Continuing to build a dementia-friendly Flanders together

Updated Dementia Plan for Flanders
2016 - 2019
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1. Introduction

The World Health Organization (WHO) estimates that there are about 36 million people worldwide living with dementia. Currently there is no adequate cure for this disease. By 2050, the WHO expects the number of people worldwide who suffer from this affliction to have increased to 115 million. The care of and support for people with dementia is a major challenge for their families and caregivers, care professionals and health and welfare facilities. The annual cost for the care and support for people suffering from dementia worldwide is estimated to be over €515 billion. This is comparable with the annual GDP of Belgium. Under the difficult economic circumstances, the available resources must be used efficiently.

Currently about 122,000 people in Flanders live with dementia. About 70 percent of these live at home, in some cases with the help of family, acquaintances and friends. By 2030, the number of people living with dementia will have increased by 25%. All the governments, caregivers and our society must ensure that people living with dementia continue to be integrated in our society and must provide the necessary care and support together.

Policymakers in various European countries as well as Flanders have developed an integrated dementia strategy, in which medical care, psychosocial assistance, social support and scientific research enhance each other. The Government of Flanders has opted in favour of adequate assistance to people with dementia and the people who live with them. The success or failure of this assistance is based on optimum care and support, which is governed by dementia patients and the people living with them and is defined by the care and support needs of these patients and the people around them.

The Government of Flanders has chosen the World Health Organization's conceptual framework for people-centred and integrated health and care services (WHO, 2015) as a care model. An approach focussing on demand-driven, person-centred and integrated care and customised support to people living with dementia purposefully starts from the perspectives of the patients, their family, friends and the community/ies to which they belong. On the one hand, the concept considers them as participants. On the other hand, they are beneficiaries of an effective welfare and care system, which inspires trust and fulfils their specific needs and preferences in a human and holistic manner. The care and support is organised with a focus their needs and expectations, rather than on their diseases and shortcomings.

The WHO concept focuses on the physical, social-economic, mental and emotional components of people’s welfare.

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2. European prevention of Alzheimer’s dementia consortium Summary.
WHO conceptual framework for people-centred and integrated health care (welfare and care), 2015.

The WHO framework explains that efficient and effective care of and support for people living with dementia involves various distinct yet integrated and mutually reinforcing aspects. The contribution of the patients, their family and friends and the community to which they belong, the universal, accessible, primary healthcare and support, the availability of specialist care and support, the living and residential environment, the organisational model, the welfare and care policy as well as the social, economic and demographic context of Flanders all define the way in which care and support can be provided and experienced in a people-centred and integrated manner.

**Continuing to build a dementia-friendly Flanders together**

The fact that our life expectancy is increasing is a positive fact but also means the number of people with dementia is continually growing. The challenge of further developing adequate services for people living with dementia is thus all the more daunting in this context. The updated Dementia Plan for Flanders (2016-2019) emphasises the controlling role of the individual living with dementia and the people around him. A good vision on care is broad: all of society, with the support of policy-makers, must play a role in this. Through, on the one hand, voluntary and informal care with the right support where possible and professional support where necessary on the other.

This demographic conclusion by definition implies that dementia-skilled basic support and specialised psycho-social support must urgently be developed. Flanders continues to focus on a consistent policy.

The emphasis is also on refinement. Not just doing more, but where necessary also taking a different approach. We have decided to adopt a broader approach, which extends beyond the medical model. A vital component of this is an appropriate dementia policy, with the support of the government and of care organisations. The present update of the Flanders dementia plan ties in with the Flemish policy for the elderly, 2015-2020. In this plan, Flanders has opted in favour of an autonomous and qualitative

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life for the elderly, while also promoting a healthy lifestyle. Person-centred, demand-driven and integrated care and support ensures that the right, coordinated mix is available to people living with dementia: in the right place, at the right time and administered by the right person. This means offering customised care. This plan also takes into account the needs of the informal caregiver(s). Creating stronger support and a stronger network around the elderly patient is part of this integrated vision.

The elderly as well as young people living with dementia are all entitled to a fitting and innovative care offering, with specific attention to needs as they arise. Priority is given to the most vulnerable sufferers and those who need the most care.

Finally, we also endeavour to ensure that anyone requesting care and support can continue to live in their familiar home environment as long and as independently as possible, in a qualitative manner.

This updated dementia plan is founded on a view of people with dementia that is consistent with reality. The cornerstones of this approach are competence-based thinking and a respectful treatment. We focus on the remaining options and consider people with dementia as being citizens with full rights, who must continue to be part of our society as much as possible. Control over their own care and maximum retention of their individual autonomy are basic premises for increasing the quality of life of people living with dementia and the people around them. This is not a one-way solution but a dialogue in which we can continue to learn from people with dementia as experts.

This plan must be interpreted as an evaluation and update of the first dementia plan, for 2010-2014. The basic premises of the first plan are still relevant. The most important shifts and new insights were included in this new plan.
2. Prevalence of people living with dementia in Flanders

We need reliable figures about the number of people living with dementia in Flanders in order to develop an adequate, future-oriented care and support policy. These figures must relate to the present and future, the next 10 to 20 years, and must preferably be broken down by region. Based on such figures, a planning schedule can be developed in line with the need for care and support.

Recently a scientific study was launched to calculate more accurate prevalence figures for Flanders, based on the best available data about risks and population figures, where possible broken down by region. These results will be available by the end of 2017. The actions in this plan may be adapted as a result.

To date, we have no exact figures at our disposal. On the one hand, this is because no central registry exists that collects information about people who are diagnosed as suffering from dementia. On the other hand, this can also be attributed to under-diagnosis. Dementia does not manifest itself suddenly, as a clear medical problem, with a clear therapy. It is a very gradual process. To date, there is still no cure for it. Moreover, there is often a lack of knowledge about dementia. As a consequence, not everyone who has dementia is given a correct diagnosis or goes in search of one.

