

**I'M STILL
THE SAME PERSON**
**TEN YEARS' WORKING
TOGETHER TO CREATE
A DEMENTIA-FRIENDLY SOCIETY**

IMPACT REPORT

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IMPACT REPORT



King Baudouin
Foundation

Working together for a better society

FOREWORD

TEN YEARS' WORK TO CREATE A DEMENTIA- FRIENDLY SOCIETY

Continuing to have a social life. Expressing one's own wishes and preferences. Becoming aware of the frameworks we all use. Taking part in political decisions. Knowing one's rights and responsibilities... So many themes which, some years ago, featured far less on the agenda when it was a question of people with dementia. Yet they all relate to such people's quality of life and that of their families, and are indicators of the quality of life in society itself.

Experts agree: over the last ten years, dementia has become a subject that is much easier to broach. We now consider this illness a challenge for the whole of society. In fact it is an issue that goes far beyond healthcare. Citizens, family carers, healthcare workers, social workers, lawyers, the police, shopkeepers, government and political decision makers, from local up to European level: we are all stakeholders. And the figures for the future are telling: the theme of 'quality of life and dementia' will remain at the top of the social agenda. As neurologist Adrian Ivanoiu described it: 'For me, this is as important a challenge as the climate'.

This impact report...

illustrates ten years of the King Baudouin Foundation's activities in support of a 'dementia-friendly society', by putting the accent on key messages and a number of projects and initiatives: why they were set up, what was involved, who were the actors concerned and what their impact was.

The Foundation's work is not in isolation. It is rather a cog that is part of a large machine, a movement in which many people have collaborated and participated: experts and researchers, the many project initiators, associations and organisations, members of the call for projects juries, political decision makers and their administrations. And first and foremost, of course, the people themselves with dementia and their families.

We will also look to the future. In preparing this report, we consulted 25 experts in Belgium to discuss what the big challenges are regarding dementia and quality of life. What role can the King Baudouin Foundation and other European foundations (continue to) play?



DEMENTIA: FACTS AND FIGURES

DEMENTIA?

Dementia, the number one priority for the World Health Organisation (WHO), is an umbrella term for a range of neurodegenerative conditions. The most frequent of these is Alzheimer’s disease (around 70% of cases). This is followed by vascular dementia, which results from small cerebral haemorrhages.

There is currently no treatment that results in a cure for these conditions. Medicines can slow down the deterioration in symptoms and much specialised help is available. During the last ten years, a non-pharmacological approach has generated a lot of interest, notably through research on evidence-based practices.

Prevalence of dementia in Western Europe - %

AGE	WOMEN	MEN
60-64	2.0	1.1
65-69	3.2	1.8
70-74	5.2	2.8
75-79	8.7	4.7
80-84	14.6	7.8
85-89	23.7	12.6
90+	45.1	23.7

World Alzheimer Report - Prince et al. (2015)

PREVALENCE OF DEMENTIA

IN THE WORLD

50

MILLION

The World Health Organisation estimates the number of patients with dementia worldwide to be 50 million. By 2050, this number is forecast to rise to 150 million.

IN EUROPE

10

MILLION

In Europe, we are getting close to 10 million people with dementia. This figure is also expected to rise in the coming years. On average, patients live eight years with the illness. In the absence of precise figures for Belgium, we have to use estimates as there is no central register with data about those people diagnosed as having dementia.

IN BELGIUM

200,000

The number of patients with dementia in Belgium is currently estimated to be a little over 200,000. It will no doubt double by 2060. One in two citizens will know someone in their close circle suffering from dementia.

IN BELGIUM

600,000 FAMILY CARERS

In Belgium today, it is estimated that 600,000 family carers are directly concerned by this problem.

Roughly 70% of those with dementia live at home and are cared for by their close family. Most elderly sufferers who need considerable care can live at home thanks to a family carer living under the same roof. ¹

The number of patients suffering from early-onset dementia (before 65 years' old) in Belgium is difficult to estimate, but might be as many as 12,000.

¹ S. Cès, J. Macq e.a.,

Mantelzorgers van thuiswonende ouderen in België: een cruciale en complexe rol, 2016.

10 YEARS' WORK ON 'QUALITY OF LIFE AND DEMENTIA', 2007-2017

- **Over 30 publications** on the theme 'Towards a dementia-friendly society'
- **Over 150,000 copies** distributed
- **Over 5 million euros** to support projects and medical research
- **More than 150 projects** in Belgium and **over 30** in Europe

GREATER SOCIAL INCLUSION

- **Research** on awareness and perceptions of the illness, communication advice, bases of large-scale media campaigns.

Objective: a different perception of dementia

- **'Dementia-friendly Communes'**: project support, familiarisation with a vision, intervention, exchange of experience...

Objective: greater local awareness and interest in those with dementia

**MORE THAN
150 PROJECTS
IN BELGIUM**

**OVER 30
IN EUROPE**

A BALANCE BETWEEN AUTONOMY AND PROTECTION

- **Spread of knowledge** about dementia: publications with contributions from lawyers and doctors. Target groups: people living with dementia and their families, lawyers, professional carers
- **Personalised advance care projects:** from research to action via support for pilot projects. With very varied partners
- **Family carers:** research. Projects: how to support them and develop their autonomy

EUROPEAN INITIATIVES

- **High level conference** in 2010 on the occasion of the Belgian Presidency of the EU
- **ALCOVE** (2011-2013): dementia from an ethical and legal perspective
- **EFID** (2011-): towards a dementia-friendly Europe

SCIENTIFIC FUNDS

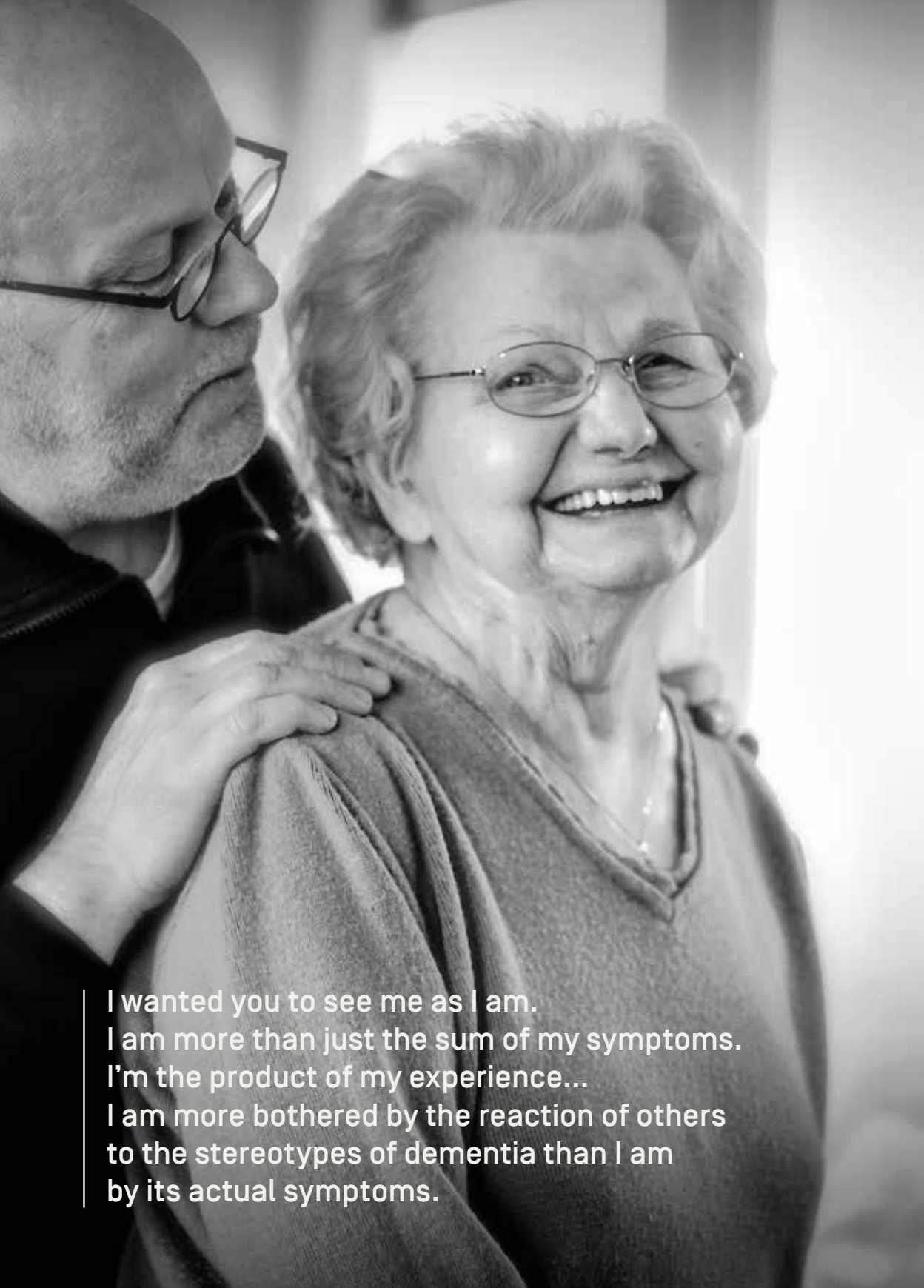
- **Support for** (biomedical and psychosocial) **research** on dementia. Aline and A.B. Fund, Marie Thérèse De Lava and Robert De Schneider Fund, Malou Malou Fund and the Perano Fund (€ 1,250,000 in total).

