Towards dementia-friendly communities across Europe

forming local alliances to support people with dementia and their families
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Never before have so many citizens lived as long as they do today. Never before were age and getting old as individual and colourful as today. Cities of long life are emerging. These are cities that allow the new growing potential of age and older people to unfold. Cities that at the same time handle the increasing essential situations of old age positively. Both are exciting new responsibilities; both are interwoven and help to shape cities of long and good life. With the progress of demographic change, the number of people with dementia is growing. More and more families, neighbourhoods, and groups are experiencing this.

Working together for a better life with dementia means getting involved locally. It is a community task to examine, develop, and link local support potential. The central government cannot do this, only communities can. And communities must shoulder this task because it involves their residents. With support and in cooperation with the Robert Bosch Foundation, we organised a city-wide learning process here in Arnsberg in which hundreds of persons participated and actively collaborated. A better life with dementia became a local issue and joint responsibility of people with dementia, families, citizens, professionals, and the city. A responsibility we continue to accept.

We have benefitted greatly from the discussion and exchange with people with dementia, their families, practitioners, and scientists. The European Foundations’ Initiative on Dementia (EFID) is an important partner, putting us in touch with active participants from all over Europe, providing knowledge, and giving us valuable impulses for our work here in Arnsberg.

The EFID network and the intensive exchange it facilitates between Foton in Bruges and Arnsberg’s “Lern-Werkstadt” Demenz (Learning Lab Dementia) is an excellent example of how we can learn from one another and support one another within Europe. We are building a social Europe from the ground up.

Without the cooperation with EFID and the network’s support we could not have learned all this. We would not have understood that the organisation of cities of long and good life is a new communal obligatory task. We hope that others will learn from our experience. This small brochure is designed to help.

Hans-Josef Vogel
Mayor of the City of Arnsberg
The demographic change and the growing number of people living with dementia are major challenges of our society. While some countries in Europe are increasing their efforts to improve dementia care, support and research, there is still a lot to do to tackle the challenges linked to dementia. In the absence of a cure, communities are key to support people with dementia and their relatives to maintain a good life. The European Foundations’ Initiative on Dementia (EFID), a group of engaged foundations of different European countries, is convinced that it is crucial to change attitudes and perception around people living with dementia and to see the condition as an opportunity for society rather than a burden.

Learning Lab Dementia Arnsberg and Foton Bruges are two notable examples of the community effort to improve the quality of life of people living with dementia and their carers. EFID is honoured to have supported the exchange between the two initiatives that allowed an inspiring mutual learning. The go-and-see visit, held in October 2016, strengthened the links between Arnsberg and Bruges and offered the opportunity to professionals, policy makers, people with dementia, carers and key stakeholders to experience the working methods of Foton and learn from each other. As one of the participants said, “Social participation is a life elixir for people with dementia and their relatives. We are on a good way to develop a dementia friendly community where dementia is not the boss”.

The positive results of the event show that people with dementia can play a fundamental role in developing policies and services for creating a successful dementia-friendly community. Meaningful participation of people living with the condition is key to ensure that decisions are made with regard to their actual needs and wishes. EFID wants to be a solid vehicle enabling community-based organisations to give people living with dementia a stronger voice, to empower them to be present in their community, and to encourage all the actors of our society to take responsibility for their fellow citizens.

EFID hopes the work that Arnsberg and Bruges are doing in their community and beyond, on promoting better lives for people with dementia and their carers, serves as an inspiring example to other public authorities, NGOs and citizens to take the initiative and to contribute in shaping communities we really want to live in – with or without dementia.

Dr. Bernadette Klapper
EFID Chair
01. Strategy for cities

Why is dementia a communal responsibility?
We are living in a society with a steadily growing proportion of elderly. Demographic change has shaped the public discourse in many European countries during the past years, and has resulted in adaptations in many places. A society of long life asks new questions, and we must find the answers.

One of the greatest challenges in this context is dementia. With increasing age, the likelihood to develop dementia also increases. According to estimates by Alzheimer Europe, there are approximately 7.9 million people with dementia living in the European Union today (1.55 percent of the population). The number of people living with dementia will rise significantly in the future. Living with dementia is a topic cities and communities in Europe will face; this is a fact.

Diagnosis dementia
A diagnosis of dementia fundamentally changes the lives of people with dementia and their environment: first there are only memory gaps and mild disorientation that cause irritation. Over time, entire life stories fade away, people with dementia no longer recognise their own children, and often their own personalities change.

Dementia initially means a change in the cognitive/psychological domain. Many people find it difficult to be open about these changes with themselves and others. Fear and shame are feelings many people living with dementia experience. Repression, secrecy, and hiding form an unhealthy triad that often leads to the people with dementia withdrawing into their own four walls and gradually becoming lonely.

At the same time, people with dementia, just like those people living without dementia, have their own ideas about their everyday lives, want to take part in their personal and public lives, and pursue their own goals. To do so, they depend in part on the right services and a supportive environment.
7.9 million: already, a great number of people with dementia are living in European cities and communities – often out of the public view. Most of them are cared for in the home by family members. But a person who must be there for a family member living with dementia is likely to feel burdened. Many family members try to combine in-home care with their professional careers or with raising their own children. At some point, they reach the limits of what they can do, suffer from overload and the immense responsibility resting solely on their shoulders. Care-giving family members are themselves in grave danger of suffering burn-out or depression due to such double pressures, which often last for years.

This illustrates clearly that dementia is more than a professional issue for a few medical specialisations, care facilities, and public health in general. Certainly, quality medical treatment and care are an essential factor that positively affects people with dementia’s quality of life. But quality of life is determined by much, much more than that.

