

PRoF Award abstract – Call 2015

<We take care!>

1. Research Outline

Acronym	
Project name in English	We take care!
Pitch (1 sentence)	Regional care-network for people suffering from early onset dementia and their relatives
Executive summary (max. 10 lines)	
<p>This project, with a network of organizations, is trying to give a paradigm shift about early onset dementia, to the region, by a number of activities. The main goal is to bring early onset dementia into the community by giving information and integrate the care for people with early onset dementia in the community.</p> <p>First we are developing activities to promote the awareness and knowledge about the different kind of diseases that are known as ‘Early onset dementia’. An accurate and fast diagnose is the next step and is crucial to a good care-attitude. Further on we support the capacity of the relatives to take care for the people with early onset dementia at home, as long as possible. A day care center in the neighborhood, with professionals and volunteers is supporting our main goal of optimal integration and staying at home as long as possible. At the end we have a small scale housing project for the residential care of people with early onset dementia. This project is unique in Belgium, and as far as we know in Europe.</p>	

2. Cause and context of the research

Due to a lack of epidemiological data, no accurate data exist on the prevalence of early onset dementia in Belgium. When we extrapolate international prevalence rates to the Belgium context, estimates are between 3.000 en 12.500 people with early onset dementia. In Belgium there are no specialized or specific care settings or arrangements for persons with early onset dementia. Diagnoses have been made too late, people stay unknown on what is going on⁽¹⁾. We heard stories of people who lost their job without any financial support or couples who got divorced, because of the change in the behavior of the person with young dementia. People often get misdiagnosed as being mentally ill, depressed or burn-out, with maladjusted treatment as a consequence ⁽²⁾.

Once the diagnose of dementia is recognized, people don't know where they can get further and specific information, education or support. They get stressed and have, after some time, no more energy to cope with the situation. Residential care is eventually the only option. Because to date there are only a few specialized residential care units in Belgium for persons with early onset dementia, they have to go to a nursing home for elderly people, where they will be surrounded by people of 85 years and older...

Our goal with this project is to set up an integrated care project for the region, for people with early onset dementia and their caregivers. We want to support the caregivers, so the people with early onset dementia can live longer in their own house and stay active citizens as long as possible. If residential care is needed, we have a specialized care unit for people with early onset dementia.

We designed our project as an network care project, involving four stages of care.

The first stage is to provide caregivers and professionals enough information about the behavioral and clinical manifestation of early onset dementia. This includes a lot of different actions on different fora. To do this we work together with the SEL, a platform of all primary care organizations (including health and social care).

(1) Van Vliet, D., de Vugt, M.E., Bakker, C., Pijnenburg, Y.A., Vernooij-Dassen, M.J., Koopmans, R.T. & Verhey, F.R. (2012). Time to diagnosis in Young-onset dementia as compared with late-onset dementia. *Psychological Medicine*, 28, 1-10.

(2) Van Vliet, D., de Vugt, M.E., Bakker, C., Koopmans, R.T.C.M., & Verhey, F.R.J. (2010). Impact of early onset dementia on caregivers: a review. *International Journal of Geriatric Psychiatry*, 25, 1091-1100.

The second stage is an accurate diagnose made by a multidisciplinary team of specialists. Here we can rely on two 'Center for cognitive diagnostics and revalidation', who are a part of the two general hospitals in the city of Bruges.

The third stage involve the delivery of specialized care and support based on the individual needs of the person with early onset dementia and his caregiver(s). This can only be realized through a collaboration between several organizations.

Regina Coeli is an active member of the SEL, Regina Coeli works closely together with FOTON, an 'Dementia expert center' in Bruges. By means of individual counselling and group meetings, Foton , supports families and patients to deal with (early onset) dementia. Educating professionals is another method.

Regina Coeli has started – as the first in Belgium - a day care center for people with early onset dementia. Here, persons with early onset dementia , can come every day in the week from 8.30 until 17.30. We provide them activities in a safe and adjusted environment. The day care center is located in a normal house in the neighbourhood. This lowers the psychological barrier to come to the day care center. It also supports the integration and activation of persons with early onset dementia in the neighbourhood. (3)

Staff members of the day center got an additional training and are supported by Foton and the specialists from the 'Center for cognitive diagnostics end revalidation' mentioned above.

In May 2015 Regina Coeli is starting up a residential unit for people with early onset dementia.

After almost four years of pioneering work we supported almost 100 people with early onset dementia and build up some experience we can and will share with other professionals.

3. Innovation results achieved

Results for people with early, onset dementia

(3) Grinberg, A., Lagunoff, J., Phillips, D., Stern, B., Goodman, M., Chow, T. (2008). Multidisciplinary design and implementation of a day program specialized for the frontotemporal dementias. American Journal of Alzheimer's disease and other dementias, 22(6), 499-506.

During our four years of pioneering work we learned several aspects :

- the period between the first symptoms and the diagnose of dementia becomes shorter.
- there is a program adjusted to the individual needs of persons with early onset dementia, so they don't have to rely on the psychiatric programs or day care programs for very old people
- the persons with early onset dementia receive adequate emotional support, and adapted activities
- although staying at home is preferable, the disease process necessitates at some point 24h-care. Since 2015 we also have a unit with adapted residential care for persons with early onset dementia in the region of Bruges.

