



Centre for Specialized Care in Early Onset Dementia





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Early Onset Dementia**

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This brochure provides a general overview of the Florence Centre for Specialized Care in Early Onset Dementia, which has been established in the Mariahoeve Nursing Home. The Centre offers a number of different types of care, treatment and support for young people suffering from dementia and their family members.

The Expertise Centre participates in a network of organizations that focus on the maintenance and development of (care) provisions for young people suffering from dementia, supported by Alzheimer Nederland. The Florence Expertise Centre within the Mariahoeve Nursing Home was the first institution to receive a quality hallmark in 2008 for developing special services for these younger patients.

With over 4,000 employees, the Florence Care Group provides home care, residential home care, nursing home care, youth health care and advice and services in Delft, The Hague, Leidschendam–Voorburg, Rijswijk, Voorschoten and Wassenaar. The Centre for Specialized Care in Early Onset Dementia operates on an interregional basis and is therefore also accessible to people outside the Centre's catchment zone.

The name Florence

We believe that a name should say something about 'who we are' and 'what we do'. We therefore chose the name Florence, after Florence Nightingale (1820–1910), who laid the foundations for the nursing profession and the care sector as we know it today. She worked tirelessly on the realization and improvement of training for nurses, wrote books and aroused interest among business people and politicians, so that they would invest in healthcare. This allowed her to make vital advances in the professionalization of healthcare.

Explanation of terms

In this brochure, we speak of young people suffering from dementia or people with early onset dementia. The term 'care-giver' refers to those people who are actively involved with the person who is suffering from dementia, i.e. family members, friends, voluntary carers or relief workers.

Furthermore, the terms 'client' and 'resident' are used:

- 'Clients' make use of the services provided by the Centre for Specialized Care in Early Onset Dementia in their home situation, such as day care, the short stay facility, the psychologist, Case Manager, etc.
- 'Residents' live in the Mariahoeve Nursing Home.



Respect and consideration

Caring for people in a respectful manner: that is the objective of the Florence Care Group. Residents and clients are given the support they need to live their lives in a meaningful manner. They are able to be themselves as far as possible and continue their lives as normally as possible. The Florence Care Group places a great deal of importance on striving to maintain a high level of independence for its residents and clients.

We respect the way in which residents and clients view the world, their morals and values, their opinions and their feelings. Respect also involves commitment, consideration and showing a high level of interest. The employees of the Florence Care Group listen carefully and are trustworthy. In short, they keep their promises.



The Centre for Specialized Care in Early Onset Dementia

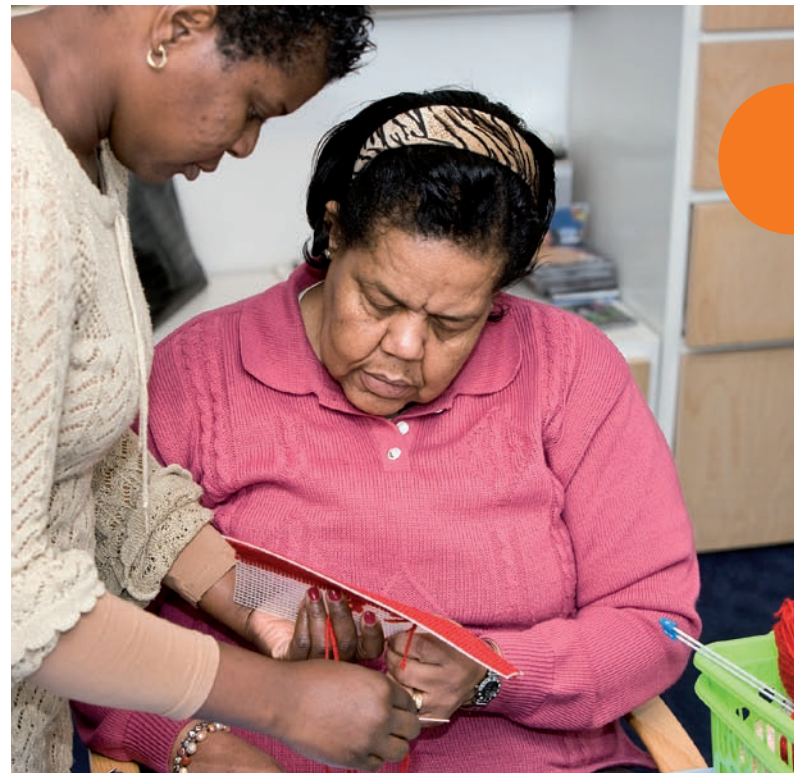
When thinking about dementia, many people initially think of a disease that is particularly prominent in older people. However, in the Netherlands there are approximately 12,000 people who develop the first symptoms of the disease before the age of 65.

