



# Centres of expertise on dementia

Motivated  
Professional  
Connecting



expertisecentrum  
**dementie**  
Vlaanderen





## ► Motivated. Professional. Connecting

Providers of care and support for people with dementia are facing a major challenge today. How can we do this in a professional way with respect for the wishes and desires of people with dementia, carers and social workers? We focus on how we can work with all these parties to ensure people with dementia can participate fully in society. Because to keep being included in all areas of life as an individual with a personality is what matters to them most.

The Flanders Centre of Expertise on Dementia and the regional centres of expertise are based on a person-centred vision with respect for individuals' life stories, needs and preferences. We do this by sharing useful knowledge with people throughout the health and welfare sector: caregivers, volunteers and professionals in your own organisation. This knowledge is inspired by literature and best practices, preferably using a bottom-up approach.

We must now focus on today's individuals with dementia with their needs and abilities. This also means that we constantly keep our eye on the quality of life of people with dementia. We love clear simplicity, so that the persons caring for people with dementia are optimally informed of the current developments in science, care and support forms. That is why we like to look ahead and we want to be a leader in our field in Flanders. We want to stimulate debate on how to organise care and support to improve the daily lives of vulnerable people. And every now and then, we dream that dementia will be treatable one day, that each person will experience his or her care as excellent. Meanwhile, we enthusiastically stay on track to proudly mean something to people with dementia and their families. We hope to meet you down the line.



Jurn Verschraegen  
Director



Wino Baeckelandt  
Chairman

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The web page [www.dementie.vlaanderen](http://www.dementie.vlaanderen) is an excellent reference for current information and a compilation of all dementia websites by key actors.

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We always keep our eye on the latest prevalence figures, new publications, inspiring projects or the latest status of scientific (care) research.

## 19 | Cooperation and networking

Together, we innovate and optimise the range of care and we make the care and support of people with dementia future-proof.

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The centres of expertise on dementia all gain knowledge and experience about one or several specific topics. More information on this is available on [www.dementie.be](http://www.dementie.be).

## 23 | Staying longer at home with dementia

International research has shown that a timely diagnosis and psychosocial support can help people with dementia live at home for up to one and a half years longer. This is one of the objectives we focus on.

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"The way you treat and talk to each person is different and depends on what he or she is able and unable to do, what he or she forgets and doesn't forget."

[ PIERRE VAN HOUCKE, SON OF A MOTHER WITH DEMENTIA ]



## ▼ Range of tailor-made training

Today, lifelong learning is the norm. This is good, because it keeps us aware of innovations in health care and evolutions in the various aspects of dementia care. There are many challenges: learning to recognise the early signs and symptoms of dementia, the impact of dementia on a person, the caregiver and the immediate environment, the impact of drugs and non-drug interventions, communication, the role of health care staff and the way organisations work together, legal aspects, autonomy issues such as driving a vehicle, questions about the end of life and palliative care...

Well-trained health professionals and volunteers can help to achieve the ambition 'to live longer at home with dementia', which may prevent people with dementia and carers from getting isolated. We focus on the remaining possibilities, rather than loss.

