

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



PARTICIPANTS

**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

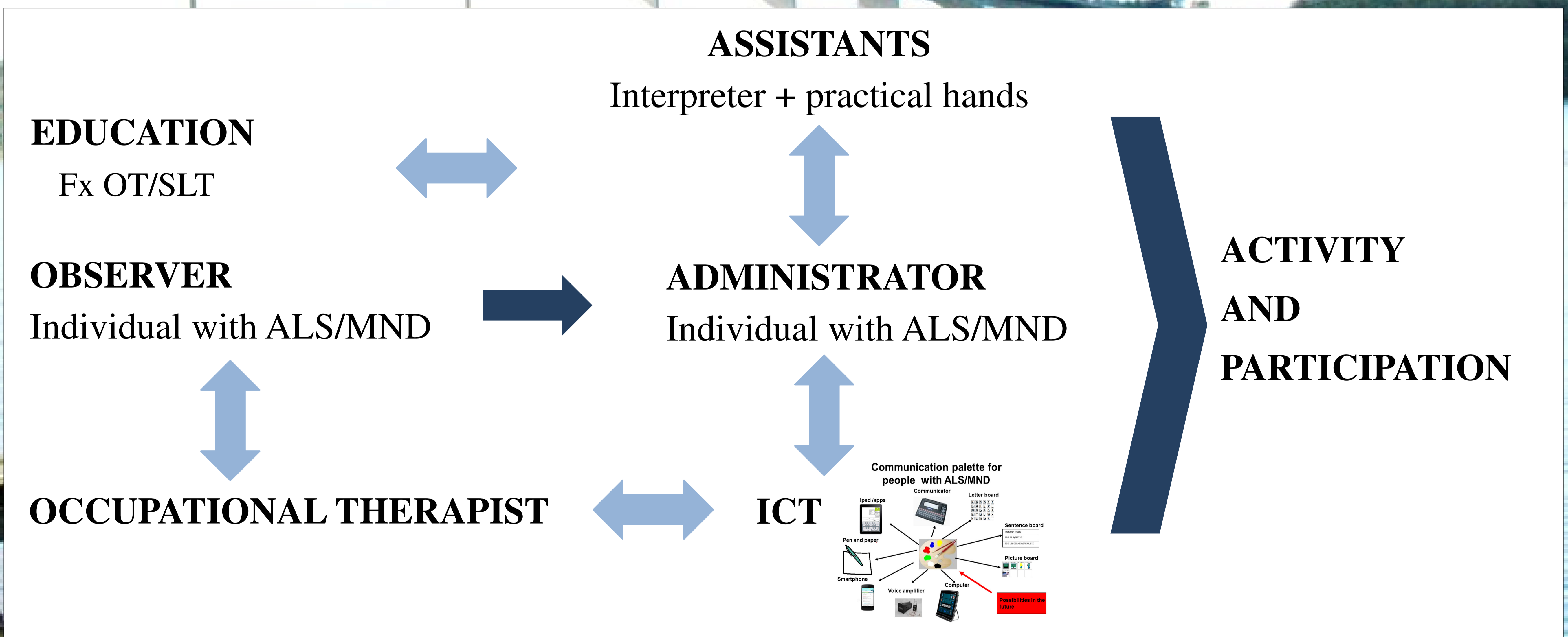
**Activity and participation**  
 Activities before diagnosis  
 Activities between time of diagnosis and time of medical ventilator  
 Activities with medical ventilator  
 Left out activities  
 Retained activities  
 New activities

**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.

ACTIVITIES



RESULTS



QUALITY OF LIFE

## CONCLUSION

**OTs 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.

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.

**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.