We rely on estimates for our figures. Essentially, this means using the most reliable prevalence estimates, by age and by gender. These estimates are then applied to the population figures for Flanders. There are various prevalence estimates in international literature. The differences between these estimates are small. Here we have based ourselves on the estimate used by Alzheimer Europe:

<table>
<thead>
<tr>
<th>%</th>
<th>30-59</th>
<th>60-64</th>
<th>65-69</th>
<th>70-74</th>
<th>75-79</th>
<th>80-84</th>
<th>85-89</th>
<th>90-94</th>
<th>95+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men</td>
<td>0.16%</td>
<td>0.2%</td>
<td>1.8%</td>
<td>3.2%</td>
<td>7.0%</td>
<td>14.5%</td>
<td>20.9%</td>
<td>29.2%</td>
<td>32.4%</td>
</tr>
<tr>
<td>Women</td>
<td>0.09%</td>
<td>0.9%</td>
<td>1.4%</td>
<td>3.8%</td>
<td>7.6%</td>
<td>16.4%</td>
<td>28.5%</td>
<td>44.4%</td>
<td>48.8%</td>
</tr>
</tbody>
</table>


Based on the population statistics for the Flemish Region (source be.STAT, reference date 01/01/2015), the number of people living with dementia is as follows:

<table>
<thead>
<tr>
<th>Number of people</th>
<th>30-59</th>
<th>60-64</th>
<th>65-69</th>
<th>70-74</th>
<th>75-79</th>
<th>80-84</th>
<th>85-89</th>
<th>90-94</th>
<th>95+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men</td>
<td>2,131</td>
<td>391</td>
<td>3,134</td>
<td>4,075</td>
<td>7,874</td>
<td>11,847</td>
<td>8,469</td>
<td>3,906</td>
<td>499</td>
</tr>
<tr>
<td>Women</td>
<td>1,177</td>
<td>1,762</td>
<td>2,520</td>
<td>5,353</td>
<td>10,513</td>
<td>19,451</td>
<td>21,292</td>
<td>14,717</td>
<td>3,049</td>
</tr>
<tr>
<td>Total</td>
<td>3,308</td>
<td>2,153</td>
<td>5,654</td>
<td>9,428</td>
<td>18,387</td>
<td>31,298</td>
<td>29,761</td>
<td>18,623</td>
<td>3,548</td>
</tr>
</tbody>
</table>

The same calculation for the Brussels-Capital Region results in 17,030 people with dementia (reference date 01/01/2015). Care regions and local governments that have population statistics available that are broken down by gender and by age can carry out the same calculation.

There are regularly items in the media, which mention the fact that the number of people with dementia is set to increase spectacularly in the next decades. These figures are mainly based on the strong demographic growth in the developing countries and our longer life expectancy. In Flanders,


6 Alzheimer Research Foundation (Stichting Alzheimer Onderzoek) and LUCAS KU Leuven.
the "double ageing" process in particular plays a role: the number of very old people will significantly increase in the following decades. It is this category especially, which runs the highest risk for dementia. In 2015, the number of people aged 90 or older in Flanders amounted to 54,312. According to the recent demographic projections, this is set to increase to 68,048 in 2020, 91,267 in 2030, 124,337 in 2040, 178,330 to 2050 and 217,725 people in 2060! By then, the number of people who are 100 years or older will be 7,843. Obviously these figures have immediate consequences for the estimated number of people with dementia. If lifestyle and therapeutic options remain unchanged, the number of people with dementia would increase from 122,161 now to 162,818 in 2030, 206,201 in 2040, 242,064 in 2050 and 251,166 in 2060. This means the number of people with dementia in Flanders is set to double. The charts show that the increase will be greater among women than among men. The higher age groups will suffer more than the "low" age groups. The risk of an individual developing dementia at a certain age will not increase in the following years. However, it may be possible to influence the incidence of dementia by adopting a healthy/healthier lifestyle. It is worth noting that these figures take into account young-onset dementia (the first symptoms and the clinical diagnosis of "dementia" is made before the age of 65 years). The number of people living with young-onset dementia remains more or less stable. It is estimated that there are about 5,461 people living with this affliction. The number of people living with dementia who are younger than 65 years may be limited; however, in view of the specific situation (still working, children still in school, a very late diagnosis of dementia etc.) this group deserves special attention. Specific information about this theme can be found at www.jongdementie.info.

The evolution of the number of people living with dementia, by gender, in the Flemish Region.
There are two factors that also influence this estimate, but which cannot be factored in for the time being. The population of Flanders is expected to become more ethnically and culturally diverse. This is manifestly evident in urban areas and among the younger generations. But gradually this diversity is also increasing in the higher age groups. On 1 January 2015, there were 498,849 (registered) individuals of foreign origin living in the Flemish Region. In 2010, there were just 396,982. In 2011, less than five percent of the people in the 65+ age group in Flanders were of foreign origin. It is expected that by 2020, almost 6% of all elderly citizens will have a different ethnic-cultural background. The situation in Brussels is even more spectacular. Almost a third of the elderly people in the capital is of immigrant origin. Moreover, this group is even very diverse.

Recently, Dutch researchers tested a sample group of Dutch people of non-Western origin for dementia. In this group the prevalence was three to four times higher than in the reference group of Dutch people of non-immigrant origin. The number of people of immigrant origin with dementia is therefore expected to double in the following years. In Flanders too, this means that we must rise to the challenge of offering every individual with dementia in our ethnic-cultural society the required care and support.

The relationship between ethnicity and the development of Alzheimer or vascular dementia is also demonstrated in other studies. Lifestyle has proven an important factor in this context.

In terms of the entire population, recent research has indicated that cohorts of elderly citizens with a healthier lifestyle ran a lower risk of dementia (Wu et al., 2016). This development can help reduce the incidence figures (the number of new people who are diagnosed as having dementia). As a result, the aforementioned estimates may have to be revised downwards. For the time being, however, it is unclear how and to which extent this effect will also continue in subsequent generations of the elderly. What is clear, however, is that the effect can be increased policy-wise by investing in a healthy lifestyle for all Flemish citizens, especially in the age group of 40 to 50-year olds. The aim is to push back the incidence of dementia in this group by 20 to 30 years.

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7 Study service of the Government of Flanders
9 Goudsmit M., Parleviet, van Campen, & Schmand, 2011), studie Health, Aging and Body Composition (Health ABC).
3. Objectives and actions

3.1 Nuanced perception as a condition for a humane dementia policy

When referring to people with (young-onset) dementia, we always use the expression "people with (early) dementia" and not "young people with dementia" or "(young) dementia patients". Using the correct terms is fairer to the individual, who continues to be a person, with dignity, regardless of their condition.