Dementia has significant consequences for the lives of those who suffer from the disease, as well as for their care-givers. If the disease begins at a young age, this often raises a number of specific questions and issues. Many regular care institutions offer care for older people suffering from dementia, however, these services are often not able to address the specific problems and needs of young people suffering from dementia and those of their family members.

The Florence Centre for Specialized Care in Early Onset Dementia at the Mariahoeve Nursing Home has been working to develop specific healthcare services that are better able to meet the specific needs of these younger people and their family members since 1994. In the beginning, only day care was available for young people suffering from dementia, however more services were gradually developed, including services relating to information, diagnostics, treatment and support, care and living. These services have been brought together within the Centre.

The team of staff at the Centre is multidisciplinary, meaning that all disciplines that are involved in the care of young people suffering from dementia

form part of the same team. This team is made up of professionals such as Case Managers, Psychologists, Doctors, Physiotherapists, Occupational Therapists, Dieticians, Carers and Activity Supervisors. As all forms of care are provided by this same team wherever possible, the client and his/her relatives do not have to deal with many different people throughout the caring process.





The range of care on offer at the Centre

(Care) provisions are available from the Centre for both those suffering from dementia and their family members. Furthermore, care providers or those involved in the caring for those suffering from early onset dementia can have recourse to the Centre for Specialized Care in Early Onset Dementia in order to obtain information or for a consultation in areas such as the psycho-social consequences of the disease or the treatment of problem behaviour.

The following services are available at the Centre:

- Diagnosis and advice
- A helpdesk
- Case management
- Support groups and informal meetings
- Home care
- Day care centre
- Overnight stay facility
- Sheltered living
- Long-term care facility

‘Caring for people in a respectful manner: that is the objective of the Centre for Specialized Care in Early Onset Dementia’.

The range of care offered by the Centre for young people suffering from dementia and their care-givers is constantly developing. Continuous efforts are being made in order to further integrate, improve and expand the care provided. The innovative forms of care on offer and under development are highly inclusive and easy to access and take into account the wishes of both those who are suffering from dementia themselves and those of their care-givers.

Diagnosis and advice

Early onset dementia is often not recognized in good time. It often takes a long time before the diagnosis is made, however even after the diagnosis has been made, there are often still a large number of questions about matters such as changes in functional capabilities, changes in behaviour and the way in which these changes can best be addressed.

The Centre for Specialized Care together with the departments of neurology and neuropsychology of the HAGA Medical Centre offer the opportunity to investigate these changes and those involved in the care of the client can obtain advice about how to care for the person suffering from dementia and about the (additional) assistance that is available to them. The investigation always takes place in collaboration and consultation with the patient's own GP.

A support and information point (STIPJD)

Mariahoeve would like to fulfil an informative function for anybody who has queries regarding early onset dementia or regarding caring for people who are developing early onset dementia. Questions can be submitted by e-mail or telephone

by contacting the helpdesk of the Centre for Specialized Care in Early Onset Dementia (by e-mailing STIPJD@florence-zorg.nl or by calling +31 (0)70 754 66 66).

Case management

In addition to the efforts of the patient's partner, children and other informal carers at home, support, treatment and care is often also provided by a number of formal care providers, i.e. institutions or health care professionals. The Case Manager can contribute towards the client being able to remain living in his/her own home for a longer period of time, by taking over (part of) the management and the supervision of all the (in) formal care provided. Admission to a nursing home can therefore be postponed or, in some situations, prevented altogether.