Does my environment perceive me as a person, with all of my wishes, fears, and interests? Can I even tell my relatives, friends, and acquaintances if I am indeed diagnosed with dementia? Can I be sure that someone will take care of me when I can no longer do it myself? Are there activities available to me that I can be excited about? Or will I be cared for on the principle: “Fed and clean” is enough?
01. Strategy for cities

Shaping the community

The answers to these questions largely depend on the local conditions regarding technical infrastructure and available services, as well as social cohesion. Within communities, there are opportunities for influencing and shaping the local social framework.

Nearly everyone wishes to be able to remain in their home even when they need help in the form of care or personal support. To make this possible, they need alternatives to in-patient care. Particularly rural areas are often still poorly equipped in this regard. Good in-home care requires a differentiated help system of out-patient, temporary in-patient, complementary, and supporting geriatric and care services. Communities can actively influence these infrastructural frameworks.

Dementia is not just a topic for professionals, but an issue that concerns society as a whole: it is about attitudes and the public position on people with dementia. Because several areas of society must be involved in order to achieve improvement at the local level.

The model idea of the “dementia-friendly community” gets to the heart of this approach: associations, political parties, organisations in medicine, care, and support, administration, groups, initiatives, and private persons with and without dementia can get actively involved at the local level to improve conditions for people with dementia and their families. Leisure programmes, medical care, support, public relations work, self-help, training – all these and much more can be initiated locally. There are countless positive examples across the globe for dementia-friendly initiatives, and each is unique in its own way.

Foton from Bruges in Belgium and the “Lern-Werkstadt” Dementia in Arnsberg in Germany are examples of this approach. Over the years, the two organisations have maintained a lively exchange and have also benefited greatly from the exchange within the EFID network.
02. EFID: Initiative and Network

Overview
The European Foundations’ Initiative on Dementia (EFID) is a collaboration platform initiated in 2010 by a group of European foundations. Today, EFID comprises the Atlantic Philanthropies, the Fondation Médéric Alzheimer, the King Baudouin Foundation, the Robert Bosch Stiftung, and the Genio Trust. The initiative is coordinated by the Network of European Foundations (NEF). In the early days, the EFID initiative benefited from the auspices of the Belgian Presidency of the European Union (July - December 2010) where dementia was placed high on the agenda. Later in 2012, the EU Year of Active Ageing and Intergenerational Solidarity highlighted the urgency of discussing the demographic challenges in Europe. In 2012 and 2014, EFID awarded 20 organisations in 11 countries with the prize “Living well with dementia in the community”. The project “Learning Lab Dementia”, developed by the city of Arnsberg, is one of the best practice examples that received the prize.

The EFID programme
Over the past years, EFID has taken up the challenge to deepen the work on the so called “dementia-friendly communities” not only by working on the promotion of the concept, but also by mainstreaming empowerment and inclusion of people with dementia as cornerstones of its approach. A series of capacity development workshops organised over different themes, offered the opportunity to the practitioners to exchange, learn and be inspired by notable practices across Europe.

In the first phase (2012-2013), EFID held a workshop on re-framing dementia and launched the publication “I am still the same person”, an invitation to communicate differently about dementia. Furthermore, following the launch of the call for awards “Living well with dementia in the community”, the organisations that won the prize were invited to a ceremony in Brussels in the presence of Her Majesty the Queen Mathilde of Belgium.

Drawing from the success of the first phase, EFID foundations continued the work in a second programme phase (2014-2015) which put emphasis on the empowerment of people living with dementia and their carers. A second call for awards “Living well with dementia in the community” was launched and several seminars were organised. The organisations selected for the awards are context-relevant initiatives at local, regional or national level that promote sustainable environments for people living with dementia and their carers. The organisations are now part of the EFID community of practice, a peer to peer network created to share knowledge on the concept of “dementia-friendly communities”.

The third phase of EFID (2015-2016) was built on three main pillars: network strengthening; capacity development; and generating knowledge. The EFID community of practice was further consolidated by a new funding instrument, the “Capacity Strengthening Fund” (CSF). The 20 organisations that won an EFID award were invited to propose new initiatives to deepen their work in the communities, through joint projects and go-and-see visits. The new fund facilitated the exchange of ideas and best practice and strengthened the collaboration among organisations. In the
02. EFID: Initiative and Network

framework of the CSF, Learning Lab Dementia Arnsberg developed a study visit to Bruges. The event was successful in creating synergies and disseminate the learning between the participants. The joint projects and study visits enriched the portfolio of the awardees’ activities and opened up new horizons that hopefully will be explored in the next years.

In May 2016, a workshop and a site visit were organised in Bruges and Aalbeke in Belgium to explore impact measurement methods. During the event, EFID launched the study “Mapping dementia-friendly communities (DFCs) across Europe: a report and collection of case studies on DFCs in Europe”. The research, commissioned to the Mental Health Foundation UK, originated from a shared interest of the foundations engaged in EFID in conducting an analysis of concepts and practices of what is commonly referred to as ‘dementia-friendly communities’ (DFCs) and similar initiatives across Europe. “Learning Lab Dementia” is listed in the report as a notable practice leading to develop sustainable, inclusive and supportive environments for people living with dementia and their carers.

Next steps

In 2017 and 2018, EFID’s fourth phase will be focusing on promoting the voice of people living with dementia, valuing their expertise and strengthen the respect for their autonomy and citizenship. People living with the condition are often marginalised and their voice is ignored, particularly in later stages of the condition. Decisions about their life and activities, their care path, care practices and services are often made FOR them and not BY them without regard to their actual needs and wishes. With this in mind, EFID launched a call for awards to prize 10 notable initiatives that encourage meaningful participation of people living with dementia. The award ceremony and the capacity development workshop are expected to take place in early 2018.