Flanders has already attempted to break through the taboo on dementia. The Music for Life campaign in 2012 still captures the imagination. Flanders revealed its concern about the issue and showed its commitment. Afterwards it became clear that people in Flanders were very much willing to help. The media continue to play an important role in this. Nonetheless the conclusion is that breaking through this taboo will still take time and a lot of continuous, sustained efforts. Too many people still continue to take a simplistic approach to dementia.

Fortunately, there are already a lot of very positive changes noticeable in practice. The ambition of the Dementia Plan for Flanders for 2010 to 2014 was to de-stigmatise this disease and create a more nuanced perception. Our ambition is to continue this approach in the current dementia plan.

To further stimulate a more nuanced perception we will:
- show all aspects and symptoms of dementia and the feelings associated with this;
- highlight the various stages of dementia. The dementia process on average lasts eight years and people with dementia live at home as long as possible, doing what they like to do. Loving contact continues to be possible, even in the later stages and must be stimulated as much as possible;
- informal caregivers must be fully involved in the patients' care and their role must be recognised;
- the autonomy of the patients must be recognised;
- continue to focus on the personality of the person;
- encourage people living with dementia to participate in society.

At the same time, attention must be paid to the perception of dementia within the various communities in Flanders. In view of the fact that every community takes a different approach to dementia, we examine, in our campaigns, which approach has the highest chances of success for providing information.

"Forget dementia. Remember the person".

During the past coalition government, a campaign with the following slogan was launched: "Forget dementia. Remember the person". (Vergeet dementie. Onthou mens)

This is not a traditional awareness campaign. This gradual process aims to change the perception of dementia, by using destigmatising counterframes or different ways of looking at dementia, that better reflect reality. The residential care stakeholders, municipalities, associations and anyone who wants to help convey the message "Forget dementia. Remember the person" can go to the website www.onthoumens.be. The platform contains information, a catalogue of resources, materials and ideas for anyone interested in developing (or reworking) a website, brochure, poster, article etc. about dementia. The Flemish Dementia Expertise Centre (Expertisecentrum Dementie Vlaanderen, EDV), the Flemish Alzheimer League (Alzheimer Liga Vlaanderen), the King Baudouin Foundation, the Flemish Council for the Elderly, the Association for Cities and Municipalities and the Association of Flemish Provinces have all contributed to this. The website also has a photo database of people with
dementia as they are, in their daily environment, in relation to people around them... The photos avoid stereotypes and focus instead on the person themselves. More than 250 organisations, municipalities or care facilities have already signed the declaration of intent in the framework of "Vergeet Dementie. Onthou mens" and have thus helped make this theme easier to discuss. We must cherish this commitment and continue to stimulate it. People living with dementia must be able to be part of our society, just like other people, in the most normal way possible.

**Actions**

1. Based on the evaluation of the "Vergeet dementie. Onthou mens" campaign, it will be adapted and continued. The idea is to make the awareness and the commitment of the existing target groups, such as formal and informal caregivers, local governments, social-cultural institutions, and so on more sustainable. Special attention will be paid to education and the media. To this end the visuals and the content of the campaign website [www.onthoumens.be](http://www.onthoumens.be) will also be reworked, with a new image database, new testimonials and ambassadors and current good practices, which support the mission of the campaign. A supervisory group will be established that monitors the actions. The campaign (website) will be further published online and offline on relevant platforms. We will use social media (Facebook, Twitter, LinkedIn) to promote the online platform [www.onthoumens.be](http://www.onthoumens.be) and convey a more nuanced perception of dementia. The EDV is responsible for this, together with the other stakeholders who provide care for people with dementia.

2. We will support initiatives that reflect a nuanced perception of dementia. Examples include the social-artistic initiative "De Alzheimer Code" and "De Stem van ons Geheugen" (contact choirs dementia). Both of these initiatives are part of the socialisation of care and the development of expertise across healthcare and culture. This will also be included in the declaration of intent that was signed, in order to stimulate a cooperation between culture and welfare policy.

3. We will promote the website [www.dementie.vlaanderen](http://www.dementie.vlaanderen) as a portal for people living with dementia and their informal caregivers, professionals and the media. The EDV will ensure that this overview continues to be updated.

4. We will check how the basic knowledge about dementia and the nuanced perception can also be introduced in education.

5. Based on ongoing research into culture-sensitive care, the EDV will take initiatives, in consultation with the stakeholders involved, to ensure the information about dementia gets across among cultural minorities in Flanders. A first, crucial objective for being able to offer qualitative care is to ensure that the issue of dementia is brought out into the open more, while respecting cultural diversity. In this framework, we were also involved in the research by the Erasmushogeschool. We incorporate these insights in the various dementia-skilled trainings and within the consultation platforms for dementia. The Dementia Consultation Platform (Overleg Platform Dementie) within the SELs (or future cooperation structure) can thus launch targeted neighbourhood endeavours, i.e. bringing together care stakeholders and relevant local stakeholders.
3.2 The concept of the Dementia-friendly municipality as a specialisation of an age-friendly policy is being further developed in Flanders.

Respect for dementia continues to be a key policy concern. Investing in dementia-friendly municipalities does not need to be prohibitive. The advantage of this is that people with dementia can continue to retain control of their care for longer and maintain a higher quality of life.¹¹ A study by Mittelman (2006)¹² in the United States revealed that permanent institutionalisation in a facility can be postponed by as much as 557 days if the person with dementia can live in an environment with a sufficient degree of understanding for their affliction. In the past years, about fifty Flemish municipalities worked towards developing a dementia-friendly local policy. A dementia-friendly municipality helps improve the quality of life of the person with dementia and the people that live with them. The idea is to give people with dementia the chance to live a qualitative life, to be able to continue to make their own choices and to be able to participate actively in society. In the meantime, other municipalities felt the urge to develop dementia-friendly initiatives. On the other hand, a number of municipalities also felt they wanted to improve their dementia-friendly policies and check them against existing initiatives. To this end two tools were developed for resolving this: a dementia meter was developed, as well as a manual by the Association for Cities and Municipalities with the support of the King Baudouin Foundation, the Flemish Dementia Expertise Centre and the Flemish Alzheimer League. This manual serves as a guide for anyone wishing to put their vision or ideas on a dementia-friendly municipality into practice.

