

E-Health support for community residing HD patients

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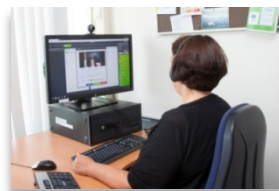
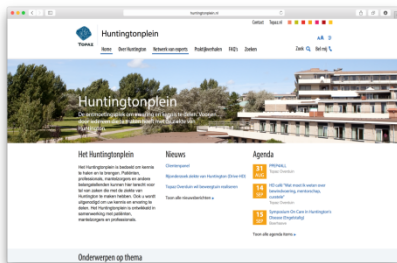
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Background

Topaz Huntington Centre Overduin is a 70 bed long term care facility with a specialized daycare facility for 25 patients and an ambulant support centre for 80 HD-patients. Following preferences of patients and society, we aim to arrange support in a way that patients can live at home as long as possible in a decent and suitable way. However, physical distance between patients and professionals with HD-expertise is a barrier to achieve this goal. Since last year we started to use a platform for e-health and e-learning for patients living at home.

Online platform

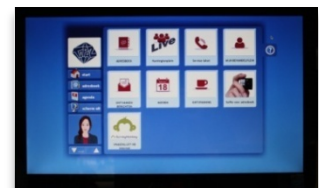
The public online platform www.huntingtonplein.nl has been developed together with patients, caregivers and professionals. It is a database of information and instruction video's. It is meant to support patients and carers dealing with Huntington's disease. They can get and bring information; ask and answer questions. They can also contact specialists and find tips and advice, stories, video's, news and meetings.



Location of residence of patients using e-health platform

E-health platform

Huntington's disease treatment and counselling is increasingly expanded with video calling. At home clients need a solid, standing touch screen. It is equipped with simple icons. With this device they can have regular contact with Topaz' social workers by video calling. They keep a shared agenda with their carers and therapists and see instructions, send video messages, participate in relaxation exercises and games. The system also provides the opportunity to stay in touch with family and caregivers in a secured environment.



Results

- ✓ The public online platform www.huntingtonplein.nl is visited by 400 people each month.
- ✓ 26 at home patients are using the secured part for video calling with possibilities to connect to professional care givers. It is mainly used by case managers, that now have in average contact with these patients once a week, instead of physical contact once every 6-8 weeks before the start of the project.
- ✓ The evaluation by the patients revealed that it helps them to stay longer at their own home, is effective in more contacts with the HD-experts with less travelling time. The majority recommends this to other patients. It increases continuity of care, helps to prevent escalations and crisis and in addition intensifies the quality of the contacts between patients, professional and informal care givers.
- ✓ Professional care givers were positive about the extended possibilities.