To know more about EFID’s activities and to download resources on dementia visit the website www.efid.info.

1The report and collection of case studies are available on www.efid.info.
03. Lern-Werkstadt Demenz – Arnsberg

The city of Arnsberg is located in the Hochsauerland district in the German state of North Rhine-Westphalia. More than 16,000 of its roughly 75,000 residents are over the age of 65. The city has been intensely involved in creating a city of long life since the 1990s. The topic “Living with Dementia” has been an important building block of the city’s demographics strategy since 2007.

Evolution

The city of Arnsberg began dealing intensively with the issues of an ageing society as early as the 1990s. In order to help shape the transformation, new structures were created and new services established:

- 1990: Foundation of Arnsberg’s Seniorenbeirat (Senior Council)
- 1992: Establishment of a Seniorenbüro (Seniors’ Office)
- 1995: Initiative „How do I want to live when I am older?”
- 1998: Development of a volunteer centre
- 2002: Qualification programme „Practical Knowledge for Initiatives”
- 2004: Foundation of the Specialist Department Future of Age
- 2008: Start of Arnsberg’s „Lern-Werkstadt” Demenz
- 2008: City “Projekt Zeitlos” (Project Timeless) with “Zirkus der Generationen” (Circus of Generations)
- 2011: End of funding project ”Lern-Werkstadt” Demenz, continuation by the city of Arnsberg
- 2014: EFID-Award “Living well with Dementia in the community”
- 2016: Go-and-See-Visit to Bruges: professional exchange

The exemplary approach of the “Lern-Werkstadt” Demenz

Goals of the activities are:

- To improve and stabilise the living situation of people with dementia
- To support care-giving family members
- To lift the taboo on the topic of dementia, to sensitise the public and create solidarity
- To develop new roles for citizen involvement.

People with dementia and their needs are the focus. The aim is to allow people without the condition to experience their world. The project intends to lift the taboo on the subject one step at a time and strengthen citizen involvement in this area. The ultimate goal is to improve the living situation of people with dementia and support their families. All citizens of Arnsberg are invited to contribute their ideas: students who get together with people with dementia to draw and paint, adolescents who practice magic tricks with the seniors, or adults who go bowling with people with dementia.
03. Lern-Werkstadt Demenz – Arnsberg

The model approach consists of tapping into the population’s strength for the benefit of people with dementia. Information about citizen activities is bundled and conveyed to people with dementia and their families individually. The city assumes responsibility and has established a coordination office that conceptualises and connects all activities. Aside from providing “classic” dementia services (such as arrangement of out-patient care services, day centres, or support with applications for insurance benefits), the focus lies on connecting people with dementia with with friends, families, neighbours, and volunteers who are committed to supporting people with dementia.

By bundling these resources, people are viewed not (only) in terms of their deficits, but their abilities and wishes are recognised and respected. The community assumes this responsibility and supports the collaboration of administration, professional participants, and citizens.

Lessons learned - Experiences in Arnsberg

In order to achieve these goals, the city of Arnsberg is implementing measures at three levels.

At the community level

The target group here is the public. The aim is to change public attitudes and opinions about dementia, provide information about the disease, and reduce fears of contact with people with dementia. We want to build understanding for people with dementia and their families. This requires extensive public relations work. Living with dementia is addressed in print, broadcasting, and on the internet, people living with the condition and their world are presented. Media reports about projects deepen the public impact of activities. Numerous presentations and events address a broad audience in order to reach as many people as possible who until now had no direct contact with the subject.

At the programme level

An education and training programme serves to specifically address different target groups, focusing on the following:

- People with dementia and their families
- Groups who (may) encounter people with dementia in their daily work, such as bus drivers and bank tellers
- Medical, care, and support professionals
- Socially active citizens

Networks are established and expanded among the different groups involved in order to open up and re-develop existing services for people with dementia. The community as a neutral partner invites, mediates, and establishes contacts. In-patient and out-patient providers, volunteer groups and initiatives, physicians and nursing professionals, district and city representatives have all come together at a round table in the “Arnsberger Netzwerk Demenz”. Countless individual projects and collaborations between partners from the fields of senior living and care, education and culture, senior and youth support, economy, and politics, associations and federations continuously expand the network.
03. Lern-Werkstadt Demenz – Arnsberg

At the individual level

It is important to be able to advise families individually and also at home. First, the mobility of people with dementia is often restricted; secondly, the entire living and living situation is improved by a house visit. The special and model approach in Arnsberg tries to convey a suitable mix of support offerings from the professional as well as the civil society in the individual case consultation.

This requires, on the one hand, a close-knit network of the counseling centers with the local environment, the professional and civil society actors, on the other hand a high divisory competence to successfully activate the available resources in individual cases.

Our years of cooperation in the “Lern-Werkstadt” Demenz have taught us:
A dementia-friendly city is a friendly city where everyone likes to live.

Only when dementia is “part of” the cityscape it can really become “normal”. Crucial skills for living together cannot be taught, but must be experienced during everyday life. With the “Lern-Werkstadt” Demenz, Arnsberg is releasing new energy and providing new forms of support. Many living networks, neighbourhoods, and caring communities have been successfully developed on the principle of shared responsibility.