The idea behind these tools was multi-layered:

- The experiences and findings of municipalities who have worked with the dementia meter will be shared with all other municipalities. The idea is to share good and practical examples.
- Municipalities are inspired to offer the right type of support to people in their municipality who are living with dementia and the people around them.
- Municipalities will have a barometer at their disposal that allows them to check their dementia-friendly policy.

Actions

1. The dementia meter will be visualised with a "widget", (i.e., a specific application) that can be shown on the local government's website, and will help make the dementia-friendly policy more visible. We also look into how a link can be established with the "healthy municipality" method from the prevention perspective.

2. Candidate municipalities that wish to become more dementia-friendly are encouraged to do so by setting up initiatives together with the Association for Cities and Municipalities, the dementia expertise centres and the Flemish Alzheimer League. The Government of Flanders commits to providing support for this cooperation and encourages local governments to include this theme in their local social policy. This support is included in the management agreement that the Government of Flanders concluded with the Association for Cities and Municipalities as a partner organisation for stimulating an inclusive Flemish policy for the elderly and the participation in policy by the elderly.

3.3 We promote a healthy lifestyle and a healthy living environment in order to reduce the chances of dementia

Prevention is vital. A large number of cardiovascular diseases, strokes, Type II diabetes and malignant tumours can be avoided if we invest sufficiently in prevention. That is why Flanders has health objectives, focussing specifically on such themes as food and exercise and tobacco, alcohol and drugs.

Scientific research has demonstrated, in the meantime, that signs of dementia can be identified in the brain even before the first external symptoms manifest themselves. Scientists are now focussing on finding methods for stopping this disease during the pre-symptomatic period in order to prevent the affliction or in any event postpone the manifestation of the external symptoms. As long as no efficacious medical treatment has been found, the prevalence of dementia will largely be dependent on the extent to which we are willing to improve our general health. Healthy living and a healthy living environment are important steps towards a future with less cancer, cardiovascular disease, diabetes and also dementia.

The researchers of the Rotterdam Studie conclude that it is possible to act pre-emptively against dementia by properly controlling the known risk factors (e.g., smoking, high blood pressure, diabetes, insufficient activity levels...) in order to reduce the number of people with dementia by 25 to 30 percent.

This means that researchers must continue to study other, less evident risk factors, that explain the remaining 75% of incidence.

Measures with the aim of preventing dementia have the best chances of success if they are pragmatic, can be easily implemented on a large scale, involve the various caregivers and do not result in high investments, costs or nuisance for the users, their physicians and their caregivers.

Prevention in middle age

The studies by Christensen and Matthews also proved that a generally healthier lifestyle and healthy living environment can reduce the risk of dementia. The main risk factor for dementia is old age. Women apparently also run a slightly higher risk of dementia than men at the same age. Age and gender cannot be influenced. The factors we can influence are mainly related to (un)healthy blood circulation: overweight, high blood pressure, smoking and physical inactivity. Attention at all ages and especially in middle age is therefore vital.

The most powerful factor we can influence (which is not always the easiest) is physical inactivity. The more we exercise, the lower the risk of dementia. The second, most powerful factor that can be influenced is smoking. This reduces the risk of lung cancer and cardiovascular disease as well as the risk of Alzheimer dementia.

14 Christensen et al., 2013.
15 Matthews et al., 2013.
16 Erol et al., 2015.
In addition to the aforementioned risk factors, there are a number of elements that can protect us against dementia. Keeping the brain active is very important. We can continue to stimulate the brain by living an active, social life. Other options include following training, courses, learning a new language, working or volunteering, leisure or social activities. People who live an active lifestyle are more capable of “coping” with the symptoms of dementia. Flanders offers maximum opportunities to all elderly citizens, together with local social-cultural organisations and Flemish sports clubs, allowing them to develop or maintain an active lifestyle.

The main problem when recommending preventative measures consists in motivating people to take action, even if they do not yet experience any negative symptoms.

Actions

1. Preventative measures against dementia can be taken on the individual, micro/meso, exo and macro level. The current LOGOs have a specific task on the regional and local level. The dementia expertise centres make agreements with these and other stakeholders who work in the field of prevention, in order to include these data in the information they provide.

2. The Flemish Dementia Expertise Centre confers with the Flemish Institute for Health Promotion and Disease Prevention (Vlaams Instituut voor Gezondheidspromotie en Ziektepreventie, VIGeZ) to ensure the theme of dementia has a place in health promotion strategies in Flanders. VIGeZ will examine how the formulated actions in terms of the prevention of dementia can be consolidated by using its expertise in the field of general health promotion, working in a targeted manner to reach the elderly and vulnerable groups. The health themes of nutrition, exercise, sedentary behaviour, tobacco prevention and stopping smoking, mental health promotion, activities aimed at the setting of local governments and healthier living environments are vital in this framework. Gains from a decline in the risk factors for dementia must be added to the existing health messages and campaigns.

3. In line with the Flemish Parliament Act on Prevention, we shall implement a process that will culminate in the Prevention Health Conference on 16 and 17 December 2016, to arrive at new prevention objectives and strategies. This health conference wants to assess support, stimulate commitments in the field and increase the knowledge of proven strategies (evidence) to map out a policy for the following years. The Government of Flanders, the municipalities, social-cultural organisations, sport federations and healthcare funds are encouraged to organise health initiatives and inspire citizens to participate in them.

3.4 We increase the autonomy of the individual with dementia and their caregiver.

Our policy starts from the needs of people living with dementia and their family and friends. In this framework, policy will create the required conditions so people with dementia can control their own life as long as possible. This means we pay attention to diversity, individual experience and everyone’s own story. People with dementia are treated respectfully - like other people - and are not pushed aside. They have equal opportunities and we start from their possibilities. We do not see people with dementia disappear behind their disease. We want people with dementia to “be part of society”, regardless of where and how they live. We want them to feel that they are being taken seriously and be able to lead the life they want as much as possible. In this framework, we also refer to the chapter on the end of life. We want them to think about how they can shape their life and their decisions about the end of their life on time, with their family and friends and other people they trust.

