

Inceased activity and participation for individuals with ALS/ MND - medical ventilator - AAC

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Introduction

- ALS/MND - in everyday life:
 - Life-prolonging treatment with medical ventilator and personal assistants 24 hours.
 - Plan for rehabilitation! How to manage life getting medical ventilator.
 - Prescribing communication aids (ICT)
 - Face to face communication
 - Alphabetical communication system - (Danish letter board)
 - Communication based on computer, as an interface
 - Communication on a distance

Introduction



CRS, Odense, DK



Hanne Bech



Sissel Madsen

CRS - goal

- To provide support for communication throughout the individuals life.
- To make opportunities for Quality of Life, as long as life is going on.
- Our tools are:
 - Technical communication aids (ICT-aids) by OT
 - strategy for communication by SLT
 - technical aids for computers by It-technician

Danish model of Rehabilitation and social law of AAC technical aid (ICT)

Health legislation and Consolidation Act on Social Services

Health legislation

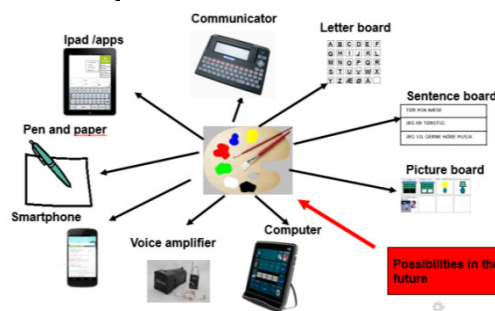
- Danish law provides that all patients are entitled to a plan for their rehabilitation when discharged from hospital.
- The rehabilitation plan outlines the patient's rehabilitation needs at the time of discharge from hospital.

Consolidation Act on Social Services

- The local council must grant aids (ICT) for individuals with permanent physical or mental impairment

Research

- CRS/HB master´s results:
 - Face to Face communication: letter board, non-verbal communication, mimics, point gesticulation and eye-pointing
 - Communication to the environment:
 - Depend on: How to activate the ICT
 - To choose the best software for the situation
 - The use of computer is for the same reasons as other people



Observations

- Observations from our contacts the last year:
 - Different ways of communication via personal assistant compared to communication via ICT - despite offered the same options.
 - Different ways of choosing activities compared to previous life situations.

Research questions

- Do people with Amyotrophic Lateral Sclerosis (ALS/MND) and medical ventilator achieve increased activity and participation through their communication aids?
- What role do OT's have in facilitation activity and participation.

Methods

- Review of medical records in CKV/CRS
- Storytelling - memoirs of dead individuals activities in/from their life with ALS/MND
- Qualitative interviews
 - incl. prepared questions to the individuals with ALS
- Experiences from the discussion of Quality of life, activity and participation related to use of medical ventilator in DK

Participants – in-/exclusion

- Inclusion:
 - ALS - Medical ventilator - ICT
 - AAC more than half a year
- Exclusion:
 - Frontotemporal dementia (FTD)
 - Social problems and crises

Participants - inclusion

- Time span: 3.1.2005 - 1.2.2014
 - registered in the client system at IKT-team CRS/CKV

Total: 99 individuals with ALS/MND

20 individuals using medical ventilator & AAC

- 6 deceased during the time span
- 14 survivors:
 - 3 excluded due to FTD and social problems
 - 11 has been sent questionnaire and/or been interviewed
 - » received reply from 8 individuals

Data collected

- Data collected consists of:
 - Quantitative data
 - Results from interviews
 - Quotes
 - Tips for other persons with ALS and healthcare professionals

Quantitative data - survivors

| ID/ | Time of Diagnose | Time of medical ventilator | Years between | Years with med. ventilator until 2014 |
|------------|-------------------------|-----------------------------------|----------------------|--|
| A | 02/1996 | 08/2000 | 4 years 6 months | 14 years |
| C | 11/2000 | 01/2006 | 5 years 2 months | 8 years |
| D | 01/1996 | 06/2001 | 4 years 7 months | 13 years |
| F | 02/2005 | 01/2013 | 8 years 1 months | 1 year |
| H | 02/2012 | 12/2012 | 10 months | 1½ years |
| J | 06/2013 | 01/2014 | 7 months | ½ year |
| K | 06/2010 | 08/2013 | 3 years 2 months | 1 year |
| O | 03/2013 | 02/2014 | 11 months | 4 months. |

