuation of existence.
- „If deep unconsciousness is judged permanent, then extraordinary measures to support life are not mandatory. One may withdraw them and allow the patient to die"

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The wish to die.....

Is in old persons frequently (<80%) associated with a psychiatric illness,

the intention to suicide, is always associated with a psychiatric illness.

Linden & Barnow: Int Psychogeriatr 1997; 9: 291-307 (n=516 >70J)

Who chooses life supporting treatment?

- Impact of cognitive impairment:
  - Outpatient with cognitive impairment decided more often for life supporting treatment than a cognitively not impaired control group (nor correlation with premorbide IQ) (n=50) (Fazel et al. 2000)
  - Similar results but not stat. Significant in29 nursing home patients (Diamond et al. 1989)

Conclusions

- Chronic severely brain-damaged patients cannot be equated with terminally-ill patients
- Do no harm
- Never solely adequate fluid without nutrients
- The illness is the killer… do not force to continue to live
- „If deep unconsciousness is judged permanent, then extraordinary measures to support life are not mandatory. One may withdraw them and allow the patient to die"
- Competent persons have a right to refuse life-sustaining treatment. This right is not lost when a person becomes incompetent