

Antonie Giæver Beiske, PhD, CEO Norwegian MS Centre Hakadal

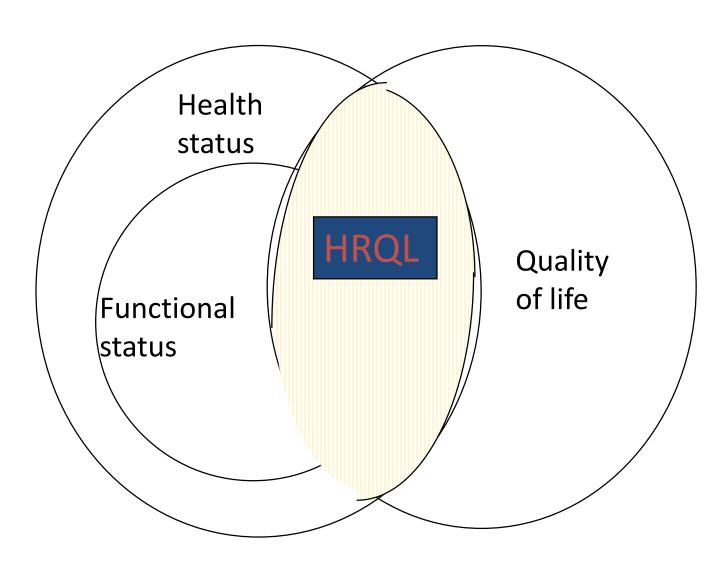
#### **Overview**

- The common goal in treatment of chronic diseases
- Statutory rights and definitions: HRQoL, Rehabilitation, Individual Plan (IP)
- Levels of rehabilitation
- Multiple Sclerosis Centre Hakadal (MSSH)
- Rehabilitation in Norwegian counties
- Conclusion and Future goals

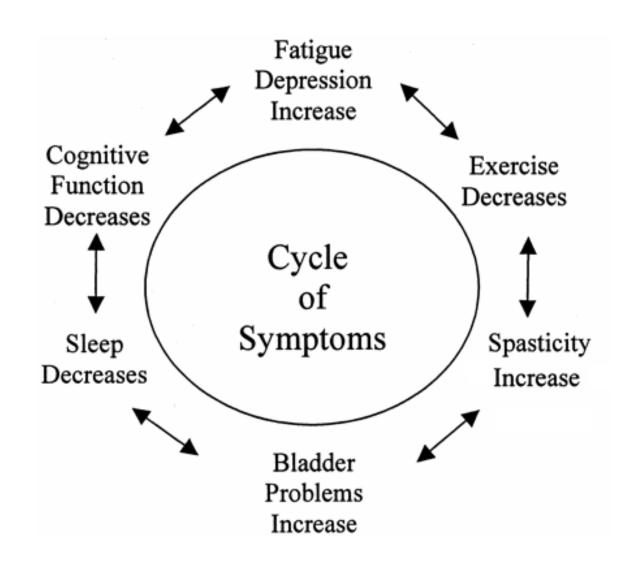
### What is HRQoL?

- more restrictive than Quality of Life (QoL)
- subset of QoL affecting health and health related services
- subjective experience
- different from functional status, often used synonymously

### Health-related quality of life



### Symptoms amplify each other



# Symptoms most negatively influencing

#### **HRQoL**

- Fatigue
- Sleep
- Pain
- Walking

#### **Employment**

- Fatigue
- Anxiety and depression
- Cognitive disability

# Rehabilitation as defined by the Norwegian Parliament

"Timely restricted, planned processes with defined goals and means where a number of professionals cooperate providing necessary assistance to the clients own efforts in order to achieve the best possible level of functionality, coping, independence and social interaction with the community"

(Stortingsmelding 21, 1998-99)

### The needs of pwMS are changing

As newly diagnosed the needs are primarily:

- information and education
- support and counselling

Later on more focus on personal needs:

 help the user to function optimaly in regard to their disability at home and in relation to their family, work and community

### We need to agree upon



Each level with different responsibilities and areas of care:

- Primary healthcare, localy, out-patient rehab, IP
- Specialized health care
- Highly specialized health care:

for pwMS in Norway: MSSH, EDSS ≤8

for pwMS in Helse Sør-Øst: Eiksåsen, EDSS ≥ 8

# Do you want and do you have the right to an Individual Plan (IP)?

- Since 2001: a statuatory right and tool for cooperation
- An IP will contain an outline of your objectives, your resources and the services you require.
- You have the right to participate throughout the planning process.
- You know your situation best, and professional personnel know which solutions and assistance are available to you.