Quantitative data – deceased

| ID | Time of diagnose | Time of medical ventilator | Years between | Deceased | Years with medical ventilator |
|-----------|-------------------------|-----------------------------------|----------------------|-----------------|--------------------------------------|
| T | ? | 02/2009 | ? | 01/2013 | 3 years 11 months |
| U | 06/2009 | 08/2012 | 3 years 2 months | 10/2012 | 2 months |
| V | 2001 | 05/2008 | 7 years | 10/2011 | 3 years 5 months |
| X | 2001 | 2008 | 7 years | 05/2011 | 3 years |
| Y | 11/2011 | 11/2011 | 0 | 03/2013 | 2 years, 4 months |
| Z | ? | 2008 | ? | 06/2013 | 4 years |

Activities before diagnosis

- Adult people, diagnosed midway or late in their working life. (Age < 65 years).
 - They performed usual activities at home, normal to their social fabric.
 - They performed common leisure activities in sport, music and gatherings.
 - Most (5/8) read for their own pleasure.
 - All had used computers either at work or at home.

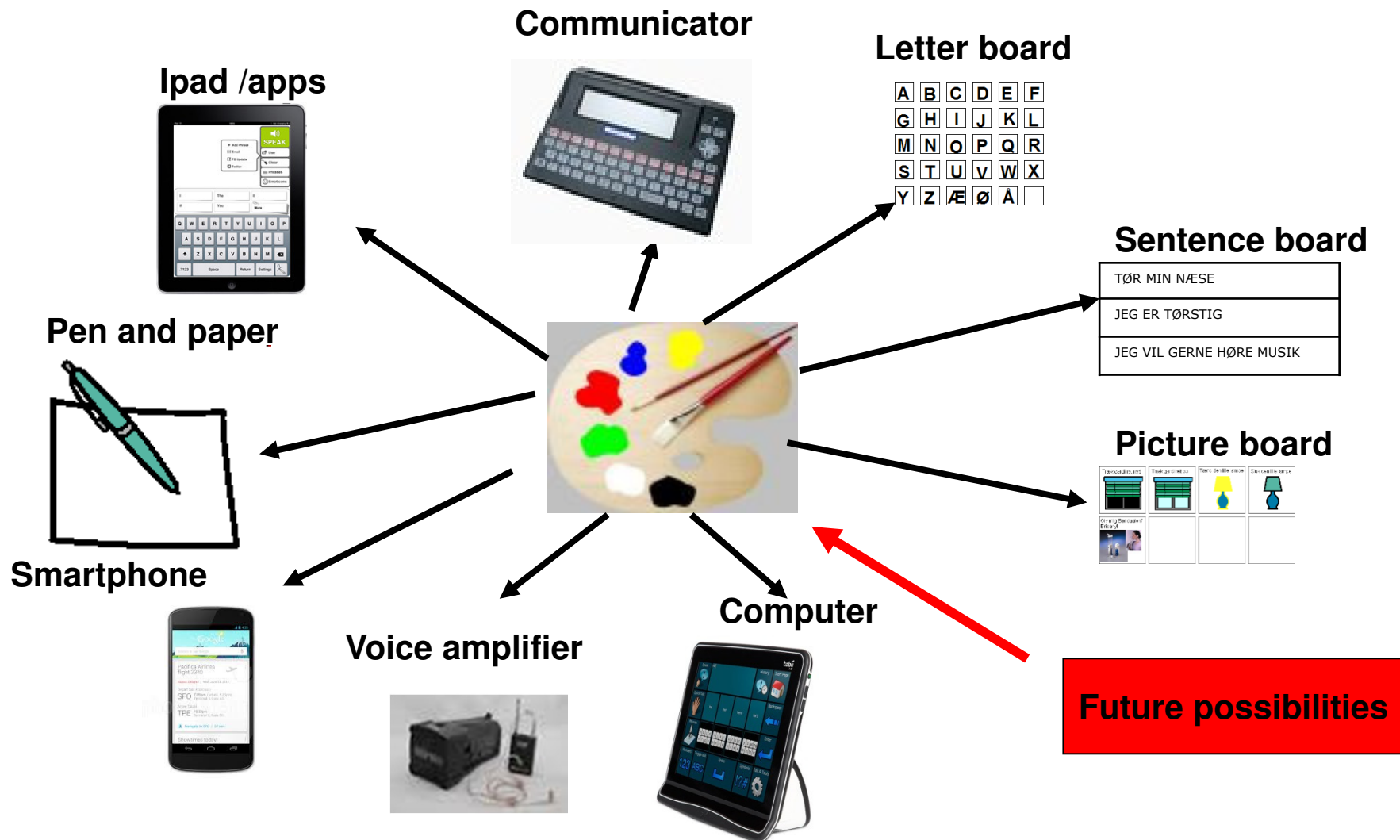
Activities between time of diagnosis and time of medical ventilator

