

HOME MARJORIE

Kerselaarlaan 27

2220 Heist-o/d-Berg

Belgium

Tel. 00 32 15 25 85 80

Fax. 00 32 15 25 85 85

home.marjorie@skynet.be



The project

Home Marjorie is a small-scale home for people with a disability. It is acknowledged and funded by the government. Home Marjorie is an initiative of the Flemish Huntington Association. In Belgium most people with Huntington's disease are taken care of in psychiatric hospitals and retirement homes. These facilities however cannot provide sufficient and adequate care for most people with HD in need of residential care. The Huntington Association's aim is starting up a number of residential projects in Flanders for people with HD.

Since april 1999 10 people with HD are living in Home Marjorie.

Target group

Home Marjorie is destined for people with HD, mainly younger people in stages 3-5 of the disease, whose social network cannot provide sufficient care for them.

The most important criteria for admission are :

- Preference for people unable to live at home because of social problems
- Preference for rather young people with HD, the average age in Home Marjorie is 43 at the moment
- Candidates need to be motivated to live in Home Marjorie. They should be prepared to live with 9 other people with HD.
- People have to be able to live in a group, extreme behavioural or psychiatric problems cannot be managed within the open setting of Home Marjorie.

Basic principles

Home Marjorie's aim is to be a home for 10 people with Huntington's disease. Circumstances there have to be as close to ordinary life as possible. Every resident's history and personality is integrated in the personal care and guidance, without neglecting the welfare of the other residents and the group as a whole. Home Marjorie strives towards integration of the residents in the community. Volunteers are engaged in this goal.

Guidance and care in Home Marjorie incorporates several areas :

- Activities of Daily Living
- Psychological support of the residents, their family and significant others
- Medical follow-up
- Paramedical treatments
- Nursing
- Assistance with daily activities and leisure

The accent lies on guidance by a multi-disciplinary team to maintain the highest possible level of autonomy, self-care and the highest possible quality of life.

There can be no uniform approach to the residents of Home Marjorie. Because the course of the disease is very different for everyone and because it is an evolutive disorder, it is essential to provide care adapted to the individual and the stage of the disease. This is a dynamic process.

Goals

Home Marjorie is a pilot project. It's function is to test and refine the ideas about residential care for people with HD. It is a part of it's assignment to share this knowledge with other facilities that have people with HD in their care.

Home Marjorie wants to take active part in building a circuit of care for people with HD throughout the course of the disease. People's needs for care will evolve with the disease. These changing needs cannot always be dealt with by one facility, but transfers should be smooth, especially for the client.

Current limitations

Very grave psychiatric or behavioural problems which require continuous psychiatric care, are a contra-indication for admission. When such problems occur during the stay in Home Marjorie, it can lead to a (temporary) crisis admission to a psychiatric hospital.

The team

Members :

- 9 members of the team provide physical and psychosocial care and guidance to the residents in their daily life
- 3 logistic employees
- staff : 1 psychologist, 1 physician, 1 manager

Except for these members of the multi-disciplinary team, residents can receive treatment from « external » professionals of their choice: speech therapist, physical therapist, nurse, medical specialists,...

Future

Since one of our goals is to make transitions in the life of a person with HD as smooth as possible, we chose to give people the opportunity to stay in Home Marjorie when they are in stage 5 of the disease. To attain this goal, we need to enlarge Home Marjorie, so we can specialize in care for people in stages 3 and 4 on the one hand and stage 5 on the other.

We are planning to expand Home Marjorie with 16 extra residents. We are hoping this will be realised as soon as January 2010.

Bart Corthals