2007-2017

A TIMELINE

- 
- 2007** ○ **MAY** Creation of a working group of 13 experts, under the direction of the Minister of State Magda Aelvoet
- 2007-2008** ○ **DEC** Multidisciplinary research on the perceptions of dementia, its legal facets and advance care planning
- 2009** ○ **MAR** Dissemination of the working group's final report and recommendations
- AUG** Launch of the first three calls for projects for dementia-friendly communes, in collaboration with UVCW, VVSG and BRULOCALIS
- 2010** ○ **SEP** Launch of the Flemish dementia plan: *Dementieplan Vlaanderen 2010-2014' Naar een dementievriendelijk Vlaanderen*
- NOV** Organisation of a high level European conference within the framework of the Belgian Presidency of the European Union
- DEC** Adoption by the Walloon Government of the *Programme wallon d'actions Alzheimer et maladies apparentées*
- 2011** ○ **MAY** Presentation of the dialogue results '*Penser plus tôt... à plus tard*'. In the following years, the Foundation supported advance care planning projects (2012-2014)
- SEP** The Flemish authorities conduct the campaign *Vergeet dementie, onthou mens*, in collaboration with relevant actors, including the King Baudouin Foundation
- DEC** The Walloon Ministry of Health participates financially in the King Baudouin Foundation's third call for projects for dementia-friendly communes
- Creation of EFID, a common programme of five foundations aiming to establish dementia-friendly environments across Europe and which actively involve those with dementia in the programme

- 2012**
- JAN** Announcement of the first series of prizewinners for the EFID-Awards '*Living well with Dementia in the Community*': ten projects in eight European countries
 - DEC** *Dementie en beeldvorming* was the theme for the 2012 end-of-year action by Studio Brussel/VRT (Music for Life)
- 2013**
- MAR** ALCOVE (Alzheimer Cooperation and Valuation in Europe) report on the autonomy, dignity and competence of people with dementia, from an ethical and legal point of view
- 2014**
- MAR** Announcement of the second series of prizewinners for the EFID-Awards '*Living well with Dementia*', with ten more projects, from eight European countries. For the first time, people with dementia were members of the jury
- 2015**
- JUL** Launch of a call for projects that support family carers
 - SUM.** Presentation of *Dementieplan Vlaanderen 2.0* (2016-2019) updated, to extend the first plan
- 2017**
- JUN** Communication by a coalition of 20 Walloon partners in a common project of advance care planning (towns and communes, home care organisations, general practitioners, care homes...)
 - OCT** A year before local elections, the Expertisecentrum Dementie Vlaanderen, the Alzheimer Liga Vlaanderen vzw, the Vereniging van Vlaamse Steden en Gemeenten and the King Baudouin Foundation draw attention to the concept of dementia-friendly communes
- 2018**
- JAN** Announcement of the third series of EFID-Awards prizewinners: twelve projects from ten countries
Theme: '*Valuing the expertise of people living with dementia*'



I wanted you to see me as I am.
I am more than just the sum of my symptoms.
I'm the product of my experience...
I am more bothered by the reaction of others
to the stereotypes of dementia than I am
by its actual symptoms.

TWO CENTRAL THEMES

SOCIAL INCLUSION AND AUTONOMY

01

In future, practically everyone will be confronted with dementia: as a patient, a spouse or (grand-) child, as a relation, friend, colleague or neighbour. As long as these illnesses remain incurable, they present society with both a challenge and a responsibility: we must all be able to answer the needs for care together.

From the moment that it began working on dementia, the King Baudouin Foundation chose two broad themes.

The promotion of social inclusion

Those suffering from dementia are part of our society, just like anyone else. We aspire to have a society that cares about their problem and that of their family carers. We share their care. For this reason, it is useful to consider together how we speak about dementia. An environment and perceptions that are devoid of prejudice are essential to ensuring the quality of life of those with dementia. And so it was on this subject that a series of initiatives and projects was conducted with a large number of stakeholders.

I wanted to attend an annual conference for carers, but I couldn't go in.

Because I had dementia. That was it for me!

I said to myself, 'This isn't right'.

And a year later, our working group had been created and I attended the same conference.

This time, however, it was as a guest and official speaker.

James McKillop, Co-founder,
the Scottish Dementia Working Group

Maintaining a person's autonomy

People living with dementia are, above all, people with rights and responsibilities, like the rest of us. How can we better manage this reality collectively – as doctors, professional carers, lawyers, decision makers, businesses and individuals? How can we take account of the wishes of those with dementia? And what can be done to better support the carers? How can the concept of early personalised and advance care become established? Some initiatives also focus on these questions.

It's often family members and the doctors who decide on the care and treatment of people with dementia. However, most of them die without their wishes having been taken into consideration.

Professor Luc Deliens,

'Zorg rond het Levenseinde' research group

I always thought that my mum would be upset if I spoke about the future with her, that she'd think I wanted to get rid of her. But in the end, I said to myself that today, it would be a proof of my love for her to have this discussion with her...

Daughter of a woman with dementia

WORKING TOGETHER TO HAVE GREATER IMPACT

The Foundation combines various working methods, each with its own objective, but all with the final objective of creating an impact:

- financial support for innovative projects undertaken by organisations working in the field of 'dementia and quality of life' and through calls for projects with independent juries;
- the launch of research and research-action projects and sharing the results with a wide public;
- increasing citizens' awareness of the scale of the problem;
- the organisation of study days, intervision sessions and debates that bring people together and confront different visions;

- collaboration with government bodies, political decision makers, NGOs, research centres, civil society organisations, other foundations etc.;
- the establishment of European partnerships, including with the EFID network (European Foundations' Initiatives on Dementia) to acquire, share and disseminate knowledge.

The experience of people with dementia, their families and numerous organisations is combined with quantitative data, research (-action) as well as contributions from experts and pilot projects.



ADVOCACY

Strategic communication
Awareness-building among political
decision makers about specific subjects

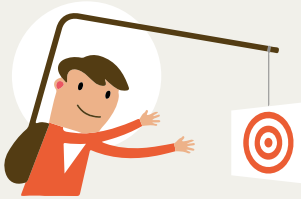


FINANCIAL SUPPORT

Subsidies for individuals
and organisations
Social responsibility investment



AIMING FOR IMPACT



CITIZEN MOBILISATION

Citizens' awareness-building about certain
subjects to bring about change



PROMOTING PHILANTHROPY

'Via' and not 'for' the KBF



RESEARCH

Collection of pertinent
facts and figures



BRINGING PEOPLE TOGETHER

Bringing stakeholders together around
themes of social responsibility

What impact have these ten years of work had on dementia and the quality of life? This is in part measurable, as can be seen in the figures given in this report.

But there is more. The recommendations and results of various research projects have been adopted, used, applied and disseminated by, among others, political decision makers from local to European level, as well as by federations, dementia centres, patients' associations, professional carers and lawyers. And this has in turn inspired new research to be undertaken, creating an interaction that enables research to be oriented towards practice too.

