



Palliative care
Termination of ventilator treatment
Legislation, criteria, follow-up with relatives



Ove Fondenes
Centre for home mechanical ventilation
University Hospital of Bergen



Legal matters regarding refusal or discontinuation of life-sustaining treatment in Norway

- “Health personnel law”:
 - .. obliged without delay to offer assistance when urgently needed – even though the patient is unable to consent or may be opposed to treatment – unless:
 - ..treatment may be regarded as a prolongation of a death process or the treatment is irresponsible according to established medical standard

- “Patients rights law:
 - The patient has a right to deny treatment...



Professional code of ethics regarding refusal or discontinuation of life-sustaining treatment

- Professional code of ethics
 - “.. promote the individual patients interest and integrity.”
 - “..respect the patients right to self-determination at the end of life.”
 - “To retreat or abstain from treatment that is considered futile **is not** regarded as an act of assisted suicide (euthanasia)



Ethical committee has previously looked at the question of discontinued ventilatory assistance in awake and fully conscious patients with ALS

- Only the patient can decide what he/ she believes to be a meaningful life and whether treatment is purposeful
- No one should be forced to accept medical treatment that prolongs a terminal process when life no longer has purpose to the individual.
- When the patient has reached such a conclusion, it is the duty of the doctor to support the patient and relatives in the best possible manner at the end of life.



The right to deny treatment

Competent decision-making

- Information given

- Information received, understood and contemplated

- Consequences understood

- Being able to communicate preferences

— Accountability

- When the consequences of denying treatment may be severe it is imperative that the patient is fully competent in making the decision.



“National guidelines for the process of limiting life-sustaining treatment in the seriously ill and dying patient”
Published: 10/2009