Research has demonstrated that it is very important to pay sufficient attention to stimulating, offering support to and restoring self-care in patients and their caregivers as soon as the initial symptoms of dementia manifest themselves. The demand for care and support usually starts with the GP, and during the rest of the assistance process, other care and assistance providers step in, on a professional or voluntary basis. This is an important process ad below we describe a number of crucial anchors and stakeholders in it.

We find it important that all care stakeholders gain an insight into the signs of early dementia (the something-is-not-right feeling) and discuss this with the person and the people around them. Moreover, it is important that the GP recognises the initial signs of dementia on time and can become responsible for the further medical monitoring of patients and their informal caregivers. A timely referral to a specialist (neurologist, geriatric doctor or physician) with whom he will work and good integrated assistance is vital here. That is why we refer to shared responsibility. Attention must be paid to care diagnostics in addition to the medical diagnosis. In this context it is also important to indicate that there is no such thing as an “ideal” dementia process. Every person is unique and everyone's context is very different. In that sense, we want to create a proper and clear framework, that respects the rights of the person living with dementia and the people around him, starting from the diverse needs of this person and his environment.

Actions

**In regards to reporting and first signs of dementia**

1. GPs play an important role in reporting and case-finding of people with dementia. Domus Medica is developing a practical guideline for primary healthcare about the attitude to detection and diagnosis of dementia. They will discuss this guideline with the EDV and with primary health stakeholders.

2. We will incorporate the conclusions of the Belgian Health Council in terms of care for people with dementia in our policy: promoting expertise, multi-disciplinarity and inter-disciplinarity, access to good information for informal caregivers, professional caregivers and the public. Along with the EDV and the regional expertise centres for dementia, we will look into whether it is possible to distribute the booklet “Dementie, je staat er niet alleen voor” (Dementia, you're not alone), which is currently published every year by three provincial councils, throughout Flanders.

3. We will examine to which extent an awareness campaign aimed at the public will help keep the time between the first signs of possible dementia and the diagnosis as short as possible. We will take into account the conclusions of projects that centre on the “Niet-Pluisgevoel” (the feeling that something's
not right). When rolling out this campaign, we will ensure that assistance, support and care is sufficiently accessible, in consultation with the various stakeholders.

4. The FAZODEM project (pharmaceutical care for people with dementia), which has been set up with the EDV, invests in a detection role for the first signs of dementia, by the local pharmacist, together with the GP. This project is consolidated in the project of the Flemish Pharmacist Network (people with dementia, their informal caregivers and local chemists).

**In terms of the need for further support by the person living with dementia and the people around him**

5. Psycho-education, that is tailored to informal caregivers, will be further stimulated with the aim of increasing the capacity and quality of life of the informal caregiver. This will become a point for attention in the overall informal care plan (currently in the process of being drawn up). Scientific studies have shown that psycho-education allows people with dementia to live at home longer. It also helps explain behaviour that is more difficult to understand. The psycho-education pack "Dementie en nu" (Dementia, now what?) is permanently monitored by the EDV and the Flemish Alzheimer League and updated where necessary. This kit is made available to all organisations who may use this within the confines of evidence-based agreements.

6. We will ensure that clients are represented in the Flemish dementia policies that are developed. For this we shall use, for example, the expertise of the Flemish Alzheimer League.

7. We will ensure continuous care and support by stimulating cooperation between the caregivers involved. This cooperation must lead to adequate support for the person living with dementia and their informal caregiver. The GP or specialist can refer the patient or caregiver to existing care stakeholders who offer skilled care for dementia, when developing a care and support plan. These include the social services of healthcare insurance funds, family care and additional home services, sitters, home nurses, day care centres, short stay centres and dementia experts who are affiliated with the regional dementia expertise centre, residential care centres and so on. An integrated care and support plan can be drawn up, which is tailored to each client and their informal caregiver, in close consultation with the patient or their representative and their direct environment, and which includes the services they prefer. All the care stakeholders can also inform family members and informal caregivers about the importance of contacts with other sufferers or self-help groups.

8. The complexity of the disease process for people living with dementia requires a specific approach. Several care stakeholders offer competence-based dementia care. This lies in with the transition plan for competence-based dementia care in the natural home environment. This means looking at how the acquired expertise and the functioning of home based consultancy by the Foton regional expertise centre for dementia and the competence-based dementia counselling of the social workers of the health insurance funds can be further rolled out within the reorganisation of primary healthcare in Flanders. A dementia expert will be on hand to assist other caregivers in the region, in every regional expertise centre for dementia in Flanders.

9. In line with the transition plan "Competence-based dementia care in the natural home environment", the dementia expert can offer direct, specialised advice to people living with dementia and their caregivers, without taking the place of caregivers who are skilled at treating dementia. The dementia experts have direct contacts with clients, based on a demand-driven approach and a specialist consultancy task. Moreover, the regional expertise centres for dementia will also help deal with requests for psycho-education, discussions with clients, meetings for people with (young-onset) dementia, meetings for informal caregivers and referrals to other caregivers. The number of dementia experts in the regional expertise centres for dementia are defined according
to the reorganisation of primary healthcare in Flanders.

10. The government continues to stimulate the coordination between caregivers within the care regions through the dementia coordination platforms. The objective is to provide the most complete range possible, including psycho-education, buddy assistance, contacts with other fellow sufferers (e.g. through the (Young-onset) dementia family groups, meetings for people in relation to dementia, home care, residential care facilities (day care, short stay etc.). They work from the bottom up and focus on the citizen/client.

11. An informal care plan is also developed, which focuses on support for informal caregivers in the case of dementia.
The points of attention of this plan are:
   * recognition and appreciation of the informal care provider
   * support for the informal caregiver
   * cooperation between informal and professional care
   * attention for young informal caregivers.
3.5 We provide for coordinated and targeted care and custom support throughout the entire dementia process.

Flanders has a qualitative care offering for people living with dementia. Nonetheless this requires continual care in order to ensure that this offering continues to be qualitative and the needs are permanent. We must ensure that the most vulnerable people also have access to this care, including people from a migration background.

When developing care and support, the specificity of the target group of people with (young-onset) dementia must be taken into account. The aim is to ensure full-fledged participation of people with dementia, their informal caregivers and/or experience experts. The Flemish Alzheimer League (Alzheimer Liga Vlaanderen), a non-profit association for patients and volunteers, stresses this participation, for example, with its role within the GGZ Family Platform and within the Flemish patient platform.

