



Activity and participation in persons with ME/CFS

Ewa Wadhagen Wedlund
reg. occupational therapist, med.lic.
ME/CFS center

Stora Sköndal



- Non profit- organization:
 - Geriatric care, social psychiatry ward, accommodation for younger people with dementia, senior housing, accommodation for child refugees, preschool

AND

The Neurological Rehabilitation Clinic

- **In-patient rehabilitation** (since 1977)
 - Stroke, brain tumors, traumatic brain injuries, Parkinson's, MS, epilepsy, etc.
- **Day ward rehabilitation** (since 1990)
 - Stroke, Brain tumors, TBI, MS, Parkinson's, epilepsy etc.
 - Group rehabilitation; Epilepsy, Parkinson's, Ci-therapy, Cervical dystonia, Huntington disease
- **Speech therapy centre**
- **Physiotherapy centre**

- **ME/CFS centre**
 - Started June 2015

Uppdraget

Avtal med Stockholm Läns Landsting

- Omhändertagande och stöd för patienter i alla åldrar med ME/CFS.
- För diagnostisering skall Kanadakriterierna användas.
- Komplettering av diagnostik vid oklarheter eller behov av omvärdering från remittent
- Omhändertagande för patienter med medelsvår/svår ME/CFS
- Vid behov teambaserad vård- och rehabilitering

Staff

- Five physicians
 - Specialists in; neurology, rehabilitation medicine, general medicine
- Nurse
- Occupational therapist
- Social worker
- Physiotherapist
- Neuropsychologist

- **Inter-disciplinary**
- professionals work in close cooperation with each other and with the patient
- towards shared goals
- the attitude of the team members is communicative

” Getting frustrated and sorry for not being able to cook, bake, drive a car, gardening, or buying groceries. To be so dependent on my husband most of the time. Not to be able to spend time with my children and grandchildren, even though they live close, and never being a babysitter is sad. It feels like being disconnected from life, being a prisoner in my own home. ”

Patients

- Adult and children n 400
- Women in majority
- Stockholm + whole of Sweden
- Bedbound n 20
- At home, few active hours
- Working part-time

Body function- Symptom after minimal exertation

- Muscular fatigue
- Myalgia, widespread pain
- Headache
- Exhausted / tired / fatigue
- Over-sensitivity to noise, light and emotions
- Difficulties to handle heat and cold
- Fever
- Soar throat, hoarseness
- Gastric problems / IBS
- Balance / dizziness
- Cognitive problems; *Attention, information processing, memory,*

Activity and Participation

- Mobility
 - walk, sit, stand, activity above work height, lift and carry things ,
 - To go with public transportation, to go by car and drive a car,
- Self Care
 - To eat, chew
 - Shower, wash hair, dry yourself, brush the teeth, make-up, shave, comb and dry the hair
- Domestic life
 - Manage purchases- Environment with a lot of impressions
 - Plan and carrying out cooking- make a menu, walk in the kitchen, take down, do the dishes, cut, chop, whip
 - Cleaning- pick up things, vacuum, wipe floor
 - Handle the laundry- hang sheets
- Work, Education, Recreation, General task and demands
 - Read, learn, socializing, care about others, talk, listen, concentrate

Environmental factors

- Residential environment
 - Stairs
 - Uphill in near environment
 - Washing machine in a distant place
 - Overcrowding
 - Sitting and lying positions
- Transport distances to work (bus / subway / walking)
- Do not be believed by health care, authorities
- No understanding from family and friends
- Economic situation !!!!

Goals and objectives

- Prevent recurring, unplanned “crashes”
- Symptom reduction.
- Perhaps, prevent prolonged deterioration
- Be able to prioritize important activities
- Increased power (to cope with) over the situation
- Quality of life improvement
- **The goal is not primarily to increase activity levels or intensity!**

Office visits

- Patients transport service, lying transport
- Access to a wheelchair
- Invite the patient to bring a support person who may take memory notes
- The opportunity to sit restful or to be laying during the visit.
- Calm environment, subdued light

Approaches

Adjust the activity level after the individual's own amount of energy and power, stop before reaching the limit that leads to deterioration, **pacing** *Goudsmit et al. 2012*

- Activity log, mapping current activity level and content
- Detailed follow-up and analysis of activity management
- Tutoring and support in the work for change

- Redistribute energy
- Long-term planning
- Disciplined and consistent
- Avoid “push and crash”

Self-management

- **Plan in calendar (with columns) next week / weeks**
 - Create menus for a week or two, or a list of dishes to pick from
 - Shopping list structured after the grocery store
 - Shop online
 - Food portions in the freezer, "crash food"
 - Schedule phone time, administrative time
 - Break down activities into smaller steps
 - Set small achievable goals

- **Be consistent in using good strategies, both mentally and physically, despite you having a good day!!!**
 - Slow down the pace in activity
 - Sit down in the shower, sit and wash the hair
 - Always sit and brush your teeth, support under your arm
 - Sit down or lay down when you talk
 - When cooking: fetch the kitchen utensils, *break*, pick up the ingredients, *break*, think through the implementation before starting
- **Always have deadlines in social contexts**
- **Clear division of responsibilities at home**
- **Use assistance!**

Change of environmental factors

- Organize items in the kitchen, bathroom, wardrobe
- Work from home
- Extended schooling, home-schooling, Skype
- Mobility service, Patient transport service, Parking permit

Aids and Housing adaptation

- Electric bed or backrest, pressure-reducing mattress
- Shower bath bench, Shower chair, Elevated toilet seat
- Transportation wheelchair, electric wheelchair/scooter
- Standing support chair
- Hand shower next to the toilet, adapted shower place

Other approaches

- Home visits, two from the team
 - Assessment of environmental factors
 - Counselling and prescription of aids
 - Observation and assessment of the need for assistance
- Therapy group with activity management in focus
- Family calls
- Assessment of activity performance



- Involving family members
- Individualized treatment
- Work with acceptance
- Teamwork is essential

Referenser, lästips

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Tack !
Thank you !
Takk !