- The work on dementia has acted as a platform so that actors from various disciplines have come together and shared information. This work has also exercised an important function of creating networks across the different disciplines. Two examples: doctors and lawyers discussed the subject of people with dementia; and very diverse actors, with very different positions, took part in focus groups to discuss advance care planning.
- Representatives of the King Baudouin Foundation sat on the working groups and steering committees that prepared the political groundwork. It was also via this route that research results and project experiences have been communicated to politicians.

- The Foundation attaches great importance to making known the projects it supports. The dissemination of good practice at national and European level is a recurring theme in its activities, including those relating to dementia and quality of life.
- For the actors and organisations in the field – such as patients' associations, family and other carers, notaries and justices of the peace – the interest shown in this often difficult problem area constitutes a fulcrum and provides moral support.

The Foundation has been the ice-breaker that got things moving. It has contributed to a turning point in the minds of people regarding the non-medical approach. It has stimulated debate in society.

Jurn Verschraegen, Director,
Expertisecentrum Dementie Vlaanderen

What struck me were the initiatives that the Foundation took to change the image of this illness in society and this for everyone concerned. This has been really crucial!

Jean-François Bier, neurologist,
Hôpital Erasme, Brussels



HOW IT ALL BEGAN

HOW IT ALL BEGAN

2007. The King Baudouin Foundation put together a working group. The key question for the thirteen experts was 'How can the quality of life of people with dementia and their families be improved?' Research was launched and the working group listened to a large number of people concerned. In early 2009, the group formulated its recommendations, which were also invitations, in a final report. Over the following years, these inspired, among others, government authorities when they were developing their strategic plans on the subject.

TOWARDS A DEMENTIA-FRIENDLY SOCIETY. THE 2009 RECOMMENDATIONS

- Try to give a more nuanced image of dementia and mobilise the social fabric to mix better with those with dementia.
- Be more attentive to the situation in the home and support family carers.
- Work to ensure that doctors communicate openly, properly and within an appropriate framework, including at the moment of delivering the diagnosis. Train all professional carers in every aspect of the problems of dementia (including non-medical aspects).
- Create home care that is better adapted and more oriented to demand, including by investigating new types of collaboration between professional carers. Support and disseminate good examples of residential care.
- Pay attention to the 'forgotten' groups, such as those with early-onset dementia, patients from an immigrant background, the isolated elderly and disabled people.
- Promote a culture of advance care planning for end of life, including when talking about dementia.
- Strengthen and clarify the legal status of those with dementia. Ensure that legal provisions correspond to their needs. Inform them of their rights and responsibilities.

The Foundation took these recommendations to heart, as this report shows, and has undertaken intensive work to date on these issues, including also in a European context as part of its field of work in Health..



A more relaxed climate has been created

Magda Aelvoet, Minister of State and President of the Experts Working Group, 2007-2009

"I can sense much more empathy. It's apparently linked to the fact that there are more and more elderly people. I'm basing this on contacts as much with people directly affected by dementia as with others. Today, one can talk about dementia and the negative reactions of before have often given way to acceptance and a sort of empathy. Things are moving. This is also explained by the fact that more and more people are confronted with these problems. I really think this.

You see it in films too, often very human, and in the books that are written... This would have been very different a few years ago. These are accounts of people who have been confronted with the problem in various ways. I think that all of this contributes to creating a more relaxed climate. The theme is now part of wider society. You see too that these films are shown in old people's homes and the subject is talked about. Big campaigns have been conducted and these also represent a step forwards. And numerous communes have undertaken steps and describe themselves as 'dementia-friendly'. The simple fact of naming it like this is already positive and contributes to further echoes."



MORE SOCIAL INCLUSION: PROJECTS & INITIATIVES – IMPACT

HOW DO WE TALK ABOUT DEMENTIA? – PERCEPTIONS

Beforehand, playing the perception card was an extremely important choice: how did people think about dementia? Because that is the prerequisite for policy in this area. It's about living well with dementia, and everything that this includes.

Jurn Verschraegen, Director,
Expertisecentrum Dementie Vlaanderen

There are fewer and fewer situations where a family will take you aside and ask you to avoid at all costs pronouncing the word 'Alzheimer's' in the presence of a patient, as used to be the case.

Adrian Ivanoiu, neurologist,
Hôpital Universitaire Saint Luc, Brussels

Why perceptions?

Dementia is a serious illness, but it is also a social construct. We all speak about it in a certain way; the media show people with dementia from a certain angle. It is both useful and necessary to be conscious of how we communicate, particularly because our manner of communication has a huge influence on the quality of life of those with dementia and their families. Stigmatisation and taboos, for instance, are an additional problem for them and further increase their isolation.

What?

- Good communication relies on a good understanding of things. This is why the brochure we published in 2010 - *Un autre regard sur la maladie d'Alzheimer (et les maladies apparentées)* - [A different take on dementia] - managed to break certain clichés.
- How can we communicate in a more nuanced way about dementia? It is useful to know the frames of reference that are often used. Professor Baldwin Van Gorp studied the key frames used and researched 'counterframes' that could be used instead, in *Framing et reframing: Communiquer autrement sur la maladie d'Alzheimer* [Framing and reframing: communicating differently about dementia] [2011].

With whom?

The results of research on the perceptions of dementia were presented and discussed during a study day and other meetings with a large number of actors concerned, including doctors and other professional carers, media and communication specialists and professionals from the social care sector.

A more nuanced image: it is undoubtedly the Foundation that laid the foundation for this. And then, this was picked up and accentuated. It has really been pioneering work, with a huge impact right up to welfare services.

Walter Brusselaers, Provincial Director, Familiehulp Antwerpen en Oost-Vlaanderen'

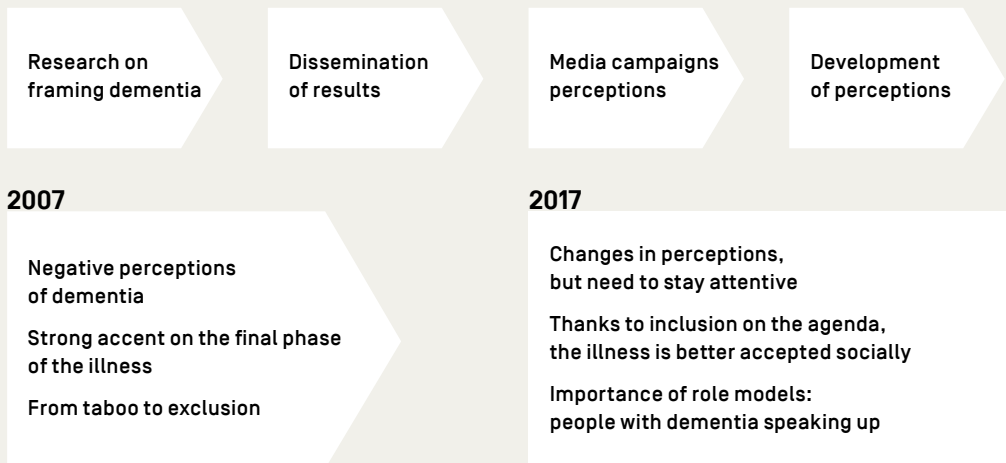
It's obvious that views have changed, and notably those of general practitioners. The King Baudouin Foundation has really shown that a person can keep his or her dignity right up to the end of life, even if the illness develops.

Michel Van Halewijn, SSMG

Impact

- The conclusions of the Van Gorp report were translated and disseminated in a practical guide containing advice about communicating for all of those who talk about dementia, whether in words or images, entitled: *I'm still the same person: a different way of communicating about dementia*. This guide was also presented and disseminated at European level (www.efid.info).
- The research on perceptions of dementia was one of the inputs to the large-scale media campaigns initiated, among others, by the Flemish Government (*Vergeet dementia, onthou mens* - Forget dementia, remember the person) and by Studio Brussels/VRT (*Music for Life*).
- The research on framing dementia was widely disseminated in academic circles, where it is known by all those who work with framing, and also presented at international level. This led to the idea of developing 'counterframes', which result in a combination of empiricism (identifying the frames) and creativity (imagining counterframes).