Support groups and informal meetings

The Centre also organizes support groups for partners and also meetings for the children of parents suffering from early onset dementia. The aim of these groups, which are supervised by a psychologist and a social worker, is for those facing the same issues to have contact with one another, to share their experiences and to provide one another with advice and information.

Additionally informal meetings for people facing the consequences of early onset dementia take place in Mariahoeve's grand café once every six weeks. Healthcare professionals from the Centre are also present during these meetings in order to answer questions and to give advice. These meetings are open to everybody.

Home care

In order to support clients who live at home, Mariahoeve works together with Florence home

care and with other home care organizations. In consultation with the client and his/her caregivers, the Case Manager inventorizes care the client's needs in areas such as self care and managing the household and supports the caregiver in arranging the services to meet these needs. If needed, use is made of the expertise of other disciplines in the Centre for Specialized Care.

Day care centre

The day care centre is able to provide support in the everyday activities carried out by the client, provides advice regarding the type of care that a client requires and, where possible, treats the symptoms that occur due to the client's dementia. Depending on the client's way of life, individual needs and abilities, agreement is reached regarding the components of the day care programme that the client will participate in, such as a support group, a fitness group or memory training.



The day care centre can also provide relief to the client in addition to the care that is offered at home, or in order to provide respite for the client's partner and the other people involved in his/her care.

Overnight stay facility

Sometimes, temporary respite care, in which the client stays overnight or for several nights within the facility, is desirable as a result of changes within his/her home situation or in order to relieve the burden that rests on the shoulders of the client's partner or care-givers. If this is the case, there is a possibility for a short stay in the long-term care facility of the Mariehoeve care facility for people with early onset dementia. Two guest rooms are available at one of the units of the long-term care facility, which can be used intermittently for instance one day a week or a number of days at one time.

Sheltered accommodation

When it is no longer possible to live alone or at home, but admission to the nursing home is not yet required, clients have the option of moving to the sheltered living facility at the Centre. The Centre has several places in its 'sheltered living project', which is linked to the nursing home. 'Sheltered living' means, for example, providing assistance with household duties such as cooking and providing everyday support with other activities of daily living.

Living with nursing home care

If the client is no longer able to continue living in his/her home there is the option of admission into the long-term care facility of the Centre. This facility provides 60 places spread over several small-scale housing units, and are intended for clients who are 65 years of age or younger. The level of service varies within these housing units.



In the residential section of the Centre, staff work with the client and his/her care-givers in order to establish how the client's way of life can be continued following his/her admission and these arrangements are set down in an individual care plan. The client receives support in areas such as carrying out everyday tasks, preparing and eating meals and personal hygiene, all based on this care plan. The extent to which the client's caregivers wish to and are able to contribute to this is also discussed.

Having your say and making complaints

“We respect the way in which the residents and clients view the world, their morals and values, their opinions and their feelings.”

Client Advisory Board

The Client Advisory Board consists of representatives of family members or relatives of residents and clients and is an advisory body within the Florence Care Group. The aim of the Board is to represent the interests of residents and clients. Requests or problems relating to the atmosphere and quality of life can be submitted to the Client Advisory Board.

Complaints procedure

At any location in which people live and work together, some things will go better than others, whilst certain aspects will function less effectively. A procedure has therefore been established in order to handle complaints effectively and a brochure explaining the complaints procedure is available at Mariahoeve.



Contact

You can contact the Centre for Specialized Care in Early Onset Dementia via the Helpdesk at STIPJD@florence-zorg.nl or by calling +31 (0)70 754 66 66.

Costs

The facilities outlined in this brochure are funded under the provisions of the National Act on Exceptional Medical Expenses [Algemene Wet Bijzondere Ziektekosten (AWBZ)]. Depending on your own personal situation, you may be asked to make a contribution towards the costs in specific cases. Additional costs not funded under the provisions of the AWBZ will be passed on to the client.







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