An example from the dialog of generations in Arnsberg’s “Lern-Werkstadt” Demenz

Six-year old Enna sits unselfconsciously beside the elderly lady and pats her wrinkled hands. The lady visibly enjoys the warm-hearted touch and smiles. The two understand one another – without words. Because words have been lost to the old lady, because of her “forgetting illness”, as Enna calls dementia. “But the heart does not get dementia,” Enna knows for a fact.

In an ageing society, the questions of relationships between the generations are renegotiated. Dealing with one another is an essential prerequisite for understanding and respect. For years, senior centres, residential communities, and day care centres in Arnsberg have opened their doors to integrate young people in their daily routines. At the same time, there are youth centres, schools, and kindergartens with open doors for the dialogue with seniors. These are encounters that touch us emotionally and shape our values.

A dementia-friendly city is a friendly city where everyone likes to live.

With this new culture of togetherness, we will be able to master the future.
Example 1: Fachstelle Zukunft Alter (Specialist Department Future of Age)
The city of Arnsberg has established structures to help shape the various issues of demographic change right here in their community. A part of Arnsberg’s Future Agency, the Fachstelle Zukunft Alter introduces the aspects of an ageing population into the city’s development. It is the first contact point for many who need help and guides them through the differentiated local range of services, improving the availability of existing services for elderly citizens.

The Fachstelle Zukunft Alter consists of an interdisciplinary team (two full-time positions, graduates in social education and geography) and has an annual budget of roughly 20,000 Euro for implementing its conceptual work.

The Fachstelle Zukunft Alter is committed to the following tasks:
➔ Creating beneficial conditions for an active and self-determined old age
➔ Support of high-quality social and medical services
➔ Adaptation of the city’s architectural structures to an ageing population
➔ Dialogue of Generations
➔ Knowledge transfer
➔ Taking responsibility

People with dementia and their families have been a key activity since 2007. Under the title “Arnsberger ‘Lern-Werkstadt’ Demenz”, and with the support of the Robert Bosch Foundation, there was three years time to try out ways to combine the professional support systems with the potential of citizen involvement and make them available to benefit people with dementia. After the project phase, the approach was included in the city’s regular funding in 2011. Since then, the Fachstelle Zukunft Alter has been coordinating the dementia network and ensures the continuity and ongoing development of the overall city concept..

Don’t demand “from above”. Enable “from below”!
The chief purpose of the “Lern-Werkstadt” Demenz is to bring together professional and civil support providers. All areas concerning people with dementia and affecting their care and quality of life are taken into consideration. The communal Fachstelle Zukunft Alter can take a neutral role mediating among the various participants from the fields of care, support, housing, economy, civil commitment, etc. It can bring potential partners together “around one table” and work with them to develop projects and initiatives.

Not just talking about it, but really changing the city
This is possible when as many citizens as possible pitch in. At the very start of the project, the Fachstelle Zukunft Alter invited every-one to a kick-off event. 400 residents came and afterward founded initiatives, developed ideas, and supported projects in the 15 city districts. The Fachstelle Zukunft Alter underpins this broad commitment and also supports good approaches financially.
Example 2: Children create laugh lines in Project ZEITLOS

For many years, the Youth Centre Liebfrauen in Arnsberg has been committed to the dialogue of generations, working on different projects as a partner of the Fachstelle Zukunft Alter. The team is concerned with bringing old and young together at eye level in order to promote young people’s social competence and empathy. Close contacts between old and young are regrettably rare within families. This is where the project ZEITLOS comes in. It builds trust, creates realistic images of old age, and promotes friendships and relationships across generations. Particularly for people with dementia and their families, this project can be a way to escape the loneliness and withdrawal into their own private world.

It is an uplifting feeling to see how children and adolescents with their sparkling energy bring out the laugh lines in elderly faces. They open the hearts and mouths of people who are often shrouded in silence, who have lost words and thoughts long ago. Young and old are living a new culture of togetherness and mutual respect, and both sides emerge as winners! Age and time do not matter. Arts and culture, acrobatics, clowns, and culinary treats are deliberately used as connecting elements. These educational approaches offer people of all generations an opportunity to participate. People with dementia are naturally in the middle of life rather than on the side lines. Active inclusion can be so easy when we overcome the barriers in our heads and see dementia as a people with dementia in an ageing society.

Hanna Radischewski, now a young woman of 22, looks back on her 15-year “career” as a child in Circus Fantastello, part of Project ZEITLOS. She says:

“After some initial shyness, we, the circus children, warmed quickly, as did the seniors. Time and again you heard encouragements like: “You can do it, we’ll help you!” Of course we realised that our new training partners were marked by age. They kept forgetting our names, and some couldn’t remember that they had been to the youth centre before. Some had shaky hands or seemed frozen. But we learned to have patience with them. The old folks tried things, accepted defeat when something didn’t work, and kept trying. The “old geezers” became the „older ladies and gentlemen”, our „grandmas and grandpas next door”. It wasn’t just we children that blossomed – the seniors beamed and laughed! The gala performance that winter was one of the greatest ever and we still have wonderful memories of it.

Projects like these are important. For one, for the children, to make them familiar with age. They learn to share responsibility, to be attentive to others and care for them. Some of the seniors completely rediscover themselves and see that old age does not necessarily take away their strength and possibilities to shape their own lives. During the project, I often had the feeling that they actually got a little younger themselves by working with the children, that a little bit of joy came back to their lives. There is a book that says: “Circus makes children strong!”, but I believe that goes not only for children. The circus lives by the differences among all participants,
and we experienced this in all directions during this cross-generational experiment. I think it was an advantage that I had close contact with older people relatively early in life. Most of the time, relationships between old and young do not go beyond the usual grandparent-grandchild relationship, and that is a shame. I learned how important it is for young and old people to re-establish bonds with one another. They can enrich each other’s lives and learn so much from each other. No matter what the idea for bringing the generations closer together, you should simply try it. Both sides, the seniors and the young people, are willing, but nobody knows it. We hide behind the assumption “They probably don’t want it,” but that is not true! In order to bring some life back to the relationships, and maybe even part of our society, and keep them alive, all we have to do is take a leap of faith and dare to try”.