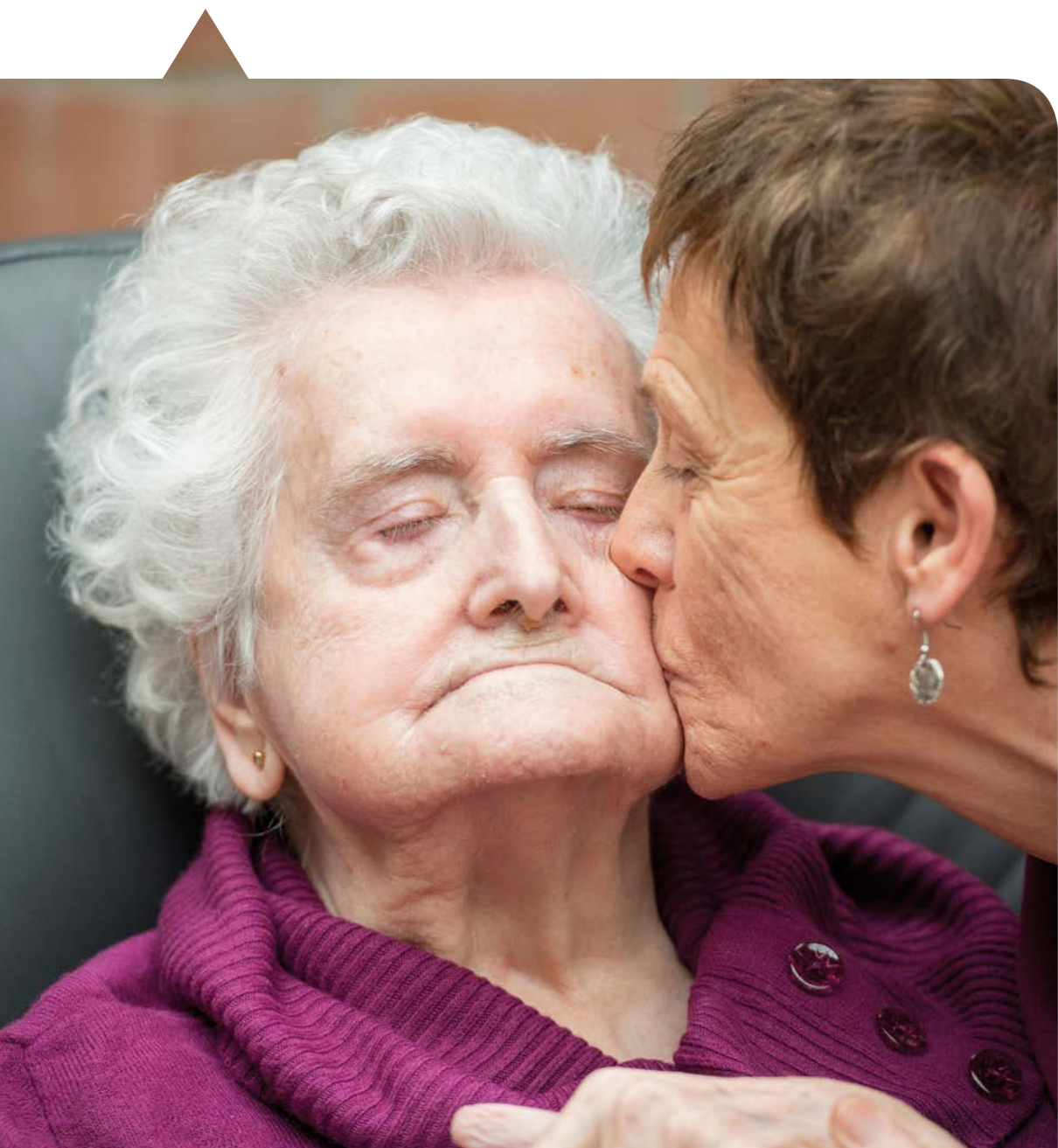
### **Skilled health care workers can make a difference for people with dementia.**

The Flanders Centre of Expertise on Dementia and the regional centres of expertise on dementia contribute by offering targeted training opportunities. We developed a state-of-the-art training course which offers professional leadership on dementia to organisations. The government makes these programmes possible. The transition plan, for example, puts a strong emphasis on training dementia expert care workers and volunteers at organisations providing health insurance and domestic services. We continue to stay in touch with health care practice through targeted peer coaching offered by the regional centres of expertise on dementia.

We regularly organise seminars on new topics to keep as many people as possible up to date on the latest insights and developments in dementia care. We always remain alert to what persons with dementia are asking us. The main focus of the training programme of the Flanders Centre of Expertise on Dementia and the regional centres of expertise on dementia is the continuous improvement of the quality of life of persons with dementia.

"I think that a lot of people are now aware of what dementia is in theory, but acceptance is not always easy in practice."

[ JASMINE COPPENS, GRANDDAUGHTER OF A GRANDMOTHER WITH DEMENTIA ]





## ▼ Low-threshold awareness raising

An inclusive approach of people with dementia and their carers starts with respectful communication. Dementia is primarily a social issue. The dominant view until now hides certain values that mainly see dementia in a negative light. The Flanders Centre of Expertise on Dementia and the regional centres of expertise on dementia recently took many steps to bring social perceptions more in line with reality. One of these initiatives was the 'Music for Life' dementia campaign, the 'Te Gek!?' project about younger-onset dementia, the 'Forget dementia, remember the person' campaign and the 'New Energy For Young Dementia' expedition to Nepal.