Order number: IS-1691

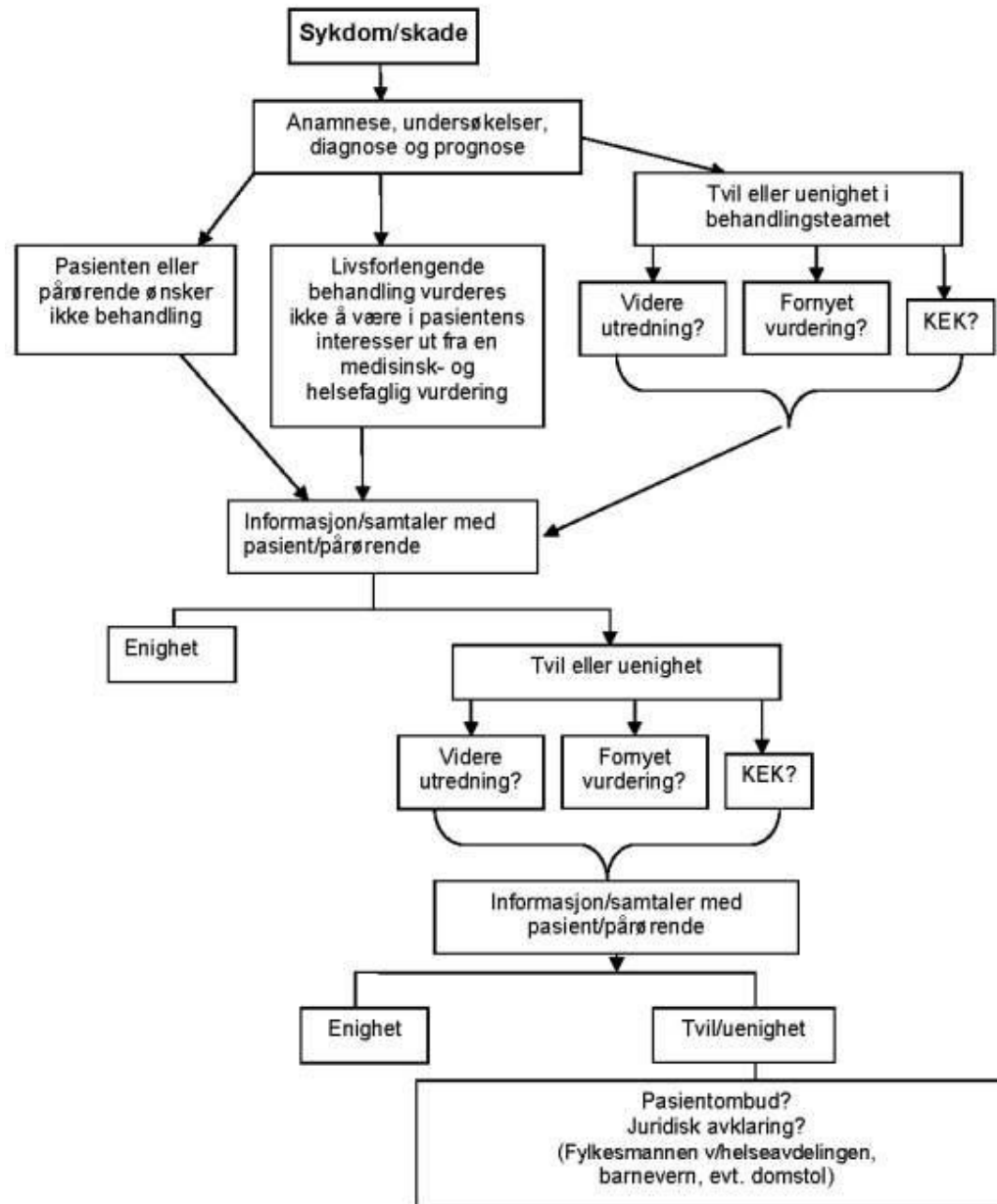
www.helsedir.no/publikasjoner/veiledere



Nasjonal veileder for beslutningsprosesser for begrensning av livsforlengende behandling hos alvorlig syke og døende
Utgitt: 10/2009



Flowchart





Discontinuation of mechanical ventilation involves:

- a) determination of the goals of care
- b) communication among the clinicians and between clinicians and patients and family members
- c) the process of discontinuing the ventilator.



ALS Multidisciplinary Care at Haukeland University hospital

A network of MDT

ALS clinic Haukeland University hospital

- neurologist
- specialized nurse
- physiotherapist
- speech therapist
- occupational therapist
- social counselor

Others:

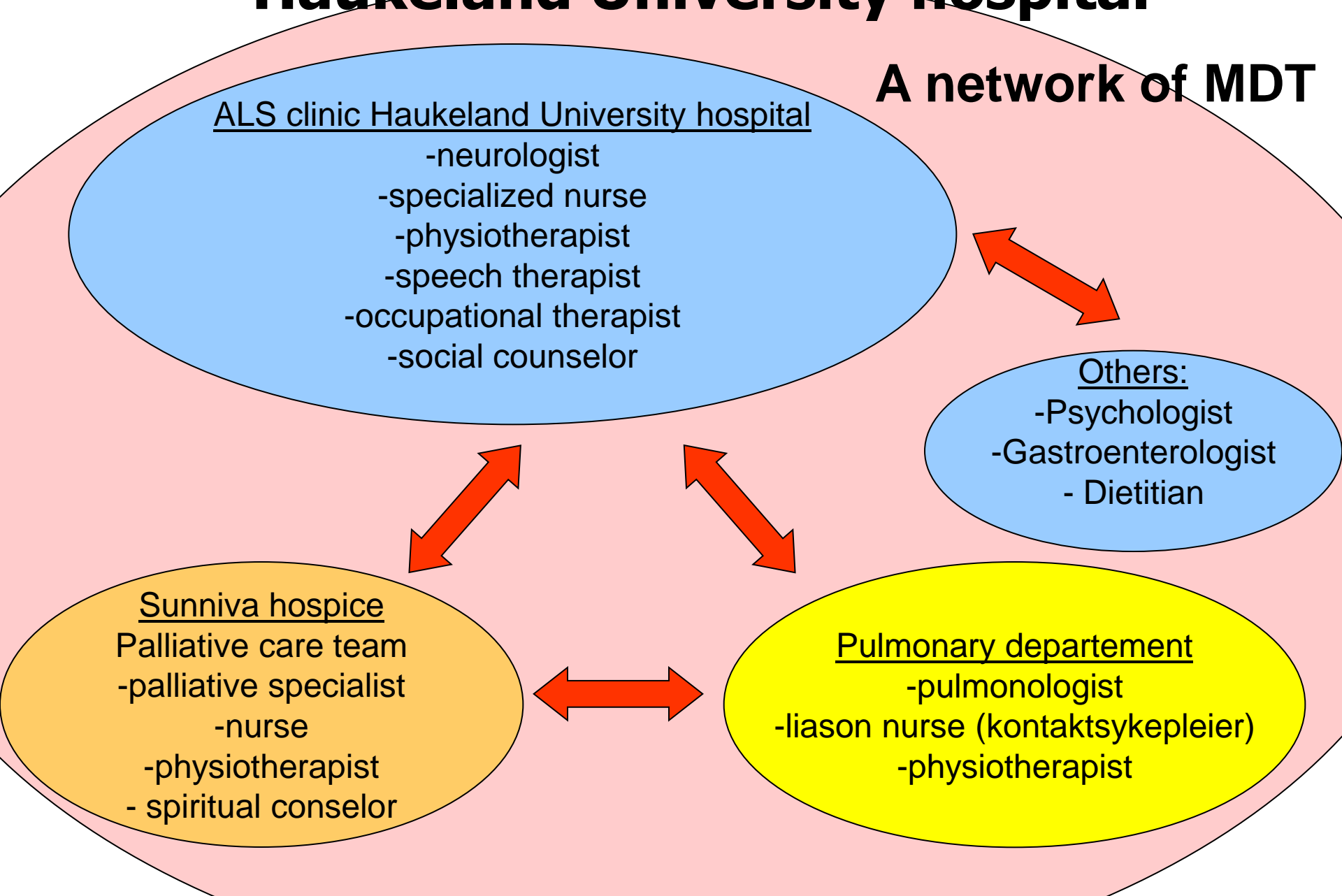
- Psychologist
- Gastroenterologist
- Dietitian

