

# Consensus on the functional diagnosis and treatment of ambulatory Huntington's disease HD patients.

## A problem oriented goal directed approach

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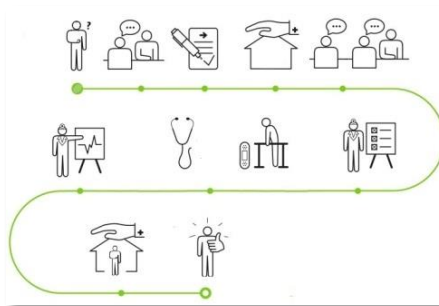
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### Introduction and materials and methods

Most HD patients prefer to stay at home as long as possible. Multidisciplinary teams from specialized nursing homes (NH) offer their treatment to ambulatory patients in support of their ambition to delay admission to a NH. This innovative form of treatment has been developed in the northern part of the Netherlands in imitation of the Standards of Care model developed by Simpson et al. In order to harmonize expert diagnosis and treatment throughout the country, 8 specialized HD centers started a consensus trajectory by means of a Delphi procedure.

### A Treatment Trajectory

- ✓ Request for help
- ✓ House visit
- ✓ Inventory questionnaire
- ✓ Visit Expert Center (NH) by patient
- ✓ Multidisciplinary screening
- ✓ Design Treatment Plan
- ✓ Implementation Treatment Plan at home
- ✓ Evaluation (every six months and on indication)



"A treatment trajectory is available for all HD patients all over the country by expert HD teams working in outpatient departments situated in nursing homes".

- ✓ Consensus was reached in two live rounds and 2 rounds via e-mail.
- ✓ A Dutch article was written with all participants as finalization of the process.
- ✓ The basis of the treatment plan is a goal directed problem analysis.
- ✓ In the Netherlands a systematic way of analyzing problems is the SAMPC method, which deals with a functional diagnosis and goal setting in the following domains: Somatic, Activities of daily living, Social (M in Dutch) Psychic and Communication.

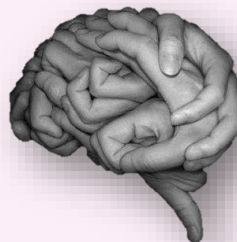


- C1**
- Mrs. Smith's speech is getting less articulated
  - ◆ Effective communication with others
  - Speech therapy
  - ◇ **Speech and Language Therapist**

- P1**
- Sudden outbursts of anger
  - ◆ Mrs. Smith's family is safe and knows how to react
  - Fixed daily structure with activities for Mrs. Smith and daily talks about her wellbeing
  - ◇ **Psychologist and Casemanager together with Home care team**

- M2**
- Mrs. Smith's family is deprived of support
  - ◆ Family feels adequately supported
  - Organizing daycare for Mrs. Smith and counselling for Mrs. Smith's spouse and sister to persevere despite challenging behavior now and then
  - ◇ **Social worker, Case manager/HD-nurse and Psychologist**

- S1**
- Chorea bothers Mrs. Smith
  - ◆ Chorea is treated sufficiently
  - Medication
  - ◇ **Neurologist**



**Example of a multidisciplinary treatment plan**  
(Mrs. Smith, a former schoolteacher, visiting the outpatient department with her husband, they have 2 children)

- S2**
- Weight loss
  - ◆ Weight increases
  - Advice and supervision
  - ◇ **Dietician and Home care team**

- A1**
- Mrs. Smith is not properly showered and dressed
  - ◆ Mrs. Smith showers regularly and dresses the way she used to
  - HD Team trains nurses how to get Mrs. Smith in the shower
  - ◇ **Home care team with support of Occupational Therapist**

- A2**
- Mrs. Smith can no longer walk the dog because of balance problems
  - ◆ Improve balance and gait problems (and walk the dog!)
  - Physiotherapist trains balance and gait
  - ◇ **Physiotherapist of an Expert Center (NH)**

- M1**
- Difficulties being a proper mum for the children
  - ◆ Proper functioning as a mum
  - Home care team helps and structures upbringing of the children (the way she used to do before HD kicked in)
  - ◇ **Home care team with advice from Psychologist**

- Legend**
- Problem
  - ◆ Goal
  - Action
  - ◇ Executor

