Home Marjorie
emmaüs

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The project

Home Marjorie is a small project, subsidized by the Flemish government. It was at first an initiative from the VZW Home Marjorie, a small part of the Flemish Huntington League. This small group focused on creating a housing project for people with Huntington's Disease (HD) in Flanders (Belgium). Contacts with several care facilities from the region resulted in a cooperation with VZW Emmaüs- DVC Zevenbergen.

Target group

Home Marjorie mainly focuses on care for people with HD. HD is dominantly inherited. It is a neurodegenerative disease, which leads to physical, cognitive, psychological and psychiatric problems.

There are three living groups, one for eleven residents and two for eight.

The most important criteria for admission are:

- People who are socially isolated or have social problems are prioritized
- Also relatively young people with HD get preference
- People choose to live in Home Marjorie with other people with HD

In Home Marjorie, there are also a limited number of places for people with a non-congenital brain disorder, who need long-term care. They have a complex demand for care, similar to the HD patient.

Home Marjorie offers residential care, respite care and home care.

Basic principles

Home Marjorie wants to be a home for people with HD, not just a house. The purpose is to create living arrangements as close to normal life as possible. Every resident has his own past and personality. These are taken into consideration together with the interests of other residents and the group. It is expected from each resident that he acts like a contributing member of the community, to the extent possible with his disabilities. A goal is integration in the neighbourhood, to achieve this we, for example, recruit volunteers.

Home Marjorie offers a multidisciplinary approach:

- ADL-assistance
- Psychological support for residents and their significant others
- Medical care
- Paramedical guidance
- Nursing
- Assistance with (leisure) activities

In care, we emphasize maintaining autonomy and self-reliance.

Because of the individual progress of the disease, which is degenerative, individualised care is provided at every moment for every resident.

Advance Care Planning – Quality of Life

In Home Marjorie we talk to residents about their future. How does someone look at his life? What matters most? What enhances his quality of life? A few months after admission we start a series of talks with the medical staff and psychologist. Staff and resident together map the resident's view on his life, disease and care. This is essential to prepare for moments in which important treatment decisions have to be taken. We also engage the significant others in this process.

Additional Goals

Home Marjorie is a pilot project which seeks to test and refine the ideas about care and guidance for people with HD. It is part of our mission to share this experience and knowledge with other care facilities and families who care for people with HD.

It is also part of the mission to be active in building a continuous care circuit for people with HD in al stages of the disease.

Limitations

Severe psychiatric disorders that warrant continuous psychiatric care are a contra-indication for admission. When this type of problem occurs during the stay in Home Marjorie, this can lead to temporary crisis admission to a Psychiatric Care Facility.

Residents can stay in Home Marjorie until their demise. In the last stage of HD the resident is completely dependent on nursing care. Home Marjorie is not a medical centre. When the medical needs exceed the expertise of Home Marjorie, a (temporary) hospitalisation can be necessary.

The multidisciplinary team

The consultation within the multidisciplinary team is the cornerstone for the workings of Home Marjorie.

Team composition :

The attendants within a living group are responsible for the direct care of the residents around the clock. An important element in our day to day work is that every resident has a **primary caretaker** in the team, a personal attendant. This attendant tries to become a confidant for the resident and also his family. Both the resident and his family can go to the attendant with their story, their questions, their hopes and fears. The attendant becomes a spokesperson for the resident and his family, alerting his team members to the needs of the resident

The head attendants / coaches coordinate and guide the daily workings of the living groups or the services for which they are responsible.

The occupational therapists are responsible for activation and leisure, for managing the mobility and comfort aids, and for functional training.

The social nurse coordinates medical care. He is responsible for contacts with families together with the psychologist and also for the social administration regarding each resident.

The psychologist is a staff member responsible for the development of care principles and the incorporation of these principles in individual support and care plans.

The general practitioner of each resident is responsible for every medical decision.

In addition to the internal multidisciplinary team, we also work together with self-employed professionals (physical therapists, speech therapists, home nurse, physician-specialists)and volunteers.

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VLAAMS AGENTSCHAP VOOR PERSONEN MET EEN HANDICAP