In the future, we will remain wholeheartedly committed to the possibilities and value of people with dementia rather than just focus on what is no longer possible. Research has shown that efforts to adjust perception pay off, but there is still a lot of work to be done. 80% of the Flemish population believes that people with dementia can still enjoy the small things in life, but at the same time half the population thinks that people with dementia lose their identity. **The perception of dementia depends on how you look at the condition. Does it adequately reflect how people with dementia themselves see their condition?**

We want to promote the growing public support for a dementia-friendly Flanders in the future. We will ensure permanent progress by sharing good practices and launching, supporting or promoting initiatives. Promoting the autonomy of people with dementia is essential, which is why we also draw attention to prevention and early diagnosis. Breaking the taboo of dementia is a long process, an ambition we want to achieve step by step. The Flanders Centre of Expertise on Dementia and the regional centres of expertise on dementia therefore want to encourage people of all ages to give people with dementia the place they deserve: right in the middle of a warm society rather than in the margin of it.

"I think it is very important that people can find the necessary information on dementia quickly and easily, and they know the right way to treat people with dementia right from the start. People sometimes forget they have feelings too!"

[ MARLEEN JORIS, DAUGHTER OF A MOTHER WITH DEMENTIA ]



## ▼ Scientific and practical information

There is a lot of research on dementia: into the medical causes, into the ways the condition can be prevented or delayed and into what constitutes good care for people with dementia now. The Flanders Centre of Expertise on Dementia and the regional centres of expertise on dementia are working on a constructive connection between the scientific world and the care we provide to persons with dementia and their families. We do this by staying in close contact with scientists, by following local and international publications, by participating in steering committees, working committees and conferences. We also bring science and practice together in our training sessions, seminars and informal gatherings for people whose lives have been touched by dementia.

We aim to make the results of scientific research more easily available and more known through reviews, articles on researchers in our newsletters and announcements of remarkable results through our social media channels. We also publish our own clear and accessible articles on science and practice, for example in our loose-leaf manual 'Dementia, from understanding to supporting'. We aim to make scientific information more accessible at our resource centres. We have thousands of publications available at our four centres in Antwerp, Bruges, Brussels and Ghent or online. Everyone can use the catalogue on [www.dementie.be](http://www.dementie.be) to find what is relevant to a particular situation. More information on literature regarding a specific question or situation can also be emailed to [doc@dementie.be](mailto:doc@dementie.be). We like to help in the search for suitable studies and relevant information.

**We want to align science and practice better by presenting the research results to the health care practice.** We also do this by bringing together and presenting the health care practice questions to the researchers. In early 2015, we published a joint research agenda with the Flemish Alzheimer's Society outlining the future challenges in care for people with dementia (available in Dutch on [www.dementie.be/home/zorg-onderzoek-2/zorg-onderzoek](http://www.dementie.be/home/zorg-onderzoek-2/zorg-onderzoek)).

"Pay attention to people with dementia  
by asking for their opinion and ...  
by letting them talk about other  
things than their condition."

[ CHRISTIANE VANDAELE, PERSON WITH DEMENTIA ]





## ▼ A wide range of communication channels

The Flanders Centre of Expertise on Dementia and the regional centres of expertise on dementia have always focused on the professionalization of their communication. We have built a wide range: books, brochures, flyers, presentations, ... and we also have a strong, integrated online presence.

- ▶ The central website [www.dementie.be](http://www.dementie.be) presents the web pages for every regional centre of expertise and the central website of the Flanders Centre of Expertise on Dementia. We also offer three websites about the key aspects of dementia care.
- ▶ [www.omgaanmetdementie.be](http://www.omgaanmetdementie.be) uses audiovisual materials and testimonials to share tips and tricks to people in the entire care process.
- ▶ The website [www.jongdementie.info](http://www.jongdementie.info) is the product of cooperation between Flanders and the Netherlands and offers up-to-date information on all aspects of young-onset dementia.
- ▶ On the occasion of the 'Forget dementia, remember the person' campaign by the Flemish government, the website [www.onthoumens.be](http://www.onthoumens.be) was set up to support dementia-friendly communication, person-centred care and an inclusive society for people with dementia.
- ▶ **Finally, there is the web page [www.dementie.vlaanderen](http://www.dementie.vlaanderen), a reference site for current information that offers an overview of all the websites of the key actors on dementia.**

We also integrate the opportunities and challenges of the various social media in our communication as much as possible. You can find us on **Facebook**, **Twitter**, **LinkedIn**, **Pinterest** and **YouTube**. We focus strongly on social media to play a pioneering role and to continue to innovate our online communication. This way, we hope to maximise and sustain the momentum of our support, information sharing and accessibility. We want to be the point of contact for anyone with any questions about dementia. The centres of expertise are always available to offer advice by phone, email or in person. The common goal of this wide range of communication channels is customised support in all areas that contributes significantly to improved dementia care.