- Conclusion:
 - 7/8 switch from working to retirement
 - 1 is temporarily a nursing home resident
 - Big changes in participation in activities in the home
 - Termination of leisure activities due to impaired motor skills
 - Sporting activity is changed to maintenance training

Activities between time of diagnosis and time of medical ventilator

- Increased use of computers and assistive devices leads to:
 - Written communication via email and SMS replaces impaired verbal communication
 - More advanced equipment such as eye tracking.
- Lack of assistive devices may lead to reduced use of personal computers:
 - Impaired motor function
- New activities via computer occurs:
 - Face to Face communication
 - Video, writing books related to ALS/MND, genealogy

Communication palette for people with ALS/MND



Activities:

Face to Face- communication

Most communication partners are assistants and cohabiting family members.

- Assistants are mentioned first.
- Communication:
 - Letter Board
 - PC / ICT in Face-to-Face communication

Activities:

Face to Face- communication

- The primary form of communication:
 - Speaking: Speech
 - Non-speaking: Letter board
 - All supplements with PC
 - All use gestures, "speaks with the eyes"
- The secondary form of communication:
 - SMS
 - PC, Lightwriter, telephone/telephone by assistant

Activities:

Face to Face- communication

- Communication primarily on practical tasks
- Communication with guests
- Fatigue with Face-to-Face communication
 - The speakers need 0-60 minute breaks between conversations.
 - The non-speakers can communicate for 30-60 minutes and then need to break for 30-60 minutes.

Activities: distance communication

General:

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:

distance communication

Communication partners are comparable to the rest of the populations communication partners.

However **the type of operation and time spent is very different.**

Type of operation:

- Independent activity
- Can be performed by assistants, such as dictation
- Can be performed with ICT

Time:

- Time perspective
- Endurance

Activities: distance communication

- Direct replacement for speech:
 - asynchronously: E-mail, SMS
 - synchronously: Telephone
- Practical activity: Web banking and shopping via websites
- Recreational activity: Reading news, posting updates on Facebook, web surfing

Change in AAC and activity level: Quotes

- I focus on what I can do !
- Communication is crucial for me and I enjoy taking part in everything around me.
- The human being has a formidable adaptability and must resort to that when calamity strikes. But it is true that one should not be a “cry baby” in order to get the best out of life with ALS.
- I would definitely spend even more time with the PC than what I am able to now, if I could.

source BBJ

Change in aac and activity level using medical ventilator

- Activities to be retained:
 - 1/8 has maintained a relationship with work (from teacher to researcher)
 - ADL: from being physically active to “verbally” initiating activities (a change of position in ones own life)
 - Gardening, sporting and musical activities: from actor to observer
 - Reading books is supplemented with audio books
 - Travel activities: Organizer and participant.
 - Photography
 - E-mails and SMS: from secondary form of communication to the primary form of communication in everyday life

Change in aac and activity level using medical ventilator

Left out activities

In general - activities that has become physically impossible:

- ADL at home, sports, physical leisure activities
- Activities with low accessibility such as cinema and choir practice

Specifically mentioned:

- Job (performing music/reduced motor skills)
- Going to church (noise from medical ventilator/other churchgoers)
- Discussions (letter board too slow => change from participant to observer)

Change in aac and activity level using medical ventilator

New activities:

- Administrative role in everyday life
- ALS union activities
- Written activities (PC): Writing books and articles, shopping, webbanking, Facebook, www sites
- Making movies, as ideas man, researcher and actor
- Genealogy
- Reading e-books and audiobooks

Change in aac and activity level using medical ventilator

Interaction with / relationships with assistants
about activities:

- Communication via letter board
 - practiced in different ways
- Everyday tasks on the PC
- Make and receive telephone calls

Tips from individuals with ALS/MND

Experiences

- Live every day as if it was the last.
- Keep up the good mood.
- 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.
- Be patient.
- Do not give up.
- Do not get frustrated, because it just makes everything much worse.
- Early implementation of the letter board is important.