Results for families and caregivers

- the families get informed sooner on the diagnose of early onset dementia. This is the starting point for adequate information, care and support
- family members are offered individual counselling in order to cope with the behavior of their relative with dementia
- families get the possibility to get in contact with other families with the same problems so they can exchange experiences, and support each other.
- if the person with dementia attends the day care center, family members get a short relief from care at home. They maintain more energy to continue to care longer for their relatives.
- We experience the organization of the transport to the day care center as a problem.. People have to bring their relative by themselves or have to rely on an extern organization and volunteers. This brings sometimes financial problems.

Professionals

- Many organizations came to visit our project.
- The network care program for persons with early onset dementia gives professional caregivers the opportunity to build expertise in this specific form of dementia. Especially, they learn to identify symptoms of early onset dementia, and strengthen their signal capacity for new cases. In this way they can contribute to a more timely diagnose of the disease, which opens in his turn the opportunity to inform and support the people with early onset dementia and their caregivers.

Inhabitants of the city, municipality (4)

- This program gives the opportunity to people with early onset dementia and their caregivers to be much longer integrated in their own community
- This project indirectly helps to de-stigmatize persons suffering from dementia, by increasing information to the public, working with volunteers and breaking the taboo of early onset dementia.
- It is the intention of the program to delay unnecessary residential care, which lowers the health care costs for the community.

In sum, this project supports the quality of life of persons with early onset dementia and their caregivers. We get very positive feedback from all of the stakeholders of this project. A student made a paper for his bachelor degree social work about the satisfaction of the families and caregivers of this project. The results of this paper supports the original feedback from the stakeholders

There are no programs for people with this specific needs. If we ignore these people we let them alone with their social, psychological and financial problems, who are, although it's a relative small group, enormous. This project deserves to be enhanced because there is a great need for an integrated care program for the people with early onset dementia.

We think this experience can be transferred to other regions and countries, because it builds on already existing structures and knowledge and reinforces it by putting them together around one problem. The external input on manpower and financial input is relatively small, but the benefits are huge for the users.

4. Link to the PRoF values

4.1. Minimal comfort

By supporting family and other caregivers, people with early onset dementia can stay at home as long as

(4) Morhardt, D. (2011). Accessing community-based and long-term care services: challenges facing persons with frontotemporal dementia and their families. *Journal of Molecular Neuroscience* 45(3), 737-741.

possible. We bring them in contact with other social services who can provide them some extra comfort, if needed. Our most important contribution with this project is a level of psychological comfort we can offer the person with early onset dementia and their caregivers. They are not alone anymore, we support them with coping mechanisms and looking for solutions for all kinds of problems that occur during the process of early onset dementia. If possible we can provide them some solutions from our care network, if needed we can collaborate with any other organisation who can help the person with early onset dementia and their relatives.

4.2. Privacy

In this project we follow the rules of our professional secrecy policy. We have a great respect for the values and power that are within every family. We believe that's our goal to explore, empower and enable the social system around every client to solve their own problems.

4.3. Security

In our activities in the day care center and the residential care unit we are always looking for a balance between self-determination and security. We always try to make agreements with the person with early onset dementia and their caregivers about their values and what is needed to secure as well the physical and the psychological safety of the individuals and the people in their immediate surrounding.

4.4. Anti-loneliness

People suffering from early onset dementia are getting more and more isolated. Once the disease occurs they are losing their jobs. They have to stay at home. After a while they can't be alone at home and their partner/caregiver has to give up his work (at least part time) to take care. So the people with early onset dementia and their caregivers get more and more isolated. One of the goals of this project is to integrate these people back into the community and to give them the opportunity to make some new meaningful contacts.

4.5. Non-stigmatising solutions

One of the goals of this project is to inform caregivers and professionals about the behavioral and clinical manifestation of early onset dementia. By informing people we hope and experience that people got another view on the people with early onset dementia. In succession of the framework 'Dementia: forget the illness,

remember the person' promoted by the government, we hold the focus on the person with dementia and avoid any stigmatization.

4.6. Intergenerational

People with early onset dementia often have children still living at home. Recent research indicates that 75% of parents report that their children have suffered psychological or emotional problems as a consequence of a parent having dementia. In our program we organize special sessions for the children of people with young onset dementia in order to give them some coping attitudes and give them a platform for sharing their feelings with peers.

4.7. Respect

Respect for the people with early onset dementia and their caregiver is the 'file rouge' through our project. We want to include them in the community as long as possible and empower them to cope with their own disease as long as possible. When residential care is needed we surround them with a care program that is as much adapted on their personal needs as possible.

4.8. Flexibility

Our program is an 'open' program. People can step in wherever and whenever they want. On the other side we are willing to collaborate with other partners who are not included in our project. The main goal is to increase quality of life of the people with early onset dementia and their relatives.

5. Applicable IPR rules

We are willing to share our experience with everyone who's interested and have no specific IPR-rules about this concept..

6. Information on the partners

- WZC Regina Coeli Brugge
- SEL Brugge Noord West Vlaanderen
- AV Sint-Jan Brugge-Oostende



- AZ Sint Lucas Brugge
- Cura thuisverpleging
- Foton expertisecentrum dementie Brugge
- Different school collaborations:
 - HOWEST bachelor education in social sciences
 - LUCAS – KU-Leuven master education

Addendum: Contact information

Identification of author: [Paul Braem](#)

Organization:

[WZC Regina Coeli vzw](#)

[Koning Leopold III laan 4](#)

[8200 Brugge](#)

[Tel.: 050/40.77.00](#)

[Email: \[paul.braem@reginacoeli.be\]\(mailto:paul.braem@reginacoeli.be\)](#)

[Website: \[www.reginacoeli.be\]\(http://www.reginacoeli.be\)](#)