"Dementia can't be prevented. This can discourage people in their search for help and information. An even better framework at the diagnosis stage can take away a lot of uncertainty."

[ LUT MOEREELS, DAUGHTER OF A MOTHER WITH DEMENTIA ]



## ▼ Dementia-friendly environment

To many people with dementia, their daily walk to the bank or the local supermarket is a ritual and a sign of their autonomy. But how should people deal with someone with dementia when he or she wants to pay for something twice or comes in to buy the same thing three times in one day? We notice that these practical situations can lead to misunderstandings and defensive reactions. These are missed opportunities, because honouring the dignity of people with dementia will benefit everyone involved.

We have come a long way in recent years. Encouraged by numerous inspiring pilot projects, the concept of a 'dementia-friendly community' is now becoming established nationally and internationally. Local councils working on this topic are gradually making society more dementia-friendly. Dementia-friendly initiatives care for people in the broadest sense of the word. They make sure that people with dementia still count and understand that their social identity should obviously be maintained and should not have to be incessantly defended and protected by the affected individuals and their families. Dementia-friendly projects offer meaningful activities in various areas involving culture, sports, tourism, ...

The dementia-friendly objectives are achieved thanks to the warmth, commitment and humanity of everyone in local communities. However, the ambition to work on a cross-policy level and to set policy priorities is also essential. The Flanders Centre of Expertise on Dementia and the regional centres of expertise on dementia also want to play a supporting role in terms of advice, networking and the communication of good practices in the future. A dementia-friendly living environment involves a lot more than the local authority alone. **It requires the help of the entire community and we need to ask the existential question of how people with dementia want to live and which support they want.**

“It is very important to be clear from the beginning, to use the ‘right’ words. You also have to believe in your own power, even though some of the people close to you will avoid your condition – or even you as a person. This is also a permanent task for the policy on dementia. Do not leave people with dementia alone to deal with their ‘problem’, stay close to them, provide customised assistance and listen to them!”

[ KRISTIEN STEELS, PERSON WITH YOUNG-ONSET DEMENTIA ]





## ▼ For a powerful dementia policy

A region, country or community without a dementia plan is like a sea without a beach. At times of increasing numbers of people with dementia, a dementia plan seems obvious, but this is certainly not the case. That is why the Flanders Centre of Expertise on Dementia and the regional centres of expertise on dementia focus on a strong dementia policy. As the partner organisation of the Flemish government, that is our role. We ensure that policy makers continue a powerful dementia policy in Flanders. **We understand the concept of 'not more, but different care' in the principles of this policy as an invitation to base our thinking on the needs of the user.** We feel that the chronic care model is an important starting point in which the control of the person with dementia and/or his representative is key. This model identifies the key elements that contribute to quality health care:

- ▶ Support of self-management, for example through patient information and joint decision making
- ▶ Support of decisions, for example with guidelines for health care providers
- ▶ Organisation of a care system, for example through interdisciplinary methods and care coordination
- ▶ Clinical information systems, for example with automated information
- ▶ Policies and tools at local community level, for example with physical activity programmes
- ▶ Organisation of health care focusing on leadership and clear organisation objectives.

In Flanders we cooperate with the National Institute for Health and Disability Insurance (RIZIV). Together, we determined the regulatory framework of the training course for professional leadership on dementia in organisations, for example. We also stay in touch with the latest dementia policy developments in the French and German speaking parts of Belgium. We also publish a memorandum during elections. Of course, these challenges do not end at our national borders. We use international networks to exchange good practices and gain new insights from health care research. This is how the centres of expertise aim to contribute to an effective dementia policy at all policy levels.

"We are very grateful to the health care staff for their commitment and support. The sector's good work also deserves to be in the spotlight every now and then."

[ WIM VAN LOOCKE, SON OF A FATHER WITH DEMENTIA ]



## ▼ A reliable media partner

The Flanders Centre of Expertise on Dementia and the regional centres of expertise on dementia act as an indicator for the various governments and policymakers, and to the media as well. We point out trends, developments and problems. We interpret and clarify current trends, pressing issues and future challenges in dementia care. **We immediately respond to the latest prevalence figures, new publications, inspiring projects and the state of scientific (care) research.** Accessibility, clear communication and professional advice at regional, national and international level are our main concerns.