Sunniva hospice

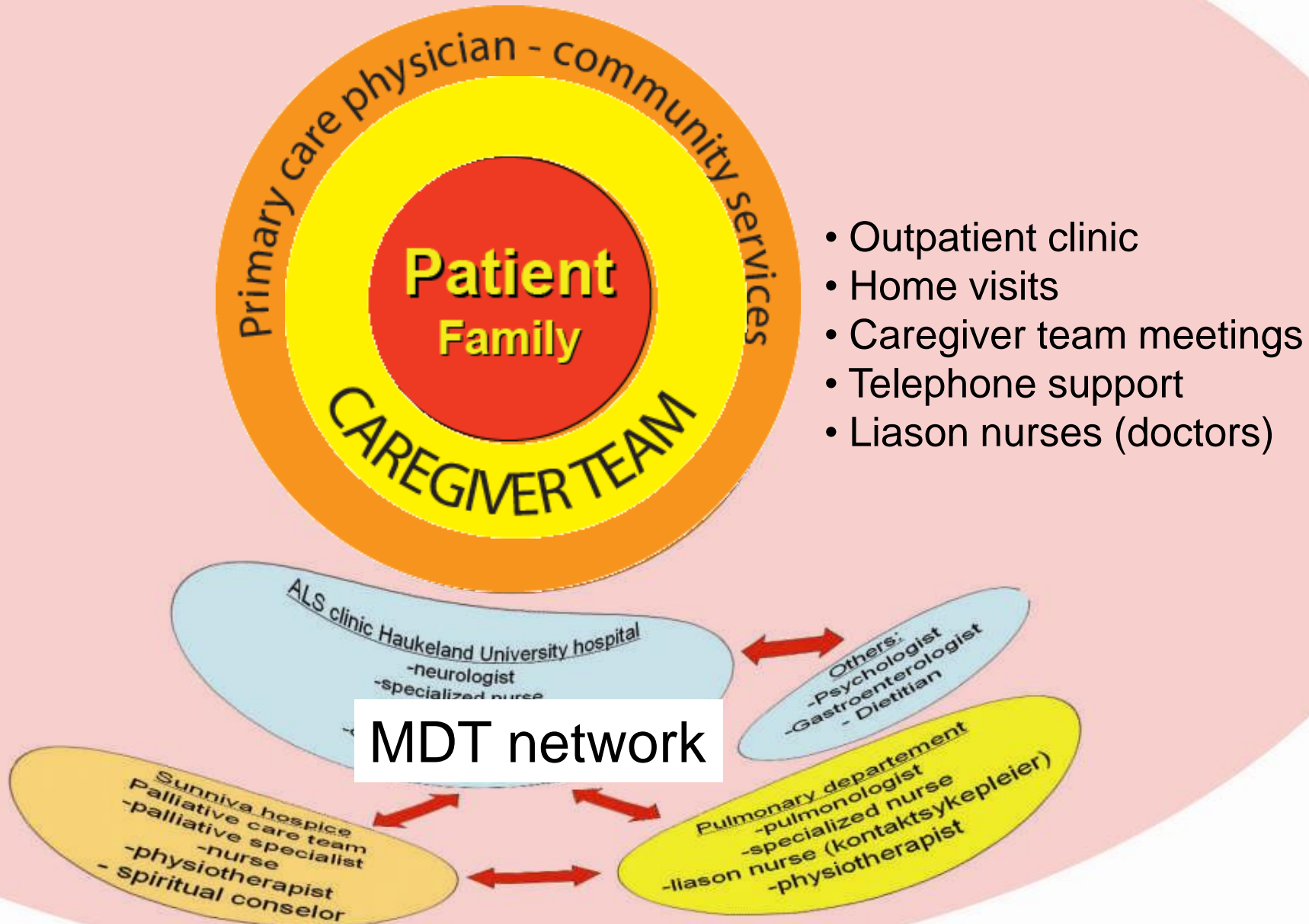
- Palliative care team
- palliative specialist
- nurse
- physiotherapist
- spiritual counselor