FROM A TABOO TO A MORE NUANCED IMAGE





WELCOME TO YOUR NEIGHBOURHOOD! – DEMENTIA-FRIENDLY COMMUNES

We're being innovative at the same time, starting from the field and changing how people look. Thanks to initiatives for family carers at local level, we came to the concepts that we really care about: 'Elderly-friendly town' and 'Dementia-friendly Communes'.

Brigitte Bouton, AVIQ

Why have Dementia-friendly communes?

Managing dementia is a learning process for the whole society, starting with the immediate environment of those with the illness and their family: the neighbourhood, the commune, the town or city. How can one create, through greater or lesser involvement and by awareness building, a welcoming environment where those with dementia are at ease and feel welcome? And how can this be rooted sustainably? How can those with dementia and their families be involved?

What and how?

Based on the model of a Japanese and German concept, the Foundation launched the idea of 'dementia-friendly communes' in Belgium, one of the first countries in the world to do so.

- A hundred or so projects were supported following several calls for projects across Belgium. They involved many different actors: the police, shopkeepers, associations, cultural centres, local authorities, day-care and other centres, etc.
- *Communes Alzheimer admis. Un guide pour vous inspirer (Dementia-friendly communes. A guide to inspire you)* was published in 2011. With copies distributed in Belgium and abroad, it was intended to be a source of inspiration for others.
- The concept of 'dementia-friendly communes' was also widely disseminated at European level (EFID, see p.26).

With whom?

The King Baudouin Foundation worked on this theme with the *Union des Villes et Communes de Wallonie*, the Brussels-Capital Region (Bruxelles-Capitale), the Vereniging van Vlaamse Steden en Gemeenten, the Ligue Alzheimer and the Expertisecentrum Dementie Vlaanderen.

Impact

In 2010, dementia-friendly communes benefited from substantial financial support approved by the Walloon Minister of Health.

The Ligue Alzheimer promoted the concept of the '*Ville Amie Démence*' (Dementia-friendly town), whose charter has already been signed by numerous local authorities. And the Walloon Region uses a concept set up by the World Health Organisation, under the acronym WADA ('*Wallonie Amie des Aînés*' – Wallonia, Friend of the Elderly).

In 2014, in the wake of the dementia-friendly communes network being established, the VVSG (Vereniging van Vlaamse Steden en Gemeenten) developed the *Dementiemeter* (Dementiameter), a check-list of action points. Following evaluation, a development process was created for this tool in 2017. The Dementiameter enables towns and communes to take decisions that take account of people with dementia and implement these decisions.

[www.dementievriendelijk.vlaanderen.be](http://www.dementie vriendelijk.vlaanderen.be)

www.dementie.be

A TAXONOMY FOR 'DEMENTIA-FRIENDLY COMMUNITY' ACTIVITY

COMMUNITY SUPPORT

Focus of DFC activity is providing community care and support to people with dementia

- Basic awareness-raising focused on community care, support services and emergency services.
- Inclusion and 'involvement opportunities' for people with dementia through community groups, memory cafes, etc.
- Led by a public health service, social care service, or specialist dementia NGO - small partnerships that may be time-limited to complete certain tasks, or be sustained.

COMMUNITY INVOLVEMENT

Focus of DFC activity involves the wider community being supportive towards people with dementia

- Basic awareness-raising, challenging stigma about dementia among community organisations, public services, shops, businesses, etc. May involve 'Dementia friends' sessions, exhibitions, films, etc.
- Inclusion and involvement opportunities include a wide range of community activities e.g. walks, exhibitions, clubs, church services, community groups, etc. giving people with dementia a visible community 'presence'.
- Range of organisations but probably led by dementia NGOs, and/or health and social care services - large partnerships but a minority of active members.



WHOLE COMMUNITY AND CITIZENSHIP

Focus of DFC activity is community partnerships co-ordinating a comprehensive 'whole community' and citizenship approach with the active involvement of a range of organisations, resources, and people with dementia

- Awareness-raising across community organisations, businesses, public services, etc.; is well resourced; includes the active involvement of people with dementia; results in positive activity to change attitudes and behaviours; removes barriers and improves access; supports inclusion and participation of people with dementia in the community; and is evaluated to assess impact.

- Active participation of people with dementia and other community members in all aspects of 'dementia-friendly community' activity, (as individuals and through groups, as equal citizens and valued members of a partnership), including awareness-raising and evaluations of impact.
- Democratic and accountable community partnerships and networks, that are coordinated by organisations with the ability to commit resources for community wide activity but who can also support and respect diversity, small, grassroots initiatives and the active involvement of people with dementia – most member organisations are actively involved and there are resources and commitments to sustainability.

TOWARDS A DEMENTIA-FRIENDLY EUROPE – EFID

(EUROPEAN FOUNDATIONS' INITIATIVE ON DEMENTIA)



Thanks to EFID, we have been able to establish international partnerships, which are great sources of inspiration to us.

Bart Deltour, Director of Methodological Development and Public Targets, Regionaal Expertisecentrum Dementie Foton

We speak about a problem at European level, which means that we can also find good ideas elsewhere. Inversely, the Foundation's activities have also influenced projects in other European countries.

Eric Salmon, neurologist, Memory Clinic, Université de Liège

We don't consider dementia as a 'weight' on society, but rather an opportunity for us to free ourselves from stereotypes and change society and its practices.

EFID

There are no words to express how much working in a network, together with the other prizewinners, can be precious for someone with dementia... You make new friends, share experiences and you become a member of the EFID family.

Helen Rochford Brennan, has early-onset dementia and President of the Irish Alzheimer Society's National Dementia Working Group

Why?

Improving the quality of life for those with dementia is a necessity throughout Europe. It was in November 2010, within the framework of the Belgian Presidency of the EU, that the work of the King Baudouin Foundation took on a European dimension through the organisation of a high-level conference on dementia. The three themes of this conference remain relevant today: the ethical and legal aspects of dementia, the quality of life of those with the condition and perceptions by society.

What and how?

In 2011, the King Baudouin Foundation was the initiator and co-founder of EFID (the European Foundations' Initiative on Dementia), a unique initiative on a European scale. EFID's mission is to improve the lives of those with dementia by creating a framework for living that is welcoming and inclusive across all the communities of Europe.

Ideas and new perspectives are exchanged to achieve this objective. What is essential for EFID is to actively involve those with dementia and to respect the culture and traditions of the various countries and regions of Europe.



MISSING PERSONS The HEKLA project

One of the EFID prizewinners was the Missing Persons Project developed by the Hekla zone of the Antwerp police, which has since been widely replicated across Belgium. The project aims to find as quickly as possible, people with dementia who have disappeared. It is the speed of reaction that is vital and this is made possible thanks to much closer collaboration, within the framework of the project, between aid organisations and the police services. In recent years, more than 85 police zones in Belgium have adhered to the project and we are witnessing a significant fall in tragic ends to cases of disappearance.

- EFID granted three series of awards to 32 projects in a total of 13 countries. The first two series related to 'Living well with dementia in the community' and the third series to 'Valuing the expertise of people living with dementia'. This change of name is significant: since 2013, those with dementia have been involved as experts experienced in living with the condition in decisions regarding the awards.
- The Capacity Strengthening Fund (CSF) helps prizewinners and other organisations to set up common projects and conduct mutual study visits (establishing networks). Workshops are also organised.
- In 2016, EFID published a map of dementia-friendly communes and initiatives in Europe, with their similarities and differences. The study was conducted by the Mental Health Foundation UK.
https://ec.europa.eu/eip/ageing/library/mapping-dementia-friendly-communities-across-europe_en

With whom?

The European Foundations' Initiative on Dementia is a partnership between the King Baudouin Foundation (BE), The Atlantic Philanthropies (IE), the Médéric Alzheimer Foundation (FR), the Robert Bosch Stiftung (D) and the Genio Trust (IE) within the framework of the Network of European Foundations or NEF.