We listen to the voice of people with dementia and their caregivers as much as possible in this respect. They are the final touchstone in everything we do. Our work goes hand in hand with the Flemish Alzheimer's Society – the patient organisation – and other umbrella organisations. The centres of expertise on dementia see the various media as key partners to translate the dementia policy to the daily practice and share dementia-friendly communication. We are always available to offer our interpretation of the order of the day. Over the years, a relationship of mutual trust developed on which we continue to build. This is essential, because dementia will continue to be an important topic for the media in the next few years more than ever. They can count on us!

"I would like to see conversations with people with dementia, rather than about people with dementia. They should always be approached with respect and dignity. It is the only way we can learn how to approach them better in everyday life."

[ BERNARD GABRIELS, CAREGIVER ]





## ▼ Cooperation and networking

The Flanders Centre of Expertise on Dementia and the regional centres of expertise on dementia choose to use knowledge that is based on the existing expertise in the field: in residential care organisations, in various professional groups (doctors, pharmacists, speech therapists, ...), at universities, colleges, palliative networks and umbrella organisations. We always consult these parties in advance and the aim is to ensure an optimal mix of care for people with dementia and their environment in a way that is driven by practice, but based on evidence where possible.

**Together we innovate the care available and we make the care and support of people with dementia future-proof.** Our health system would not be what it is now without electronic care records, for example. Dementia care in this country would be very different if the dementia consultation platforms did not exist in the various care regions. We want to be part of a positive story in which we can make mutual contributions. The work of the regional centres of expertise on dementia complements the Flanders Centre of Expertise on Dementia in this respect, so we can learn from each other's expertise and combine our knowledge. One example of this is knowledge sharing on early care planning in cooperation with palliative networks.

We also cooperate very closely with the Flemish Alzheimer's Society. Both our organisations are driving forces behind the dementia policy in Flanders. The Flemish Alzheimer's Society is a patient organization that mainly shapes policy by addressing the families. We developed 'Dementia and you' together, a support package of good practices for carers. The Flemish workgroup for young-onset dementia has also joined forces and expressed the need for the future policy. The Ten Point Plan of the working group joins the promoters in their pursuit of a coordinated policy.

Singing makes people with dementia more alert. The Flanders Centre of Expertise on Dementia brought together the worlds of culture and health and worked with Koor & Stem, Den Olm and VSPW to establish 'The Voice of our Memory'. We see more and more 'contact choirs' in Flanders: social gatherings where people with dementia can sing together. We also work together internationally on various topics: living, architecture, innovation in care, culture, ... Inspiring and supporting each other goes well beyond our national borders!

"We need to make sure that people with dementia are still seen as people. We have to encourage them as much as possible to participate in social events and stay in touch with family, friends, other people affected by dementia ... This will prolong their quality of life."

[ KARIN WILLEMEN, CAREGIVER ]



## ▼ Expert advice

The centres of expertise on dementia have gained a great deal of knowledge. We want to share this knowledge as training and education, but also as specialist advice. Take the topic of dementia-friendly living, for example. By focusing on staying longer at home with dementia, assisted living facilities have also started to evolve into places that feel much more like home. We therefore offer focused knowledge on functional housing, construction and interiors tailor-made for people with dementia to project developers and architects. We also work with the Flemish working group seeking to make assisted living and other care facilities small-scale and feeling more like home.

We work with Dementia Care Mapping to evolve towards good practices with the care team based on the residents' perspective. The dementia experts of the regional centres of expertise provide focused support to carers, people with dementia, officers and other care providers. The focus is always on the best possible care. This targeted support does not replace the expert dementia care workers at the various residential care facilities.

**The regional centres of expertise choose to specialise in one or more topics, which are available on [www.dementie.be](http://www.dementie.be).** You can also contact them for expert advice and targeted referrals with regard to certain care demands and a training programme that meets the current needs and requirements. The regional centres offer specific training packages about young-onset dementia, the learning ability of people with dementia, mealtimes in dementia care, ...

"People with dementia are people with a condition who can give a lot back that will enrich your inner life."