Pulmonary departement

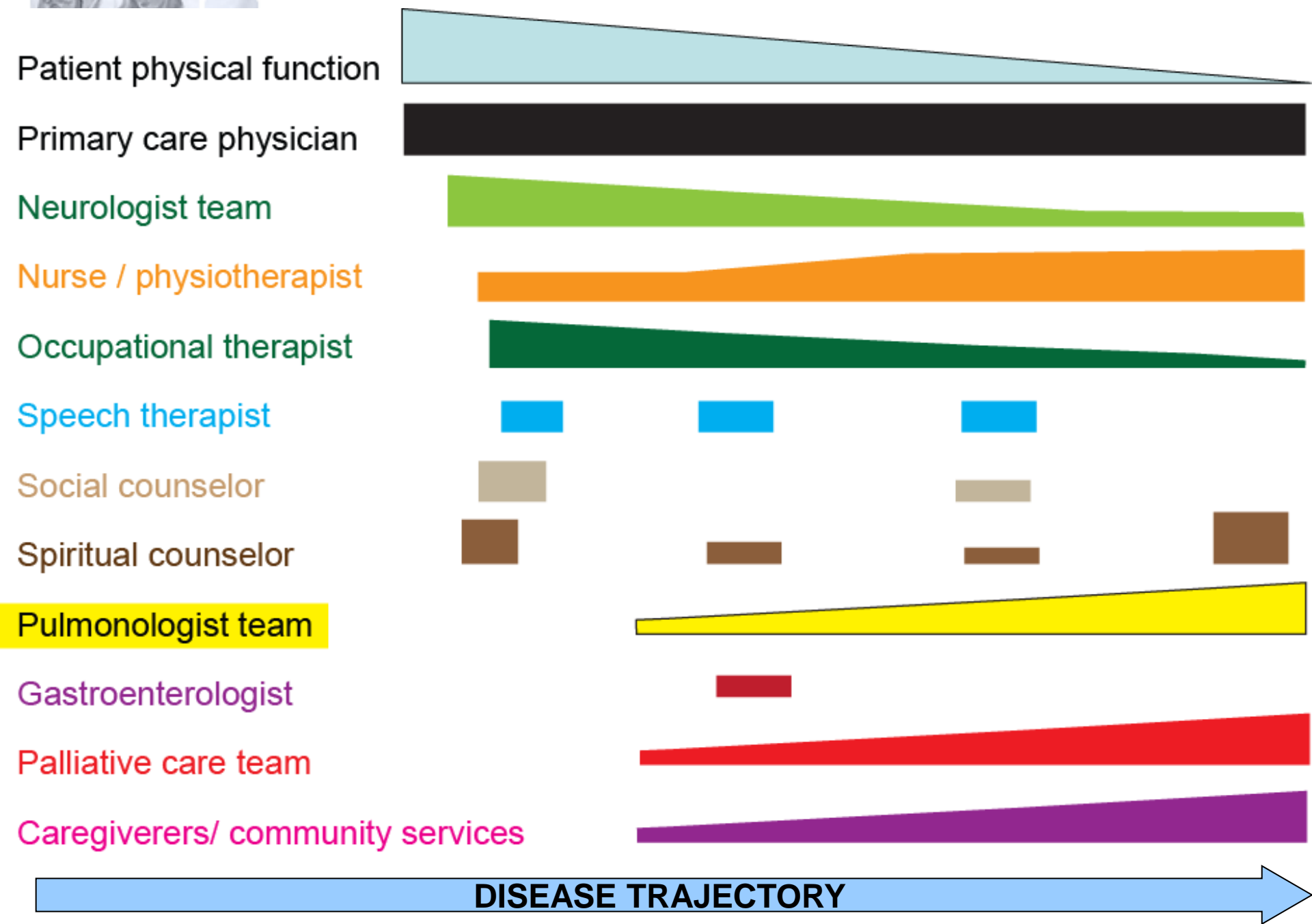
- pulmonologist
- liason nurse (kontaktsykepleier)
- physiotherapist



Integrated care



Changing role of the participants of the MDT network





Withdrawal or refusal of treatment in practice

- Repeated information and discussion with patient..
- The use of advance directives
- Fully competent and repeated wish of patient
- Agreement within treatment team
- Planning of the actual withdrawal
 - Home or Hospice
 - Family, priest, etc
 - Gradual withdrawal of ventilatory support with the use of anxiolytics and opiates
 - Hypercapnia, coma and death
- Follow-up



Follow-up

- Offered routinely
 - Relatives
 - Caregiver team
- Variable timing (1 month or more), rarely more than once



«As individuals, dealing with our fellow man, we a carry a piece of their destiny in our hands .»



**Knud Ejler Løgstrup
(1905 – 1981)**