Supplementary Material

The following consensus was reached and is given in the form of statements:

Integrated care

1. Diagnosis of gene mutation carrier is performed by Clinical Genetics departments of the University clinics.

2. Diagnosis and treatment of manifest disease is done by neurologists, preferably with a specialisation in HD.

3. Diagnosis and treatment of psychiatric manifestations of HD is performed by psychiatrists, preferably with a specialisation in HD.

4. Functional diagnostics and treatment of ambulatory HD patients and mutation carriers is carried out by the multidisciplinary teams of specialised HD clinics (HD-team). Functional diagnosis includes the assessment of all functions the patient wants to or should perform and whether these functions have been changed as a consequence of HD.

5. The head practitioner (medical or psychological specialist) of the multidisciplinary team works intensively together with the clinical geneticist, the neurologist, the psychiatrist and the GP. The GP is responsible for daily treatment and care and may consult members of the multidisciplinary team for all HD-related questions (e.g., specific medication advice for sleeping disorders).

6. Because integrated care is the main goal of the treatment all members of the care and treatment network around the patient are specialised in HD and used to collaborating together.

7. All over the country, the ambulatory care and treatment is comparable and of similar expert quality.

8. “Huntington’s disease outpatient clinic for diagnosis and treatment” is the title used for the outreaching multidisciplinary care performed by the HD-teams.

9. Besides symptomatic patients, asymptomatic HD-gene mutation carriers and persons at risk of having inherited HD can be treated and counselled at the outpatient departments of the long term care facilities.

Ambulatory care by the multidisciplinary team

10. The functional diagnosis and treatment of the HD outpatient department is organised like a carrousel, which comprises a systematic problem analysis by each therapist of the multidisciplinary team twice a year. Depending on the situation this can be more or less often.

11. The problem analysis is performed in the Dutch SAMPC structure, which includes Somatic, Activities of daily living, Social (M in Dutch), Psychological and Communication domains. In each domain the problems are analysed and the functional capacities are assessed.

12. This analysis is performed with patient and his or her informal caregiver together as well as separately because it is known that patient and informal caregiver perspectives might differ considerably on severity and nature of problems. Treatment always aims for wellbeing and optimisation of functioning of both patient and family members/caregivers.

13. Each patient has his own individual treatment plan in which goal setting is completed with patient and caregiver through shared decision making. Wishes of patient and caregiver/family are always the starting point of the outpatient visit.

14. This treatment plan is updated twice a year after a thorough analysis of the functional symptoms of the disease and evaluation of the goals from the former treatment plan. A multidisciplinary deliberation is always part of the updating process of the treatment plan.

15. Each outpatient visit consists of assessment, analysis, multidisciplinary deliberation on the content of the treatment plan, feedback of this plan to patient and system and start of the execution of the plan after consent of patient and caregivers.

Execution of the individual treatment plan at home

16. The HD-team communicates the treatment plan with GP, neurologist, psychiatrist and all the referred therapists in the dwelling place of the patient and homecare nursing teams involved in executing the treatment plan of the patient. In case the patient is living in a long term care facility the treatment plan is integrated in the treatment plan of the facility.

17. If necessary and possible the treatment can be performed by the multidisciplinary HD-team Patient and system are involved in this form of treatment for optimal functioning of the patient at home.

18. The HD-team head practitioner is responsible for the contents of the treatment plan, the case manager (usually a nurse or social worker with an HD specialisation) coordinates the plan (see Fig. 1 coordinator at the HD clinic).

19. The head practitioner knows the competences and skills of therapists and all the HD-team members are available for knowledge transfer and deliberation on the proper approach, which is regularly specific in HD.

20. Each therapist is responsible for the execution of his or her part of the treatment plan and for proper feedback to the head practitioner