[INGRID VANDAMME, CAREGIVER ]\*





## ▼ Staying longer at home with dementia

Many studies confirm what our intuition suggests: people in Flanders prefer to live in familiar surroundings for as long as possible, even if they have care needs caused by dementia for example. Sadly, living at home becomes more difficult as people's autonomy decreases. Fortunately, Flanders has well-developed support ranging from domestic help with service vouchers to in-home help, short-stay centres and day care provided by residential care centres or collective autonomous day care centres. It is also important to see whether aids or home modifications could help. An occupational therapist can be very useful in that respect.

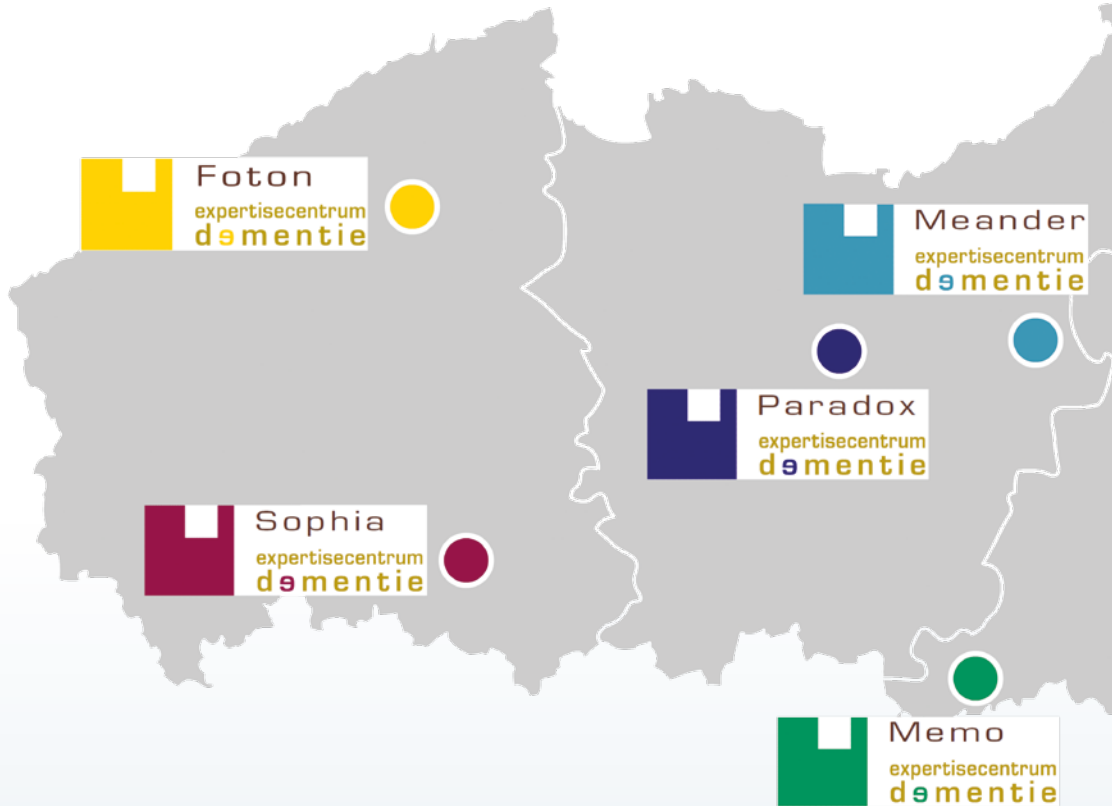
A key success factor for staying longer at home is family, mostly the spouse or children. Although they are not trained in providing special care unless they happen to be nurses or social workers, they are the prime carers of people with dementia, often 24 hours a day. This can be pretty intense. The centres of expertise on dementia therefore assist the person with dementia and their families as much as possible to increase their resilience. The psycho-education package 'Dementia and you' was established to help them. It contains ten sessions, which are offered by the regional centre of expertise on dementia, health insurance or hospital, for example.

Topics such as the perceptions of a person with dementia, how to deal with changing behaviour, financial aspects, ... are discussed in a small group. The focus is not solely on information, but also on the resulting feelings and emotions. **International research has shown that such support may allow people to live at home for up to one and a half years longer.** However, staying at home should not be a frustrating target when care becomes too overwhelming. The quality of life of both the person with dementia and the family determine whether the transition to an assisted living facility is desirable. The good care, rest and regularity this brings often results in a significant improvement.

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\* All quotes can be found on the website [onthoumens.be/ambassadeurs](http://onthoumens.be/ambassadeurs). The quotes are not related to the people shown in the pictures.