Example 3: Carnival of Generations
An inclusion project that has become an integral part of social life in Arnsberg. For the 6th time, Arnsberg’s Senior Council in cooperation with the Fachstelle Zukunft Alter and the local carnival association is inviting people with and without dementia to share in this celebration. It allows people at this vulnerable age to take part in community life. Moments like these make a city worth living in and worth loving. Arnsberg is on its way to becoming an inclusive city, where men and women with all manner of disabilities are part of life. The project “Karneval der Generationen” [Carnival of Generations] is an example of caring communities in the overall social context of a city.

400 people come together to celebrate “Karneval” [traditional German carnival], people with dementia dance and sing along. This kind of project becomes possible through cooperation among the in-patient and out-patient care and support institutions, the families, friends and acquaintances, who have all set out to just forget about everyday life for a while.

The list of participants includes district police officers, Red Cross helpers, and sponsors for people with dementia. There is hardly a taxi in the city that is not being commandeered to transport the ageing “Jecken” [revellers]. You never see so many walkers in front of a music stage as on this day. Hand in hand, wearing a welcoming smile, older residents hold this festival for the oldest in the city.

Children and adolescents use their creativity to put on an imaginative programme. A feast for the senses. Here and there a tear rolls down the cheek of an elderly person. Being part of this makes them happy. These are unforgettable moments that touch the heart.
Ways out of loneliness in old age
For the past 6 years, Mr. and Ms. Gland have been enthusiastic revellers at the “Karneval der Generationen”. Their personal statement about it:

„We don’t let anything get us down, even though we certainly have to overcome some challenges in our everyday lives. Being part of this is important to us. We don’t want to tumble off the face of the earth. It feels good to be part of something and to be important to other people.“ says Ms. Gland, the carnival enthusiast from Arnsberg.

She sewed her lovely costume herself, festooned her hat with roses, and sprayed her shoes with gold paint. She looks fantastic. Her smile is enchanting. With a gleam in her eyes she says: “Just to forget the world around you for a few hours. To savour the moment. To live! In the here and now. What remains are wonderful memories that warm the heart and give you something to talk about even in bad times. For us, these are ways to escape the loneliness of old age every now and again.”

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Developing dementia-friendly communities together: International Exchange

Arnsberg and Bruges support international knowledge exchange and inspiration
04. Foton – Bruges

Bruges is a City with appr. 118,000 inhabitants in the province Westflanders, Belgium. There are some 25,000 inhabitants 65 years old or older living in the city. The number of people living with dementia is an estimated 2,600. The non-profit-organization Familiezorg West-Vlaanderen vzw is running the initiative Foton since 1996 in order to support people living with dementia and their families.

**Evolution**

- **1996**: Familiezorg West-Vlaanderen vzw founds the initiative Foton as a dementia expertise centre and specialised home care service for persons with dementia and their caregivers
- **1996**: Award from the King Baudouin Foundation: ‘solidariteit met dementerende ouderen’
- **1999**: Start of psycho-education programme for family of people with dementia
- **2000**: Winner of the Johnson & Johnson award for Welfare and Healthcare
- **2001**: Sensibilisation campaign: dementia is worse when society is not able to deal with it.
  - 21 September: World Alzheimer day in Bruges – a heartbeat of hope
- **2004**: Start of a peer group „partners of people with young onset dementia“
- **2005**: Start of the regional dementia-platform (first in Belgium)
  - Start of the Meeting-Group for people with dementia (first in Belgium)
  - Formation of trainers on dementia
- **2008**: First open house in Belgium for people with dementia.
- **2009**: King Baudouin Foundation: “Beter omgaan met personen met dementie”.
- **2010**: Cooperation with the King Baudouin Foundation for a dementia-friendly society.
- **2011**: Participation in the demonstration-project of the Flemish Ministry of Welfare and Healthcare
  - Start of the Foton-choir
- **2012**: Winner of the European EFID-Award
- **2014**: Start of annual exchanges with Japan and more sporadic other international contacts
- **2016**: Host to EFID Workshop with European EFID-Awardees
The exemplary approach of Foton
The initiative Foton consists of a variety of services and activities.

**Foton’s project**
- contributes to a nuanced perception of dementia
- highlights and confirms the abilities of the persons with dementia
- promotes the social (re)integration of people with dementia in their immediate surroundings and the wider community
- contributes to the quality of life of the persons with dementia and their environment
- seeks an active involvement/consultation/participation of the persons with dementia and their environment
- creates an atmosphere of solidarity and joint commitment between generations
- creates and/or supports cooperation between different sectors of the urban community
- promotes the civic and communal responsibility from an urban community for a vulnerable group
- contributes to a humane and quality-minded care and attention for people with dementia and their environment within the urban community
- increases the resilience of people with dementia and their family
- improves the health of persons with dementia and their family
- prevents intake in residential institutions or delays this intake.

Foton strives to improve the quality of life of persons with dementia and their environment by bringing about a mentality change in all citizens, organisations, businesses, institutions and officials, all leading to more respectful, equivalent communication and interaction. The organisation has set up various actions to improve the social integration of persons with dementia so as to let them be considered as “full citizens” again.