Custom care implies sufficient competence-based basic dementia care in the context of the "socialisation" of care. Flanders is already implementing this with the transition plan entitled "Dementiekundige basiszorg in het natuurlijk thuismilieu" (Competence-based basic dementia care in the natural home environment, March 2014), which is designed to increase the expertise of caregivers. The aim is to offer timely, qualitative and targeted support for anyone living with dementia and their informal care provider. Where possible, this can be done in the natural home environment where both informal care (by a relative or by volunteers) and professional care are important. The support is provided where possible within the specialised (intra-mural) residential care offering.

A study by Mittelman\(^\text{20}\) (2006) demonstrated the preventative impact (i.e. in terms of the isolation of the person living with dementia and informal care) and the cost-saving effect of an integrated and customised offering. In this context, the researcher referred to the use of basic care, psycho-education, specialised psycho-social support, home assistance for dementia (Foton), informal meeting opportunities and meeting groups for people living with dementia and their informal caregivers.

Finally, needs-driven and targeted care also takes account of the wishes and views of people with (young-onset) dementia in terms of care and quality of life and end of life when they potentially suffer from a chronic affliction.

This requires a permanent process of consultation between the patient, his relatives (trustee) and the caregivers. The aim is to formulate objectives and choices, about how the patient wishes to be cared for, wishes to experience his life, also when he is no longer capable of (fully) controlling his own care. An early care planning is part of this process, especially for people living with dementia and their family. According to the project partner of the scientific INTEGRATE project (Integration of palliative care into home, nursing home and hospital care into the community in Flanders - Vrije Universiteit Brussel, KU Leuven LUCAS, University of Ghent), there is increasing scientific proof that care relating to the end of life should ideally be started up early on in the disease process. That is why we argue in favour of a stronger integration of targeted care, in regular care facilities, the home setting, residential care facilities and in hospitals, as well as in the community as a whole.

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Actions

1. In terms of care policy
   a. We will develop dementia-specific quality indicators and studies, for integration in the ongoing Flemish indicator project.\(^{21}\)

   b. The issue of the protection of privacy, which is currently still an obstacle for the survey of trustees or informal caregivers of people living with dementia will be analysed by legal counsellors to find possible solutions. A legal arrangement will have to strike a balance between the protection of privacy and studies of specific quality indicators in the care for patients who no longer can defend their own interests.

   c. Customised care also means facilitating the automatic granting of compensation to the people involved and their informal caregivers. In the framework of establishing the Flemish Social Protection (Vlaamse Sociale Bescherming, VSB), Flanders is investing in maximum transparency and the automatic granting of rights.

   d. We must also draw attention to abuse in the care context. The integrity of people with (young-onset) dementia demands special attention. People living at home can report abuse to the "abuse, violence and child abuse" hotline. The Dementia Expertise Centre Flanders helps increase the notoriety of the centre, for example through the website www.dementie.be. Caregivers can turn to the Flemish support centre for elderly abuse and care. (www.ouderenmisbehandeling.be). We also work on raising awareness about abuse and about these support centres. The public can contact the Flemish residential care hotline about abuse in residential care centres.

   e. We also request advice from the Advisory Committee for Bio-Ethics about the application of measures that restrict the liberty of people with dementia in a residential care setting. We examine, together with the sectors, how this advice can be incorporated in the quality care of the residential care stakeholders.

2. In terms of orientation and support
   a. The existing expertise, which has been developed by the regional expertise centres for dementia and the Flemish Alzheimer League for the orientation and support of people with (young-onset) dementia and their families will be perpetuated.

   b. The dementia hotline was launched, as one of the working points of the transition plan. It is an accessible hotline for professional caregivers. In practice, this amounts to a free home visit, within the week after a request is made for further monitoring by the social services of the health insurance fund. After the home visit, the decision can be made to launch long-term assistance. Professional caregivers will be further informed about the dementia hotline. We will also monitor which groups of caregivers use the support centre to undertake targeted information initiatives.

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\(^{21}\) The residential care centres measure several indicators, for care, safety, caregivers and the organisation. They measure these throughout the year and twice a year they send their data to the Agency for Care and Health.
3. **In terms of support for the care offered**
   
a. As described in the transition plan for competence-based basic dementia care in the natural home environment, we will provide sufficient support for people living with dementia and informal carers through professional and voluntary basic care by people familiar with dementia and specialised assistance: sufficient care hours, training hours and support in order to offer qualitative home care, support for home care and residential care.

b. We are investing in the further growth and support for the volunteer network Actions that have been set up in the framework of the coordinated Flemish volunteer policy are of a supporting nature.

c. We recognise the importance of reference persons for dementia. Federal resources are now flowing to Flanders following the sixth state reform. We evaluate the boundary conditions and competence profile of the reference person for dementia. Besides the content of their training, we also define the further conditions, both in residential and home care. This takes into account developments in primary healthcare.

d. We will support and encourage innovative forms of care and support for people living with dementia in calls for projects. We find it important that these are evaluated and that good practices are shared. The EDV plays a permanent role in this.

e. The EDV will be tasked with developing an integrated reference framework for the quality of care and life for people living with dementia. The network group for small-scale normalised living as well as the umbrella organisations will be involved in this review.

f. The entertainment function in residential care centres continues to be a key anchor in the transition from a medical care model to a more social and person-oriented approach to people living with dementia, with special attention to residential and welfare aspects.

g. We continue to stimulate triadic work in home care and in residential care centres: this means that we strive to achieve optimum interaction between the professional caregivers, the individual living with dementia and their family and friends.

h. Flanders will continue to invest in the further growth of qualitative professional home care and residential care. We will develop the residential recognition calendars and the growth path in family care.
4. **In terms of dementia-friendly living and building.**

   a. We will continue to invest in dementia-friendly building and living. The EDV plays an important advisory role in this context and offers this to future clients (day care centres, short stay centres, residential care centres and so on).

   b. Ergotherapeutic advice at home for people living with dementia by the Regional Services Centres and other local service providers will be further published (i.e. by the EDV, the Flemish Alzheimer League and so on).

   c. Easy access to dementia-specific aids - domotics - is encouraged. An overview is kept up to date through the Flemish Dementia Expertise Centre for this purpose. The required support is provided in terms of possible aids and facilities.

   d. People living with dementia tend to exhibit wandering behaviour. A social safety net with a missing persons protocol helps the police search in a more targeted and efficient manner. A package is being developed that can be used during police training and which incorporates dementia. The government stimulates the implementation of the protocol in coordination with the Unit for Missing Persons. The developed protocol is further published for local implementation in consultation with the competent authorities. The recommendations of the Advisory Committee for Bio-Ethics are hereby taken into account.

   e. Innovative forms of residential support, such as the informal care residence, the intergenerational home, co-housing and ICT innovations such as the dementia app are encouraged, receive support and are evaluated. Good practices will also be made accessible to other stakeholders as a result. We also refer to the pilot projects, which receive support from the Flemish Agency for Innovation and Entrepreneurship (Vlaams Agentschap Innoveren en Ondernemen, VLAIO) and Flanders Care.