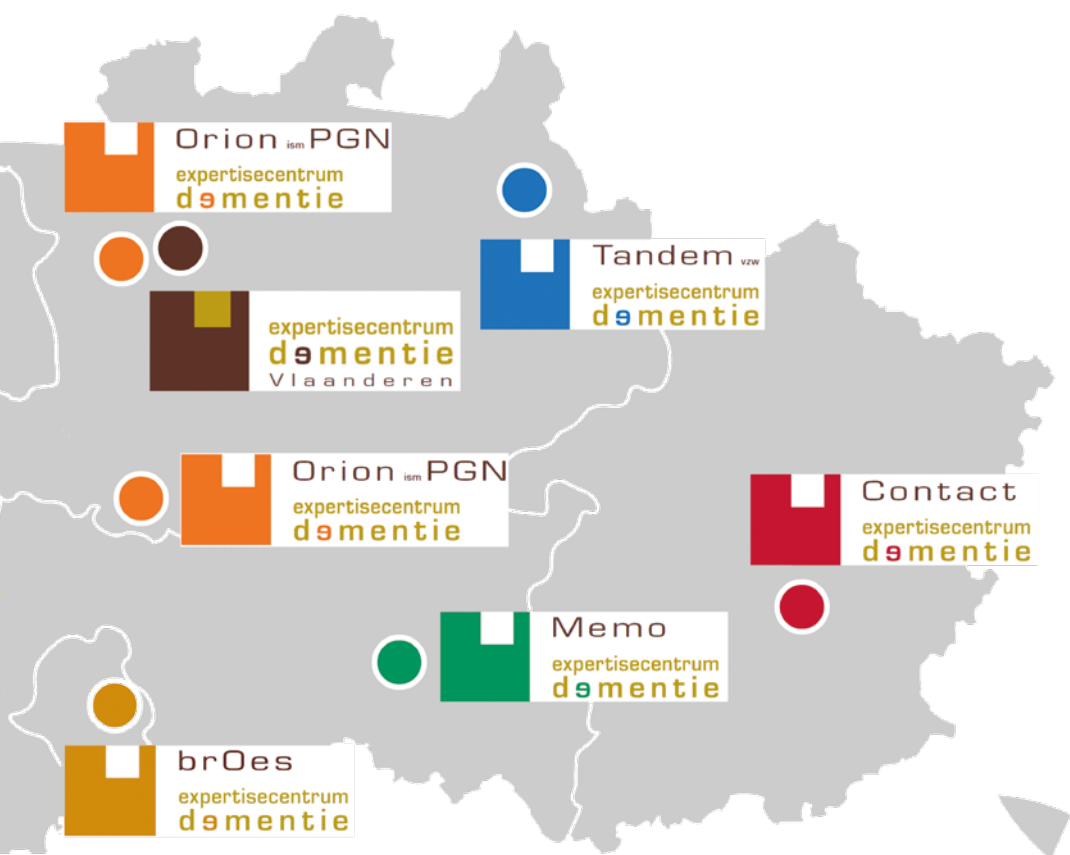
## ▼ An effective partnership



The Flanders Centre of Expertise on Dementia and the regional centres of expertise on dementia want to strengthen the environment of people with dementia. Based on an emancipatory vision, together we find suitable answers to the present needs. This may involve information, expert advice, training, support and strengthening the social network, cooperating with other services, organisations and the field of education.

Strengthening expertise in dementia in existing organisations and care providers is also essential. The gaps in what is currently available are reported to the government.

A lot of knowledge on dementia is available in Flanders. We aim to make this information accessible. The centres of expertise on dementia develop their own expertise, are in contact with local and foreign experts



and therefore bridge the gap with the user and his broad (care) network, by means of the dementia consultation platforms for example.

We are aware of new tendencies and innovative projects and aim to inspire others with this knowledge. We try to achieve quality care and support of people with dementia through cooperation and

coordination without competition, but with respect for everyone's convictions. The Flanders Centre of Expertise on Dementia and the regional centres of expertise on dementia are accredited as partner organisations under the residential care decree and are supported by the Flemish government.

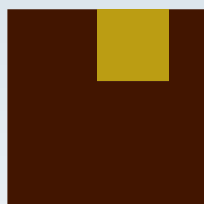
Please find below the contact details of the Flanders Centre of Expertise on Dementia and the regional centres of expertise on dementia:

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Accredited partner organisation of the Flemish government



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