**The objectives of this project are:**
- Breaking the existing taboo on dementia by organising different sensitization actions that present dementia, the people living with it and their families in new ways.

- Painting a more nuanced image of the disease and the capacities of persons with dementia and installing a more respectful communication by providing correct and complete information through workshops, brochures, art projects, educational material, etc.

- Installing a climate of solidarity and shared responsibility through various actions involving all sectors and ages of the city community, with distinct press coverage and the visible support of the mayor, the city council and important local organisations. Improving the access to and the awareness about existing dementia-related services.
04. Foton – Bruges

➔ Identifying the problems and needs of persons with dementia and their families, both in day-to-day social interaction as in dementia care related issues, and finding sustainable solutions for them (projects on mobility, faster localisation of missing persons, etc.).

➔ Motivating, inspiring, advising and supporting organisations and individuals to set up or continue their own dementia-friendly actions, with a special focus on cross-sectorial partnerships and intergenerational initiatives.

➔ Long-term, structural support and attention for the needs of persons with dementia and their informal care through the organical development and implementation of concepts such as ‘dementia-friendly business’, ‘dementia-friendly socio-cultural organisation’ and ‘dementia-friendly neighbourhood’.

The Foton-concept is a very global concept. On the one hand we strive for a dementia-friendly social care and healthsector and an open culture of cooperation between organizations. On the other side we strive to infiltrate in the city and influence the attitude of every citizen. We think this global approach is the strengths of the success of Foton in Bruges.

The deep vision and the whole mission/programme of Foton is included in the name “foton”. A foton is a little light-particle, almost invisible for the eye. So we wanted to bring light to the people but more important we wanted to see, to notice the light which is present in every situation, even the darkest and most shadowed one. But there are also deeper significations who come from the insights of the quantum-physics. We just mention them short here.

We learn to manage the unpredictable aspects of life and dementia. We are very attentive for our way of looking and perceiving because we know the importance of the way the observer interprets the world. A light particle here is connected with a light-particle on hundred billions lightyears far from here. So there is a mysterious connection between them. We focus on this connection between people. The lifespan of a light-particle is infinite. What an exploration. So we try to connect us with this infinite part of people with dementia.

Here is the summary of a whole programme in a nutshell:

Lessons learned - Experiences in Bruges

One of the most important but most difficult challenges to create a dementia-friendly city is to change the negative perceptions about dementia. After 20 years of efforts to realize this change we know that this will be a work of decades.

Beside the necessary sensibilisation-projects which try to influence this negative perception to a more nuanced perception we think that creating meeting places is very important. Direct contact and shared experience with people with dementia is necessary to experiences the fact that people with dementia are normal human
beings with the same needs and desires, the same wishes that we all have. There is
more that connects us with one another than what divides us. The more we accept
this, the more we will act in a normal and including way and not a way which ex-
cludes or infantilizes people with dementia.

Meeting places with people with dementia can be music-afternoons, choirs, cafete-
rías, cultural events, visits of local shops, etc. Good mediators in all these situations
are also very important. A good mediator is a living example of a good and inclusive
approach of people with dementia. She or he represents an attitude of equality and
respect. One of the examples of such a mediator is the specialised dementia-coun-
selor: a key-person in the actions for a dementia-friendly city. The specialised de-
mentia counselor is a professional helper who is exempted from other duties in or-
der to support the person with dementia and his family. He is introduced in the first
line health care from the moment family members notice that something is wrong.
The dementia counselor works on demand.

The dementia-counselor is specialised with regard to:
- all dementia related matters
- all psycho-social aspects of the disease
- relationship and family dynamics.

The dementia counselors are particularly well trained in Nagy's contextual thinking.
They offer more than merely information and advice on dementia. They have an eye
for on-going family dynamics and relational issues and adjust their interventions
accordingly due to which they can often work in a very preventive way.

Another very important way is training and formation. We have given formation and
training at professionals, volunteers, caregivers, citizens in small and huge groups.
Beside the practical information about the disease and the matters related to com-
munication, we also focus on the positive attitude, this is also an attitude of equality
and respect.

And then there is a great focus on cooperation. In Bruges we have worked on a “cul-
ture” of open cooperation. Of course there is also a structure: a dementia-platform.
But that platform is working on a “non-bureaucratic” dynamic way. With residential
homes and hospitals there are also cooperation projects. In this case, too, it is all
the more about attitude than structures. So often in cooperation, people work on
care-paths and protocols. We do not think that this is helpful or necessary. We be-
lieve that we need to create a sufficient quantitative and qualitative offer and that
people need to know about what is on offer, so that they can find the way to the spe-
cific help that they need.

For us, an inclusive approach is very important when working towards a demen-
tia-friendly city. This idea is typical for Familiezorg West-Vlaanderen vzw, the mo-
ther organization which founded our initiative. Since the foundation of Familiezorg
West-Vlaanderen vzw its employees strive to make an inclusive approach possible
for everyone who needs help.
Towards dementia-friendly communities across Europe

04. Foton – Bruges

We try to make this a reality by making connections between the different departments and their projects, by working with other organizations and by focusing on the person as a whole. Examples of this can be found in the following services that Familiezorg West-Vlaanderen vzw provides:

- Specialised dementia family care: 190 home health care workers who participated in a four-day dementia training and attended two follow-up days.
- Specialised dementia volunteers at home: 230 volunteers who had a training similar to the one of the health care workers. Familiezorg offers day and night care with volunteers.
- Specialised occupational therapist for people with dementia.