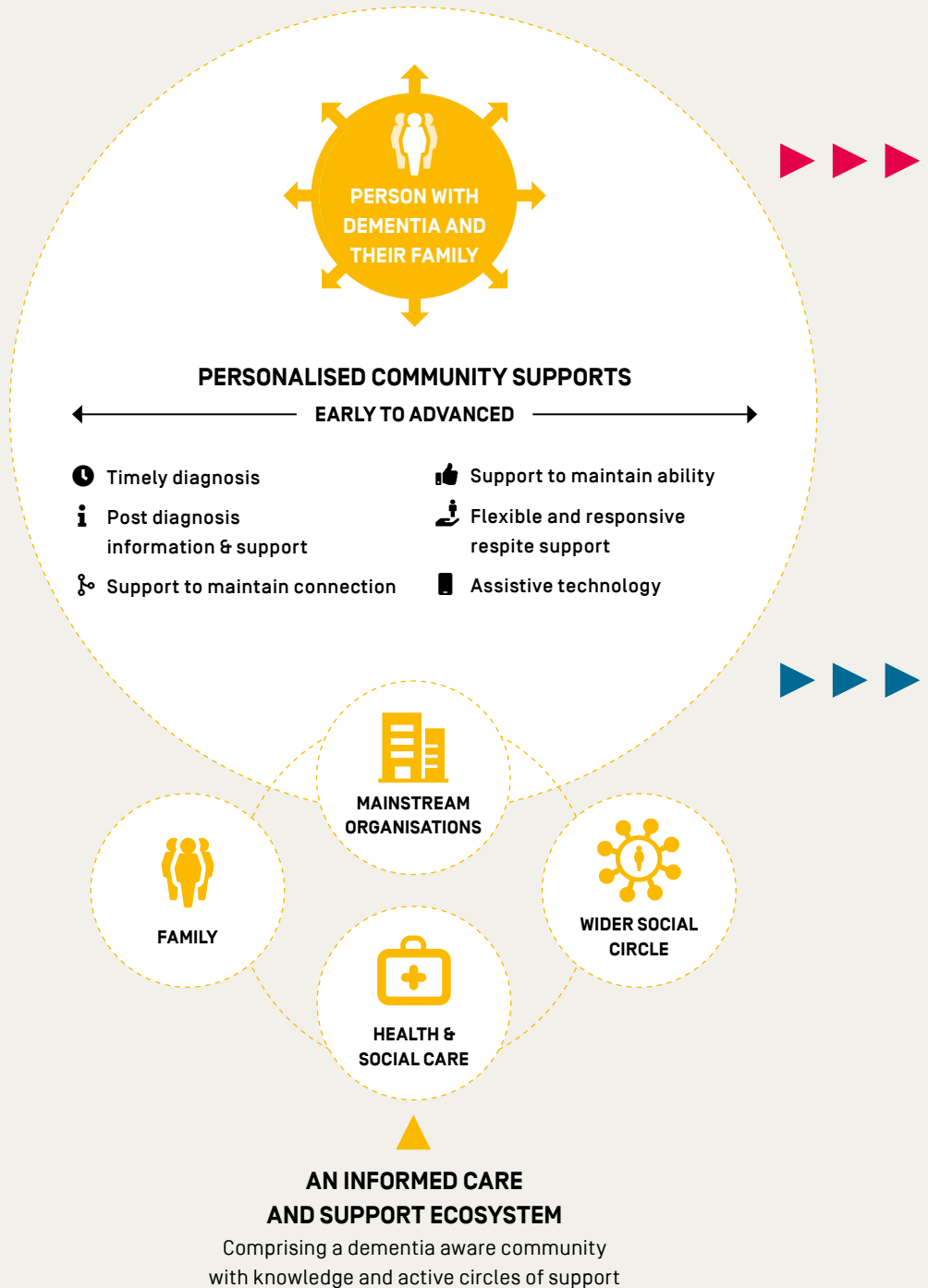
Impact

- The community approach to dementia is disseminated during national and European forums through, among others, Alzheimer Europe.
- The links between the organisations of various European countries that act at local level is an important added value for the dissemination of good practice.
- EFID is a tool for international dissemination of awareness messages, as was done with *I'm still the same person*, the translation of the KBF brochure *Je suis toujours la même personne*.
- EFID is a pioneer and a model for the involvement of people with dementia and their families as active partners in setting up projects, initiatives and so on.

EFID Awards News from Bulgaria

During the first EFID Awards in 2012, Bulgaria was selected for its project 'Twinning programme of Alzheimer's Disease International'. The Foundation Compassion Alzheimer Bulgaria indicated at that time that the subject of dementia was not at all on the agenda. Since then, EFID has organised for 2018 its official award ceremony 'Valuing the expertise of people with dementia' at the University of Sofia, under the Bulgarian Presidency of the European Union and in the presence of political decision makers.

COMMUNITY SUPPORTS MODEL PERSONALISED





DEMENTIA CONSORTIUM

People living as included and valued citizens

- People with dementia & family carers
- GPs & primary health care services
- Acute hospitals
- Mental health services
- Home help & home support services
- Mainstream services agencies
- Non-health agencies e.g. Transport
- Community & voluntary organisations



DEMENTIA CO-ORDINATOR

- Lead on developing & promoting a personalised approach to service delivery
- Single point of contact for a designated area providing specialist dementia information, advice & support to health and social care professionals
- Work with community to develop & promote integration of person with dementia
- Promote dementia awareness and education opportunities for family, community & health and social care professionals

A MODEL THAT WORKS

What are the results of the dementia-friendly communes projects that have been running for several years?

This was the question for the study *Community Supports Model for People with Dementia*, published by Genio, EFID's Irish partner.

Here are some of the conclusions:

- Living well with dementia above all means accepting patients' right to live as long as possible in their own community. The authorities can support this objective by re-orienting services and means towards care that is based on the individuals and which begins with the community. This does not necessarily mean large investments.
- Thanks to new types of support like this, a considerable number of people with dementia continue to live at home longer. In other words, a relatively limited investment in an innovative and personalised type of support changes lives and reduces the costs of residential care. The community approach is also financially beneficial.
- The experience to date illustrates what are the factors for success in moving towards a global community care model for those with dementia. These local learnings can be applied on a larger scale.



A BALANCE BETWEEN AUTONOMY AND PROTECTION: PROJECTS & INITIATIVES – IMPACT

WHAT? WHERE? WITH WHOM? WHY? – ACQUISITION AND DISSEMINATION OF KNOWLEDGE

Why?

What should be done when the dementia diagnosis is made? Where to find help and care? Who can you trust? What are the rights and responsibilities of those with dementia? These people and their families need clear, correct and up-to-date answers to their numerous questions. However, the answers and information are spread around numerous places.

But professionals too feel a need: basic legal knowledge for doctors, basic knowledge about dementia for justices of the peace, notaries, lawyers and provisional administrators... Their decisions have a huge influence on people's life and autonomy. It is important to provide them with knowledge and information about specific aspects of the illness so that they can take the correct decisions.

The King Baudouin Foundation has played an important role through the work on perceptions of dementia, seeing things from a different angle, the question of rights and responsibilities involving notaries and judges, everything relating to the dementia-friendly communes...

The issue in all of that is being aware that the group of actors to be mobilised cannot be limited to just the carers. And those with dementia are not just patients, but citizens too.

We can see that being reflected in the various projects in an applicable manner.

Fabrice Gzil, philosopher, Fondation Médéric Alzheimer (France)

What and how?

The King Baudouin Foundation has served as a platform and a forum where the actors from the various fields can meet. The objective: to disseminate quality information about how doctors and other professional carers, justices of the peace, notaries, lawyers and so on talk about dementia. Multidisciplinary discussions of this nature between those who take crucial decisions for people's existence are rare but extremely useful.

- The Foundation and the Fédération Royale du Notariat belge jointly published the brochure *Que faire face à la maladie d'Alzheimer?* [What to do when dealing with dementia?] [2011, re-published in 2017].
- Another practical guide, *Les droits des personnes atteintes de la maladie d'Alzheimer ou de maladies apparentées* [The rights of those with dementia] [2010], answers commonly asked legal questions in relation to the illness.
- The Foundation worked with a committee of experts to publish a practical guide specifically aimed at lawyers: *Praticiens du droit et personnes âgées en difficulté cognitive. Pour des interactions réussies* [Legal practitioners and elderly persons with cognitive difficulties. For successful interaction] [2011].

With whom?

The Foundation has collaborated with the Fédération Royale du Notariat belge et l'Union Royale des Juges de Paix et de Police asbl.

Impact?

The number of copies disseminated of the brochure *Que faire face à la maladie d'Alzheimer?* – some 70,000 copies – illustrates the need for printed and accessible information that sheds light on all facets of dementia.