5. **In terms of care for the end of life**

   a. Early care planning, which is embedded in an all-encompassing vision on welfare and care, will become a point for attention in the needs-driven and targeted work of caregivers. A VZP dementia guideline (by the Federation for Palliative Care in Flanders and the EDV) is currently being developed. This guideline is assessed and shared with experts in the field such as LEIF (LevensEinde InformatieForum). The early care planning for dementia guideline will be made available at [www.pallialine.be](http://www.pallialine.be). This guideline will also be incorporated in the quality indicators that are to be developed.

   Early care planning is also a task of every residential care facility. Attention is paid to this as a vital part of the support and assistance during intake and throughout the residency in the residential care facility.

   b. We stimulate the coordination between the regional expertise centres for dementia and the palliative care networks, with the aim of further implementing the directive for early care planning in the event of dementia among care employees. Early care planning is part of targeted care and support for people living with dementia from the start.

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22 Opinion no. 56 of 16 December 2013 regarding ways for preventing wandering of patients in the home, Belgian Advisory Committee for Bio-Ethics.
c. We encourage opening the wishes of people living with dementia for discussion throughout their further lives. Following from scientific research, we examine to which extent the VZP dementia app (developed by the De Ruyschaert residential care facility in Marke) can be distributed among residential care organisations so the tool can be used. This is being done in cooperation with the EDV and the Flemish Palliative Care Federation (Federatie Palliative Zorg Vlaanderen).

d. By analogy with the palliative care reference physician, the profile of a reference GP for dementia is mapped together with Domus Medica. This reference physician must be very alert and recognise the first symptoms in order to set a timely diagnosis. But he is mainly there to help his own professional group. He emphasises the importance of the correct approach of the individual living with dementia and checks where the patient requiring care and the informal care provider need further support.
3.6 We also pay attention to people who develop dementia at a young age and recognise the specific care and support needs.

It is safe to say that professionals and informal caregivers still do not know enough about the various manifestations of young-onset dementia. When the first symptoms and the diagnosis of “dementia” is made before the age of 65, this is called young-onset dementia or dementia at a young age. The clinical performance and needs of people living with young-onset dementia and their family can be very different from those in people who develop dementia later in life. The time between the manifestation of the first symptoms and the ultimate (correct) diagnosis is significantly longer in young-onset dementia than in dementia later in life, i.e. 4.4 years compared with 2.8 years\textsuperscript{23}. Often late or wrong diagnoses are made and often wrong and even useless treatments are started. This can cause serious relational and emotional damage in the patient and their informal caregivers.

Once a correct diagnosis has been made, an approach is recommended which is adapted to the manifestation of the condition, the age of the person with young-onset dementia and the specific psycho-social context.

In Flanders, there are an estimated 5,400 people living with young-onset dementia. Flanders has opted in favour of an integrated approach of this target audience, with attention to the specific needs of the patient and the informal care provider. This includes quality criteria and a properly agreed regional spread of the initiatives. Following from the scientific research (NeedYD study, 2013), the care and assistance to people with young-onset dementia requires a specific approach. Obviously the problem of young-onset dementia will have to be incorporated in (care) education programmes.

The Government of Flanders has relaxed its criteria for the institutionalisation for people younger than 65 years of age in care homes for the elderly. This means that people with young-onset dementia can receive qualitative care and support in an adapted environment. However, the care for people under 65 years of age in recognised care facilities for the elderly cannot yet be enforced. The only exception to this rule are the day care centres, which exclusively provide care and services to users with a specific chronic condition.

Besides this, the specific care for people with young-onset dementia is stimulated and further developed based on the experiences of people over 65 years of age. An example of this is "Het Anker" in Tongeren.

In every approved residential centre, the number of users younger than 65 years may occupy no more than 10% of the total number of approved units of the residential care facility. For every additional user above this 10% figure, the centre must have a specific report available. Moreover, the Government of Flanders has made it possible for residential care facilities to care for a group of users younger than 65 years of age who have shared care and support needs, based on a substantiated request, if more than 10% of the users of the total approved capacity of the residential units is under 65.

A day care centre that exclusively provides care and support to users with a specific chronic condition, as a result of which these users require support in their daily life, is not subject to age restrictions. This target group includes people with young-onset dementia. In other day care centres, 25% of the users under 65 can obtain care and support without any additional motivation.

**Actions**

We are working on a qualitative network offering for young-onset dementia in a regulatory framework with a guarantee for quality. This means having an affordable and controllable offering at the care region level.

1. We are investing in the future role of cooperation initiatives for primary healthcare (SEL) and the dementia expertise centre, which raises the awareness of professionals and informal caregivers about the various manifestations of young-onset dementia and publishes the regional offering for this target group.

2. We coordinate our efforts with the federal government in order to establish a cooperation between a "memory clinic" and, where applicable, a "centre for cognitive revalidation", associated with a general hospital in view of a timely, correct diagnosis and further treatment and monitoring, in close consultation with the doctors providing treatment.

3. Together with the stakeholders involved we stimulate the development of specialised assistance and psycho-social support of the individual with young-onset dementia and his environment.

4. The specific offering is updated online on the website www.jongdementie.info. We check where there are gaps and examine with the sector how these can be filled in within the existing programme.

5. When drawing up reconversion criteria for residential care centres, we examine whether an additional expert employee can be hired for residential units that specifically cater to people with young-onset dementia. He or she will support the contextual situation of people with young-onset dementia and their relatives and friends.