From the “inclusive” point of view a dementia-friendly city has to be more than events and actions that are visible in the urban community. Of course this is an important part of the concept ‘dementia-friendly’, but it’s not the only element that contributes to a more dementia-friendly city. Often forgotten, but just as meaningful is the other pillar on which the concept stands: dementia-friendly care. We believe that in a dementia-friendly city the urban community and the care for people with dementia come together. Community and care are like two sides of a coin, one cannot exist without the other.

Dementia-friendly health care means the right care at the right time. It’s starts by listening to the requests and needs of a person with dementia and his environment. What are their requests and needs? Which goals do they have? It’s the task of the professional to search together with the family for the most ‘fitting’ care, like a jacket tailored perfectly on the body. Another aspect of dementia-friendly care is that when people with dementia receive care, they feel that they are treated in a respectful, warm way and that certain procedures are adapted to their needs. (For example: a hospital with a special procedure for people with dementia when arriving at the emergency room.) It is also important that professionals in healthcare know each other and share their information. This can be organised in many ways, the dementia-platform is one example of the cooperation between healthcare professionals.

Example 1: Foton-choir

The Foton-choir started in 2012 after some visitors of the Fotonhouse had seen an English BBC-documentary about a choir for people with dementia on television the day before. The people with dementia and their caretakers took the initiative, and so the choir was born.

A musical Foton counselor leads the choir together with two volunteering musicians. The volunteers of the Foton house are also present for support and a listening ear. It is clear that in addition to the joy of singing together the contact itself is very important. The Foton counselor encourages any chances of encounter, of contact or of connection, or helps channelling emotions. Together with the choir members we chose the name Foton choir (and not: memory choir) because in the first place we want to offer the experience of a pleasant shared activity between the person with dementia and his caregiver. Many times, during this gatherings persons with dementia got up to express their gratitude for the opportunities offered in this meetings.
04. Foton – Bruges

Another positive effect of the choir is the support for informal contacts outside the choir. They phone each other to support one another on difficult moments. Three couples go together on holiday for one week once a year. They are not alone any more. There is always someone with a listening (a golden) ear.

The Foton-choir is often asked to sing for a public. For example on the EFID-award-celebration in 2014 in Brussels (photo) and on the EFID-workshop in Bruges.

But also very important is their performance in the city. There was a concert together with a folkgroup and a choir of a residential home. The whole afternoon they had a programme and they performed for more then 300 people. The mayor and the alderman participated.

Another example is the concert in the public library on a Sunday-morning on a weekend of World heritage around the theme “Care”. More then 100 people where there.

The importance of this public performances is that the public sees another image of dementia. They see that people with dementia can be happy and joyful. They see the solidarity and the warm energy in the choir and between the people. They see the way they are taking care for each other also. This positive perception is important to create an inclusive and adult way of communication and that has a very good effect on the people with dementia.

Example 3: MEMORABEL
Experiencing art at a different pace
A Bruges’ partnership between Foton and the Saint-Johns Hospital Museum was written in the stars: both institutions share a love for beauty and light. It was only a matter of time till they met and decided to embark together on this exiting adventure called MEMORABEL: experiencing art for people with dementia.

Everyone has its own unique way of perceiving reality. This goes particularly for people living with dementia. Though they tend to visit museums on their own long after being diagnosed, at some point in time, the need for a secure and safe environment becomes a striking reality. The project MEMORABEL offers people living with dementia and their caretakers, the chance to experience art at their own pace within the comfortable walls of a museum.

Specially trained guides accompany these groups and provide them with an ‘experience’ rather than to shower them with information. By not treating them as children, but approaching the people with dementia as equals in a respectful and dignified manner, they still feel worthwhile, acknowledged and part of our society. Skilled volunteers assist these guided visits with care, very much aware of the vulnerability and sensitivity of its participants. Both guides and museum staff took part in a course, organised by Foton and The Saint-Johns Hospital [in cooperation with the Museum of Contemporary Art, Antwerp] before taking on this project.
04. Foton – Bruges

The Bruges’ Saint-Johns Hospital Museum is part of a 800 year long tradition of care for those living at the edge of our society. Originally founded as a shelter for anyone who needed a bed and food, it slowly evolved into a hospital before it became a museum. MEMORABEL fits this longtime continuation of this attentiveness for those struggling with health issues perfectly. It is the consolidation of earlier art projects for the blind, and future intergenerational initiatives where the museum, a school and house for the elderly are creating together.

The Flemish name MEMORABEL contains both the words ‘memory’ and ‘unforgettable’ in the best sense of the word. A more then perfect description of what this project wants to embrace.

Example 3: Solidarity Logo

To tie a knot in your handkerchief in order not to forget something. Everyone does it. Not only persons with dementia. That’s exactly the reason why we chose this image as symbol for a dementia-friendly Bruges. Bruges, a city where persons who forget a lot are not forgotten. Traders, shopkeepers, service centres and the hotel and catering industry are invited to put the sticker of the knotted handkerchief in the window of their business or shop as a sign of solidarity.

By doing so the traders express that persons with dementia and their family are welcome in their business and can count on a warm and dedicated service.

We had a profound discussion in the dementia platform about the meaning of the logo, about the pro’s and contra’s: Could it be stigmatizing? Must there be a kind of certification? A kind of sign of qualification after being conform with a checklist of obligations in the accommodation, in the communication? Can you only put the logo if you have followed a training/formation and an examination? Etc... We discussed it also with the local-economy-advice-group from the city-council. They argumented that there are already too much obligations and orders and that the idea of sympathizing with the dementia-friendly idea is already an important commitment. The alderman for health and welfare argumented that if a shopkeeper who put a knotted handkerchief would not be dementia-friendly that the ombudsman of the city should know it very fast and that we can come in contact with that shopkeeper to change the attitude and act confirm the knotted handkerchief symbol.