The guide was updated and reprinted in 2017.

PROTECTION STATUS

A new statute for protected persons has been in force since 1st September 2014, which replaces all previous dispositions.

The new law relates to enabling so-called 'vulnerable' people to retain the greatest possible autonomy: they must be allowed to exercise their rights themselves as much as possible and must therefore be actively involved in decisions that concern them. The law creates tailor-made support and protection.

[La maladie d'Alzheimer...Que faire ?](#)



FAMILY CARERS: HELPING THOSE WHO HELP

The initiatives undertaken in psychoeducation for family carers have shown their usefulness. They slow down admissions to care homes and reduce costs, in the first place for the families themselves. Psychoeducation also implies forming groups, and thus new contacts, with people in the same situation.

Kurt Segers, Neuropsychiatry Department, CHU Brugmann, Brussels

I have the impression that there is more expertise when it's a question of communicating with confused people. Psychoeducation for family carers is manifestly bringing its rewards: how to converse, how to show kindness, etc.

Géry de Walque, Justice of the Peace

Why?

The figure has remained stable for years: roughly 70% of those with dementia live at home. Family carers play an essential role in caring for them: the partner, children and grandchildren, other members of the family, neighbours and friends. How can they be supported and their capacities be built further so as to respond better to their needs? How can we put in place a network of help around an elderly and disoriented person, especially if he or she is vulnerable and lives alone? The law of 3 April 2014 gives official recognition to family carers, but does not link social rights and financial support to this recognition.

What and how?

A large-scale quantitative survey [2016] conducted by UCL at the request of the King Baudouin Foundation, examined the situation of over 5000 vulnerable and elderly people and their family carers. The role of cohabiting carers and non-cohabiting carers was studied. The research provided an image of their situation, their needs and risks, such as overwork and exhaustion for example. The overall finding was that people living with an advanced form of dementia live longer at home if there is a family carer living with them.

A few figures about family carers of people with cognitive conditions:

- caring for the patient can represent over 10 hours per day for live-in family carers;
- if one converts this time to calculate the remuneration that a professional carer would receive, the economic value of a family carer who does not live in could be as much as € 1194 per month;
- for people suffering from functional and cognitive problems as well as behavioural problems, the presence of a live-in family carer reduces the length of hospitalisation from 15 to 5 days on average, a considerable saving.

The King Baudouin Foundation supports innovative initiatives that help the family carers to assume their role as well as possible. These are projects that strengthen the network of formal and informal care partners within the close environment of elderly people.

Family carers play an important role in health-care. For people who have difficulty in conducting Activities of Daily Living (ADL), such as getting dressed, eating or going to the toilet, and Instrumental Activities of Daily Living (IADL), such as shopping, cooking, cleaning, washing up or transport, the live-in help of a family carer helps prevent falls, proper eating and early medical intervention in the event of a problem.

Family carers spend an average of 4.2 hours per day, but this can be as much as 10 hours per day for those with dementia.

SUPPORT FOR FAMILY CARERS

The Isidèr Project at the Ciney Healthcare Centre aims to identify and inform family carers in rural areas and establish a support network for them.

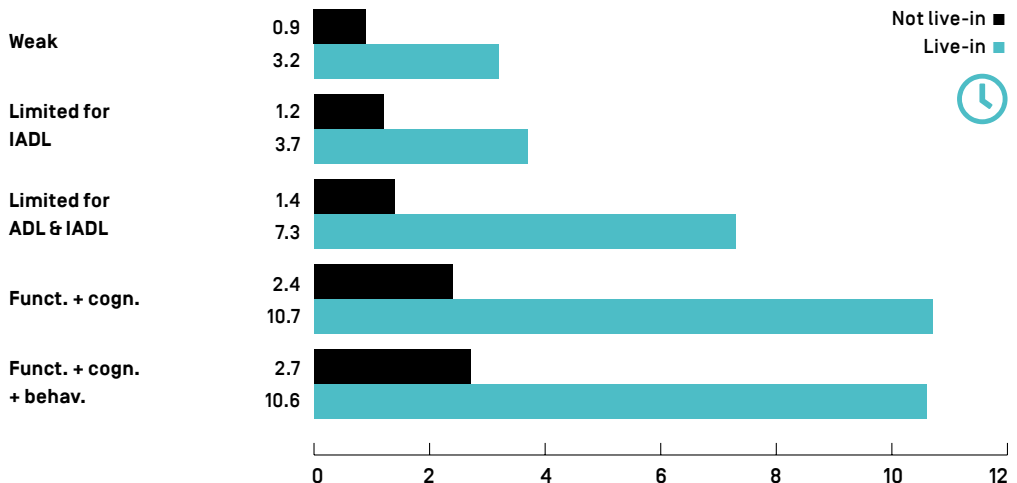
"Family carers have a high risk of exhaustion and other health problems" says Claire Vanderick, Coordinator of the health centre. "They often go beyond their limits to look after a vulnerable person, but feel guilty about asking for help, such as that of a day centre. This psychosocial support is thus indispensable for the family carer too."

Claire Vanderick, coordinator of the health centre

Family carers are the frontline of care but they too have their needs. We are seeing a change in mentality in the field of care, towards more contextual care for a family, but the systems pose an obstacle. We must give the carers the place that they deserve, but everything is linked to the patient in the patient's dossier and we don't have access to that as home carers.

Walter Brusselaers, Provincial Director, Familiehulp Antwerpen en Oost-Vlaanderen

AVERAGE DAILY TIME THAT FAMILY CARERS SPEND ON CARE



Little by little, we're also becoming better prepared.

Elena Bins-de Ru, Family carer for Nico

"Seven years ago, we contacted Foton. It was our GP who sent us. Until then, we didn't know anyone in the same boat as us, a couple where the husband was in an advanced stage of dementia and whose wife had become a bit like his bodyguard, a full-time carer. Friends and family kept their distance.

Foton has changed and enriched our lives enormously and that of lots of others. We console each other mutually, we have laughed and cried together, we've been on excursions and made real friends with people who understand us. Foton reaches many more people than we think. Not everyone can participate in public activities and dementia is always a taboo subject.

Foton has shown for us, and with us, the way to dementia-friendly shops, cafés and restaurants, even though this is only happening slowly. But little by little, we are also becoming better prepared ourselves. We can go to museums again and to cultural activities, with guides who have been trained for us. We are learning to speak openly about dementia and to accept it. We continue to care for the person at home and we do it well.

And my husband? He thinks it's great! Nibbling biscuits and drinking coffee non-stop, which he never did before. He never wanted to go out. One day, an English friend who hadn't seen him for several years said to him 'Are you still around? Oh, of course, you have Foton!'"





THINKING ABOUT TOMORROW – PERSONALISED ADVANCE CARE PLANNING

Why?

The personalised advance care planning project (PACP) is a dynamic and continuous process. Together with the family and carers, a person formulates beforehand his or her preferences regarding how they wish to be cared for when they are no longer able to take decisions about this themselves. These 'care objectives' can be adapted at any time in function of an evolving situation.

Yet, the advanced care planning project and questions relating to end of life are rarely raised with dementia patients. This is linked to several aspects, including the taboo concerning this illness, the lack of training for professional carers, the lack of information about the various

possibilities, the choices available and the flexibility. It is often the doctors who decide. When there is dialogue, it is often in a crisis situation. The aim must be to give greater respect to the choices of those who are confused when communication about these questions gets difficult.

End of life care and advance care planning remain enormous taboos and are a real challenge. Speaking about death and end of life is not our strong point. Sometimes people refuse to listen. I suppose that will change for the better with the trend towards aging and the multiplication of positive models. It's already the case with cancer.

Chantal Van Audenhove,

Vice-Rector, KU Leuven and Director of LUCAS

What and how?

- The Foundation initiated a long-term process on this subject, concentrating on the subject of dementia and setting out to gather the scientific knowledge as well as existing models and examples [2009].
- Citizens, professional carers, psychologists, social workers, spiritual mentors and care home managers discussed in focus groups comprising people with wide-ranging points of view. The results, with practical possibilities, difficulties and practical examples, were set out in the publication
- *Penser plus tôt... à plus tard. Projet de soins personnalisés et anticipés: Réflexions sur son application en Belgique avec une attention particulière pour le déclin cognitif*, 2011). [Think earlier...about later. Personalised advance care planning: reflexions on its application in Belgium with particular attention to dementia].