7. We stimulate initiatives that focus on a buddy programme for (young-onset) dementia, in view of the empowerment this engenders for all the parties involved.

8. The residential care pilot project in mental healthcare, "Expertise Dementie Vlaams-Brabant", which uses the model of care circles for people living with young-onset dementia, has been selected and will receive support.
3.7 Flanders stimulates scientific research in terms of dementia and care for people living with dementia.

Flanders can be proud of its top-class research into genetics, molecular biology and diagnostics.

In the past, scientific research has made an important contribution, increasing public health and pushing back what at one time were terminal illnesses. Society continues to hope that dementia can be "disciplined" and become a treatable disease. That is why it is vital that Flanders continues to invest in fundamental scientific research into Alzheimer's disease. It is the only way to be able to offer tomorrow's patients a disease-modifying medicine or medication which effectively slows or even stops the disease's progress. If ongoing research can lead to effective medication that may prevent or stop the proteins from forming in the brain and Alzheimer's Disease can be treated during the (long) pre-clinical stage, the origin of the symptoms may be deferred or even completely prevented. We now know that Alzheimer's Disease has a very long pre-clinical manifestation (about 10 to 20 years), followed by a stage of mild cognitive impairment and finally the terminal stage of dementia. Nowadays we can diagnose this condition in the preclinical stage. Further research is needed for the validation of these diagnostic instruments so these are ready by the time the disease-modifying drugs become available. Moreover, once these diagnostic instruments are validated, they can also be used for clinical studies with new medication in the preclinical stage.

In 2015, a first breakthrough was made and shared at the CTAD conference. This involved a clinical study using aducanumab in patients with MCI as a result of Alzheimer's Disease. The researchers established that the number of amyloid plaques decreased in the treated group (but not in the placebo group). The condition of the actively treated group deteriorated slower or not at all while the placebo group continued to deteriorate. We are closer than ever to a real, causal treatment of Alzheimer's Disease.

In this Dementia Plan, we have argued in favour of a two-track policy. The aim, on the one hand, is to provide an impetus for fundamental and clinical scientific research and invest in a further improvement of the quality of care and care research (e.g. quality research, which focuses on themes such as people-centred care, early care planning, methods and instruments etc.). The practical relevance of this care research is under pressure. Working in an academic context increasingly means publishing internationally in so-called "blind peer review" journals and working on doctorates. Raising funds for research requires a substantial effort and is very competitive. The transposition of research into the Flemish care practice often suffers as a result. Publications take too long to become available and are only available to those who have access to expensive, scientific journals. The method and the scientific substantiation often detract from the implications for good care, dissemination and implementation of the results in the Flemish practice. This imbalance between global academic performance norms and practical relevance must be eliminated. We ask Flemish universities and university colleges to focus on practical relevance and the implementation of their research results into proper care for patients of dementia (or other diseases).

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24 http://www.ctad-alzheimer.com/
25 http://www.alzforum.org/therapeutics/aducanumab
Actions

Fundamental research

The Flemish Initiative for Networks for Dementia Research (Vlaams Initiatief voor Netwerken voor Dementie-onderzoek, VIND) has provided impulse funding until 2018.

Support is also possible through the Research Foundation Flanders, including the possibility to submit strategic basic research projects and applied biometric research with a social purpose.

Care research

1. Flanders has chosen to stimulate the interaction between fundamental scientific research and care research. The practical relevance of the current care research must, however, be increased. Further coordination with the EDV is ongoing for the dissemination of this research. The objective in care research must always be an adequate translation of the research results into the Flemish care practice.

2. We also want to make sure that the dementie.be website (which can also be accessed through www.dementie.vlaanderen) becomes the hub for various forms of research, in order to counter fragmentation. The knowledge agenda "Op weg naar een moderne dementiezorg", which was developed by the EDV and the Flemish Alzheimer League is also made available to education and care research. The research must also be offered to interested citizens in a language that they can understand.

3. Subsidised research must be available in open access to interested citizens. Flanders stimulates this option.

4. We are heeding the conclusions of the European Council, which requested support starting from a gender-sensitive approach to scientific research and the development of dementia strategies, including target audiences with specific care needs (people from a diverse cultural background and the rights of people with dementia and their primary caregivers).
3.8 Education and training

Flanders has resolutely opted in favour of skilled dementia caregivers. Attention must also be paid to chronic care, in this case competence-based dementia care in the training of various caregivers. The starting point for this must always be competence-thinking and a needs-driven approach towards people with dementia. The dementia sufferer and his surroundings must always control the situation. We must also search for a common language for all caregivers. This requires the further development of competences and a culture of cooperation in care and assistance.

The issue of dementia must be covered in all educational programmes in order to develop a nuanced idea of this disease. This ties in with the aforementioned notion of competence thinking. Dementia and the vision on a people-centred approach must also be part of basic care programmes.

Actions

1. The dementia transition plan will continue to focus on the education and follow-up training of dementia-skilled basic aid workers.

2. The transition plan will be evaluated at the end of 2017 and adapted where applicable. Lifelong learning is also vital in the context of dementia in order to continue to guarantee socially responsible care.
4. Conclusion

The inspiration for this updated dementia plan continues to be the ambition to provide an adequate answer to the physical, mental and social needs of all people living with dementia and their carers, in a dementia-friendly Flanders.

This plan is permanently monitored in consultation with the Government of Flanders and the Flemish Dementia Expertise Centre (Expertisecentrum Dementie Vlaanderen). We have decided to organise an interim evaluation of this plan together with all the stakeholders.

The main premises for this evaluation are human dignity and the quality of life. People living with dementia are full-fledged citizens of our society. They are encouraged to have a vision of and control over their quality of life and receive support for this.

People who decide to care for or assist their family and/or friends must feel that they have support and that their efforts are appreciated. At the heart of the care and support that is offered, by informal carers and the many professional care stakeholders, is quality of life.

A constructive dialogue involving people living with dementia and professional and informal caregivers is vital for qualitative care for dementia.

We need to continue building a dementia-friendly Flanders, across all the policy areas and policy levels, together with people suffering from dementia, the people who live with them and many other stakeholders.

Jo Vandeurzen

Flemish Minister for Welfare, Public Health and Family