Tips to professionals

from individuals with ALS/MND

The desired:

- The same specialist over time
- Direct hotline - at the right time
- Information on all options
 - Testing and follow up in relation to ICTs
- Use previous experience from individuals in same situation
- Mediate contact with others in similar situation

Tips to professionals from individuals with ALS/MND

Activities and participation:

Remember:

- That individuals are helped to see options / not limitations.
- That the individuals are asked what they want and need.

Tips to professionals from individuals with ALS/MND

Wishes in relation to ICT:

- Being informed of developments in things like:
 - Software and hardware
 - Environment control
 - Voice Amplifiers
- The ICTs are implemented as early as possible so that it can be learned.
- The software is quickly adapted to the individual needs and the progression of the disease.
- To grant portable ICTs that allows you to communicate independent of location.

Conclusions



Do people with Amyotrophic Lateral Sclerosis (ALS/MND) and medical ventilator achieve increased activity and participation through their communication aids?

- Left out activities that were previously very significant and contributes to meaningful life.
- It turns out that it's only very few activities that individuals do not participate in because of the reduction in communication skills. For example: Job, teaching, taking classes, going to church, choir practice.

Do people with Amyotrophic Lateral Sclerosis (ALS/MND) and medical ventilator achieve increased activity and participation through their communication aids?

Changed level of participation:

- A part of the user's activities have changed. This is justified by physical disability and environmental factors such as lack of access. Not due to impaired communication ability or the use of assistive technology for communication.
- Individuals participation has changed from spoken to written communication, but they are still active and participating in for example sports, music, ADL, teaching, conversation and PC work.

Do people with Amyotrophic Lateral Sclerosis (ALS/MND) and medical ventilator achieve increased activity and participation through their communication aids?

- New activities:
 - The individuals has initiated new activities carried out with a high level of participation despite significantly decreased functioning and compensation through technical means.
 - The most important new activity is to delegate all the tasks that the individual not 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.

What role do OTs have in facilitation of activities and participation: In general

Individuals let go of some activities, retains others but with a different level of participation and adds new activities.

The role of the OTs can be through discussion fx:

- 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.

OTs must be aware of the interdisciplinary aspect, so action around the individuals will be coordinated, coherent and based on knowledge.

What role do OTs have in facilitation of activities and participation: Discontinued and retained activities

Through the whole process the individual can be about to give up activities.

OT must direct its action using:

- Activity Analysis
- Examination of materiality of the activity of the individuals (COPM)
- Knowledge of help / support options to continue the activity:
 - Compensatory strategies
 - ICT's
 - Adjustment of the surroundings
 - Personal assistants
 - Coordination of interdisciplinary approach

What role do OTs have in facilitation of activities and participation: New activities

To be the administrator of your own life:

A substantial part of the individuals ADL activities has changed from participation to observation. By mastering the role as administrator they can change back to participation.

The role of the OTs

- Through analysis of the activities and motivation to facilitate the Administrator role and thus obtain individual activity and participation in the Administrators own lives.
- Advise assistants to join the performing role. For example:
 - Interpreter at conversations
 - Practical performer in a variety of activities promoting individual participation

What role do OTs have in facilitation of activities and participation: New activities

Communication – ICTs

- Letter board (through interpreter) or ICTs:
 - Helping the individuals to choose if the communication must be via letter board / interpreter or using assistive devices and whether they can manage to have both options.
 - Raise awareness among individuals about the advantages and disadvantages of different ways of communicating.
- Prepared conversations:
 - The OT must give the individual opportunity to prepare conversations. The OTs must secure that conversation about activities and participation are based on written material known by both the OT and the individual in advance.

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