ACTIVITY AND PARTICIPATION FOR INDIVIDUALS WITH ALS/MND AND MEDICAL VENTILATOR

**Participants – Inclusion**
ALS - Medical ventilator - ICT
AAC more than half a year

Time span: 3.1.2005 - 1.2.2014 at IKT-team CRS/CKV
Total: 99 individuals
20 individuals using medical ventilator & AAC
Data from: 8 survivors + 6 deceased

**Activity and participation**
Activities before diagnosis
Activities between time of diagnosis and time of medical ventilator
Activities with medical ventilator
Left out activities
Retained activities
New activities

**Communication and ICT**
Face-to-Face
Most communication partners are assistants and cohabiting family members.
• Assistants are mentioned first.

Distance
Same distance communication like any other people, but it is chosen because it is the individual with ALS's only option to perform the activity independently.

**EDUCATION**
Fx OT/SLT

**OBSERVER**
Individual with ALS/MND

**ASSISTANTS**
Interpreter + practical hands

**ADMINISTRATOR**
Individual with ALS/MND

**OCCUPATIONAL THERAPIST**

**ICT**

**CONCLUSION**

The most important new activity is to delegate all the tasks that the individual no longer is capable of doing.

"To be the administrator of your own life". (Quote from one of the participants.)
The “administrator” task is to make the assistants do all the daily activities the way the individuals would have done them themselves.
Mastering the Administrator role provides the opportunity to participate in ones own life instead of being a spectator to it.

**RESULTS**

**QUALITY OF LIFE**

**Tips from individuals with ALS/MND**
• Live every day as if it was the last.
• Keep up the good mood.
• Be patient.
• Do not feel sorry for yourself.
• Use all your communication options:
  – Letter board, PC, facial expressions and hand signals
  – Stay in touch with other people
  – Decline no visits from former friends.
• Early implementation of the letter board is important.

**Otis role through discussion**
• To increase focus on the individuals possibility of activity
• To motivate activity and participation
• To visualize activities
• To render activities plausible
• To support using ICTs and guidance towards an active life and toward independency in carrying out activities in order to make the individuals active participants in their own lives.