- The Foundation launched a research-activity with twelve experimental projects, supported by LUCAS and Braises. This led to political advice and recommendations, the common thread being: there is more than one good way to do things, each organisation has to develop its own vision: *Le projet de soins personnalisés et anticipés en pratique*, [Personalised advance care planning in practice], 2014.
- The practical brochure *Osez le dialogue! Le projet de soins personnalisés et anticipés* [Dare to discuss! Personalised advance care planning in practice], published in 2014, was addressed to carers. A new call for pilot projects followed in 2015.

Ageing is something people don't want to hear spoken about. But it's precisely this that makes us unhappy. We need to ask ourselves how we can prepare, adapt, change things. It can be part of a life project, a bit like an insurance policy.

Eric Salmon, neurologist,
Memory Clinic, Université de Liège

We put a lot of work into the project. Thinking earlier about later and this experience showed us what a difficult subject it is to broach. This really raised awareness among our professionals and volunteers.

Nathalie de Wouters, psychologist, and
Anouk Dufour, occupational therapist,
Alzheimer Belgique



With whom?

The Foundation worked on this subject with Braises (an inter-university network of expertise in aging) and LUCAS (Centrum voor Zorgonderzoek en Consultancy, KU Leuven).

Personalised advance care planning: an example

The project 'Vroegtijdige zorgplanning in West-Vlaanderen' (Early care planning in West Flanders) created a charter. Signatories to the charter subscribe to its vision and undertake to disseminate this vision in West Flanders with the tools that have been developed, notably:

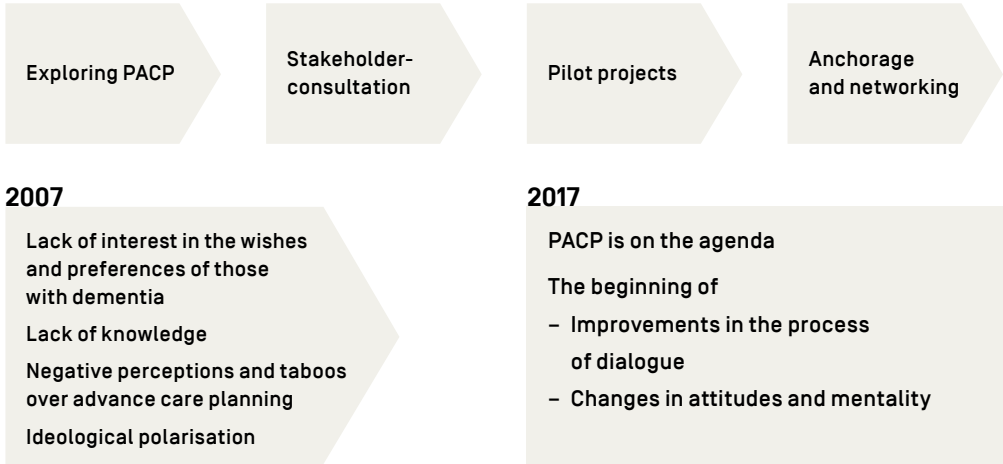
- the communication plan (including a map containing information for the citizen, an approach to be followed by professionals, a transfer document, etc.);
- the website and social media contacts;
- conventions with speakers and reference persons;
- needs and recommendations,...

Produced by the West Flanders Samenwerking-sinitiatieven Eerstelijnsgezondheidszorg (SEL), Netwerken Palliatieve Zorg and LEIF

Impact?

The concept of PACP has been introduced to important actors, going beyond philosophical and community frontiers. It is increasingly becoming one of the indicators of quality for organisations working in the sector of support for the elderly. There remains a great need for training and awareness-building to sustain this momentum.

FROM EXPLORATION TO SUSTAINABLE ANCHORAGE OF PACP



PROJECTS IN PRACTICE: TWO EXAMPLES

Domus Medica

With the support of the KBF, Domus Medica, the Flemish and Brussels general practitioners association, developed a module for advance care planning, which is aimed at 'Quality local care groups'. There are more than 60 of them, reaching 600 doctors.

En route pour la vie

For the French-speaking region, *En route pour la vie* [En route for life] is an ambitious project with 15 partners, including organisations from the healthcare and home care sector, care homes, palliative care platforms and associations for the elderly. An e-learning module was developed in collaboration with the SSMG [Société Scientifique de médecine générale].





DEMENTIA FROM AN ETHICAL AND LEGAL POINT OF VIEW - ALCOVE

[Alzheimer Cooperation and Valuation in Europe]

At the request of the Ministry of Health at the time, the Foundation was a partner in the temporary project of the ALCOVE European network (2011-2013), during which there were exchanges of knowledge and expertise regarding dementia. This joint action project was also supported by the European Commission. 30 partners from 19 countries took part. At the heart of the project was a need to increase and improve information for, among others, political decision makers.

One of the five central themes concerned the rights, autonomy and dignity of those with dementia. The King Baudouin Foundation managed the project. In 2013, a working group published, under the auspices of Professor Herman Nys from Leuven (Interfacultair Centrum voor Biomedische Ethiek en Recht), a [partial] report on the subject, with recommendations foreseen from an ethical and legal perspective. Practices in Europe on the anticipated declaration were notably reviewed. A group of European experts developed proposals and recommendations.



SUPPORT FOR RESEARCH INTO DEMENTIA - FUNDS THAT SUPPORT HEALTHCARE RESEARCH

The King Baudouin Foundation has supported a number of research projects, both biomedical and psychosocial, into dementia. Some fifteen projects received a total of € 1,250,000.

The Aline and A.B. Funds focus on biomedical research. They work in partnership with the Fondation Recherche Alzheimer.

The Marie-Thérèse De Lava and Robert Schneider Funds provide support for geriatricians and the Malou Malou and Perano Funds provide researchers with the opportunity to study non-pharmacological treatments, including for dementia. Interest is thus shown in the impact of psychoeducation on family carers for those with dementia. Do patients stay at home longer? Does their quality of life and that of their carers improve? Another research project looks at whether step-dancing can persuade those with dementia to move more, reduce loneliness and diminish the risks of falling.

TOWARDS A DEMENTIA-FRIENDLY WORLD

The World Health Organisation (WHO) is also very concerned about the problem of dementia. At the end of 2017, it therefore created an observatory to follow the development of the illness. The Global Dementia Observatory will examine, among other things, whether national plans exist in this field, what efforts are being made to reduce risks and what are the psychosocial consequences of the illness.

For the period up until 2025, the WHO will work with a plan that has seven fields of action, including better knowledge and perception of dementia as well as awareness and support for family carers. The other fields of action are prevention, research and innovation, diagnosis and treatment.

As well as a certain number of countries, the European Commission will also support the WHO initiative. It is known that there are already initiatives being conducted in numerous countries regarding the acceptance of dementia, awareness, and participation of those with dementia in social life and so on.



WHAT NOW?

Recommendations for future challenges

03

Much work has been done over the last ten years on the theme of dementia and quality of life. What are the challenges now, short and medium term? 25 experts, from various fields, were asked this question individually. All are closely associated with the problem. Several recurrent issues emerged during these interviews.

In short

Continuity: the working themes adopted during the last ten years have lost nothing regarding their relevance today and their urgency: the perception of the illness and the taboos, social inclusion, dementia-friendly environments, advance care planning, the need for training for medical personnel and lawyers, support for family carers...

Combinations of problems: everything indicates that, in the coming years, we will witness an increase in situations where dementia combines with another societal problem, such as patients' diverse cultural origins, solitude, disability or poverty...

Empowerment: the need to let those living with dementia speak for themselves and to involve them in decisions, we must exploit the power of culture, support citizens' initiatives, adapt legislation... The possibilities for living better with dementia – by being involved in society and respecting a person's autonomy – are many.



CONTINUITY

It is enough to examine the recommendations of the Aelvoet Working Group in 2009 (see p16), or those formulated in 2010 after the high level European conference (see p49) to observe that many of the recommendations and challenges regarding social inclusion and the autonomy of people with dementia have lost nothing in their pertinence today.