#### **Overview**

- The common goal in treatment of chronic diseases
- Definitions: HRQoL, Rehabilitation, IP
- Levels of rehabilitation
- Multiple Sclerosis Centre Hakadal (MSSH)
- Rehabilitation in Norwegian counties
- Conclusion and Future goals

# MS Centre, Hakadal (MSSH)



Founded 1976, owned by the Norwegian MS Association. Non-profit and without costs for in-patients.

- Renewed and expanded 2005:
- 28 in-patients
- Implementations of nationale guidelines
- Evidence based knowledge



# Tailor-made rehabilitation depending on individual needs

Years of experience (40) has developed our interdisiplinary team to include

- Neurologist
- Neuropsychologist
- Psychologist
- Physiotherapist
- Occupational therapist
- Social worker
- MS-nursing team
- Urologist/Uroterapeut
- Specialist in diet and nutrition
- Speech-language therapist



# Problems solved by interdisiplinary teams

- Fatigue
- Cognitive difficulties
- (Pain....), Insomnia, sleep apnoe
- Urinary and bowel problems
- Employment difficulties
- Delivery of premises for an Individual Plan

### Offers at MSSH for non-pwMS

- Health care professionals at other rehabilitation centers are invited to visit us and participate in courses promoting cooperation between different centers
- Courses for caregivers and familiy members
- Professionals at MSSH are often invited speakers and teachers at congresses and at courses arranged by the Norwegian MS association

Have a look at our homepage www.mssenteret.no

### MSSH exclusively for pwMS

- The interplay among 28 pmMS during the in-stay is priceless
- Fellowship for weeks with others sharing the same diagnosis is an experience no professionals are able to deliver
- Many pwMS form longlasting friendships after a stay in Hakadal

#### Research at MSSH

PhD: Rehabilitation with an Cogntive focus

Master in Pharmacy: Polypharmacy and interaction

of medications in MS

#### Ongoing:

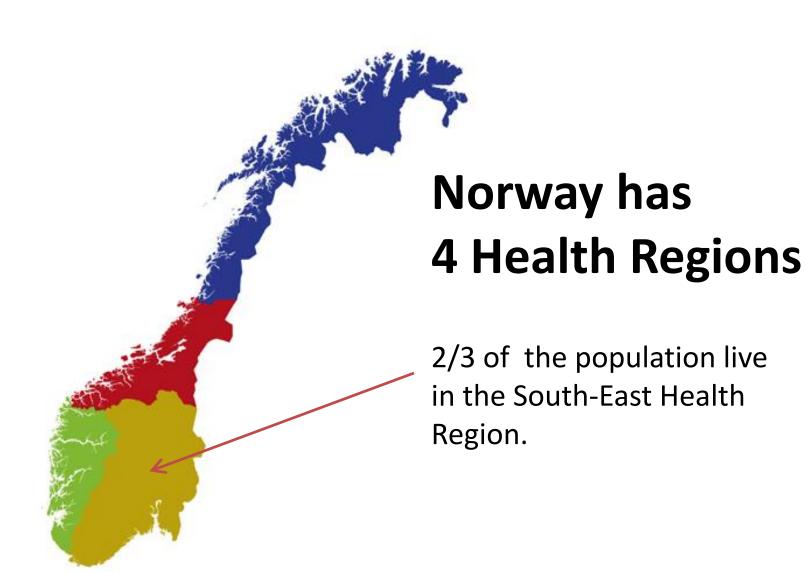
Fatigue and Sleep apnoe: 300 registrations

**Master grade:** Occupational therapist, physical therapist...

# The possibility for Highly spesialized rehabilitation (HSR) depends on where in Norway you live

Norwegian Health Regions prioritize HSR differently

 Institutions offering rehabilitation to patients suffering from different diagnosis will not be able to give the same HSR often necessary for pwMS



## Conclusion (1)

- Rehab is the only way to improve physical impairment
- PwMS should have the possbility to deside themselves what is most important for me?
- Research and continuos quality evaluations are necessary for giving pwMS the best follow up, treatment and rehabilitation
- Research is the best way to encourage enthusiasm among employes, and an effective measure to recrutie qualified staff to work and focus on rehabilitation

#### Wishes for the future

 PwMS should be offered the necessary level of both treatment and rehabilitation due to their needs

- ... through all countries in Europe
- ... in all the regions in Norway

# Thank you – for your time and attention

Antonie Giæver Beiske