This is confirmed by our interlocutors:

- Has the image of dementia in society changed? The answers go from "Yes, a lot has changed" to "It's going very slowly". There has been no recent 'measure'. **In any case, image is never an acquired result. It is an on-going challenge that must stay on the agenda**, involving partners, notably in the media. As more and more people are confronted with dementia in their

immediate environment, there seems to be much greater familiarity with the problem, which may lead to the disappearance of taboos and stigmatisation. But this will not happen on its own and it is a development that requires monitoring. According to EFID too, stigmatisation and social exclusion remain important challenges.

- The **phenomenon of dementia-friendly environments and communes is growing in strength**, including at European level. However, securing political interest in this problem is not easy. It will no doubt be easier in the future, in part because of the increasing number of people with dementia. It is even more important that the local level in Belgium is given more competencies.

- There is a **constant need for quality training** in every aspect regarding the problems of dementia: for doctors and other professional carers (notably in care homes), lawyers, family carers, reference persons...
- **Disseminating accessible and quality information to a wide public** remains a permanent mission, in collaboration with notaries, legal representatives, justices of the peace, professional carers and other experts.
- **Psychoeducation of family carers** is still a concern of great importance. Research shows that well-equipped carers positively influence the quality of life of those with dementia and can prolong their stay at home. From a purely economic point of view, investing in this field is thus a source of economies, for both the families and the authorities.
- Our interlocutors agreed about the usefulness of having a **platform and a forum** for dementia, where relevant actors can come together, inspire and inform each other and create networks...
It has been suggested that a permanent group be created that could sustainably anchor the current occasional contacts.
- **Good examples and good practices can never be disseminated too much** on a national and international scale. 'Buddies' projects that inspire great empathy, such as Het Ventiel, are also crucial for caring for patients. These examples, which combine personal characteristics, knowledge and experience, can inspire others and deserve to be made more widely known.

MESSAGES THAT REMAIN RELEVANT

The report prepared following the high level European conference on dementia in 2010, came up with some fifteen important measures and messages. Some of them are mentioned here in order to emphasise the continuity of themes and problems:

- Quality of life and social exclusion, the need to increase awareness and reduce stigmatisation
- Respect for the autonomy of those with dementia
- Treatment that is worthy of people with dementia and which takes account of their wishes
- Local support to prevent exclusion: dementia-friendly communes
- Support for family carers
- Promotion of good practices

COMBINED PROBLEMS

- There is great unanimity among all of the experts regarding **the urgency of the subject of 'ethnocultural diversity and dementia'**, including among others those with little education. The prevalence of dementia will also increase among people of immigrant origin. This is demographic data.
How can such people be approached [sensitivity of care to culture]?
And how will the perception of the illness develop specifically amongst people of diverse cultural origins? Initiatives are seeing the light of day, mainly in cities, but still in a somewhat hesitant manner. This issue could be included in a wider policy of diversity.
- **The solitude experienced by elderly people with dementia** is a difficult problem, which is becoming, and will become, more and more frequent. This is related to the growing 'mobility' of families, whose members go to live further away from each other, to the increase in the numbers of step-families, greater stress and individualisation. Community care and work can play a major role. It is important in this context to support basic [citizens'] initiatives, at least if they wish this.

- Among other combined problems, there are those of **dementia and poverty** and **dementia and the disabled**.

A dialogue must be established with organisations and movements devoted to these aspects. What are their needs?

What specific difficulties do they encounter?

What can be done to remedy these issues?

POSSIBILITIES FOR EMPOWERMENT

- It is still too rare in our country for **those with dementia to speak up and be actively involved in decisions that concern them**, both individually and collectively. Equality and inclusion have to be the order of the day and the objective, as is increasingly the case in mental health. As far as care is concerned, we must develop towards involving the user, as is already the case in the EFID group.
- **The importance of culture** for people with dementia is an area that is still largely untapped. There are quality initiatives, such as in the fields of music and [cultural] heritage, but there are still many other possibilities. Collaboration with the culture sector must be thought of as obvious. An adequate cultural environment enables us, for instance, to show the richness of communication possibilities, which go beyond just language.

- We can see more and more **citizens' initiatives** regarding dementia and quality of life. They generally serve their local/ regional environment. The effects of these initiatives on people with dementia can be spectacular. Such developments can be stimulated, for instance within the framework of community projects.
- According to several interlocutors, our **legislation on the administration of property and early declaration of intention** is good, but its application in the field often leaves much to be desired, among both justices of the peace and family members. Day centres, among others, can contribute to disseminating this philosophy.

What is also changing now is that one takes more care to let the patients speak.

You can feel that this subject has gained in importance internationally and that it is beginning to take root here too.

It's a real change, saying that it's not just the relatives who have something to say, but the patients themselves too.

Nathalie Rigaux, sociologist,
Université de Namur

Putting the accent on what people are still able to do

Anita Gancwajch, CPAS de Charleroi

"Dementia is an illness that creates fear for many people and which is a heavy burden to bear for those in their close circle who are confronted with the problem. The media also contribute to projecting a bad image. Me, I'm an optimist by nature and I'm also observing some very encouraging changes in the sector. It's taken thirty years. You need a generation to change a mentality.

What still needs to change more according to me? It's good to work in support of the family carers the way, among others, the Foundation does. But we need to go further. Today we constantly insist in our support on the things that people can no longer do – this is also indispensable for financial reasons – but to really change perceptions, we have, on the contrary, to put the accent on what they are still capable of doing. And we have to give patients more opportunities to speak. If legislation prevents this, then we have to do everything to change the law."

EXPERTS WE CONSULTED FOR THIS REPORT

Magda Aelvoet, Minister of State and President of the working group that bears her name

Stefaan Berteloot, Cabinet advisor to Minister Jo Vandeurzen and former Director of the 'Gezins- en Thuiszorg' service

Jean-François Bier, neurologist, Hôpital Erasme, Brussels

Brigitte Bouton, Inspector General, AVIQ

Sandrine Boyals, Attaché-expert in the Department for the elderly, AVIQ

Sigrid Brisack, Director, asbl Aidants proches

Caroline Ducenne, Coordinator, asbl Aidants proches

Walter Brusselaers, Provincial Director, 'Familiehulp Antwerpen en Oost-Vlaanderen',

Bart Deltour, Director of Methodological Development and Public Targets, Regionaal Expertisecentrum Dementie Foton

Géry de Walque, Justice of the Peace

Nathalie de Wouters, psychologist, Alzheimer Belgique

Anouk Dufour, occupational therapist, Alzheimer Belgique

Anita Gancwajch, CPAS, Charleroi

Fabrice Gzil, philosopher, Fondation Médéric Alzheimer (France)

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Herman Nys, Emeritus Professor of Medical Law, KU Leuven

Nathalie Rigaux, sociologist, Université de Namur

Eric Salmon, neurologist, Memory Clinic, Université de Liège

Kurt Segers, neuropsychiatrist, CHU Brugmann, Brussels

Lise Switsers, Staffmember, Vereniging van Vlaamse Steden en Gemeenten

Chantal Van Audenhove, Vice-Rector, KU Leuven, Director, LUCAS

Roel van de Wyngaert, collaborator, Zorgnet-Icuro

Baldwin Van Gorp, Professor of Journalism and Communication Management, KU Leuven

Michel Van Halewijn, General Practitioner, SSMG

Jurn Verschraegen, Director, Expertisecentrum Dementie Vlaanderen

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Démence en de rechten van de patiënt.

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Une analyse de littérature

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Dix années de travail commun pour apprivoiser la maladie d'Alzheimer

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This impact report illustrates ten years of the King Baudouin Foundation's activities in support of a 'dementia-friendly society', by putting the accent on key messages and a number of projects and initiatives: why they were set up, what was involved, who were the actors concerned and what their impact was.

The Foundation's work is not in isolation. It is rather a cog that is part of a large machine, a movement in which many people have collaborated and participated: experts and researchers, the many project initiators, associations and organisations, members of the call for projects juries, political decision makers and their administrations. And first and foremost, of course, the people themselves with dementia and their families.

We will also look to the future. In preparing this report, we consulted 25 experts in Belgium to discuss what the big challenges are regarding dementia and quality of life. What role can the King Baudouin Foundation and other European foundations [continue to] play?