We did a lot of sensibilisation-actions to the local shopkeepers but today there are only a hundred shops in the centre of the city who have the knotted handkerchief. Last year a bottom-up action started in Sint-Kruis Brugge, a small village, part of the city of Bruges. These bottom up action was a cooperation between Foton, ’t Veldzicht (an organization for people with a handicap), neighborhood committees and socio-cultural organizations. In a short time around 80 shops have put the knotted handkerchief on their window. So we hope other parts of Bruges will follow this bottom-up movement. The idea to use/to recognise the knotted handkerchief as international solidarity logo for dementia is growing. Every city who wants to do so can do it if they agree the principle ideas of a dementia-friendly city and just refer to the first use of the logo by Foton in Bruges.
Towards dementia-friendly communities across Europe

04. Foton – Bruges

The organisation of new forms of social responsibility, the development of caring communities in a spirit of shared responsibility among professionals, families, and citizens, are the challenges we have to master if we want to create cities of long and good life where people with dementia have a place and can actively contribute.

05 Shaping of dementia-friendly communities – Interview

What does ‘dementia-friendly community’ mean to you?

Bart: It usually starts with social organisations, welfare and health care institutions becoming dementia-friendly: they make this explicit choice, offer adapted training, work with professionals, and employ dementia reference persons.

Furthermore a ‘dementia-friendly community’ means that a city decides to support their citizens with dementia, stating: “you belong to this community and we will do our utmost to ensure you can be part of it as long as possible”.

But most of all it means that the image people have of dementia is changing. A negative image excludes persons with dementia: they are being cavilled at, treated childishly, are not being involved, not addressed. A dementia-friendly community strives for a nuanced image and thus inclusion: persons with dementia are being listened to, treated equally, and taken seriously.

Martin: In a dementia-friendly community, I do not have to hide or to feel ashamed if I develop a dementia or one of my family members does. I can count on the sympathy of my friends, colleagues and neighbours and rely on their support. Thus I can remain an accepted part of the community and continue to live my life according to my ideas, hopes and aims.

A dementia-friendly community, relevant public services as well as health and support services are sensible to the needs of people with dementia. And more than that, everybody wanting to get engaged is a very welcome partner in the local initiative – regardless of whether it is a kindergarten, a culture club, a volunteer, or a business company that wants to get involved.

Why do communities have to become ‘dementia-friendly’?

Bart: You can’t cope with dementia on your own, this is too difficult. Persons with dementia and their family must know that they are being supported. A dementia-friendly city can increase the resilience of people with dementia and their family and can contribute to humane and quality-minded care for these persons and their environment.
Martin:
For people with dementia, the local environment matters a lot. When we establish an atmosphere of respect and sensibility on the local level, people with dementia can feel supported, safe and part of society.

And from the perspective of a public authority: a life with dementia needs adequate services in the fields of transportation, housing, health and care, spare time activities, employment, volunteering, and many other fields of work our cities and communities are engaged in. So communities (as public bodies) have a lot of possibilities to get active and make a difference.

Both dementia-friendly initiatives in Bruges and Arnsberg have their own characteristic approaches that relate to the specific local circumstances. At the same time, you are connected to many other cities. What can you learn from other projects?

Martin:
Arnsberg has gained a lot from the support of network partners and supporters from Germany and Europe. From the start, the Robert Bosch Foundation has offered us orientation and support to develop our approach and to connect with other initiatives. Being part of the EFID-network gives a lot of inspiration and assurance, we see we are not alone with our approach, but that there are many, many people pursuing the same goal.

Bart:
Participating in the EFID-workshops and coming together with other initiatives from all over Europe has been a great experience. The feeling that we are not alone, that in other countries there are brothers and sisters striving for the same purpose, for the same goal, makes such a workshop worthwhile and gives sense to it.

It was very inspiring to see how other projects try to break the taboo, and contribute to involving people with dementia in everyday activities: welcoming them in cafeteria, have them participating in sports activities, in art, in day care. With this in mind you return home very inspired and refreshed.

Exchange of expertise between Arnsberg and Bruges.
06 Summary

In Bruges as well as in Arnsberg, countless people with and without dementia are committed to establish a dementia-friendly community. We will continue down this road, because we have learned:

➔ It is possible to successfully lift the taboo on the topic of "dementia". The consequence: more knowledge, more prevention, more and better support from the family, and more and better support of people with dementia and their families through committed citizens and professionals. Prerequisite: local participants have to take responsibility – it does not happen on its own.

➔ A better life with dementia is possible when we closely and individually intertwine family support, professional help, and civil commitment. Prerequisite: Openness to one another, early information and consultation, qualification and local networks. A local coordination agency initiates, mediates, and supports.

➔ Of particular importance is early consultation that is not deficit-oriented but looks at the individual potential of people with the condition and their families and provides tailor-made combinations of professional and volunteer support. Individual, flexible, and varied support opportunities are created that we did not even know before.

This new kind of support for people with dementia and their families makes the city socially more productive and livelier. It connects generations and forges social cohesion.

Setting free these constructive forces in our cities and communities not only makes them friendlier for people with dementia, but for all citizens.

The examples of Foton and the "Lern-Werkstadt" Demenz illustrate how the potential of entire cities can blossom into better, friendlier interaction with one another, which lets people with dementia lead self-determined lives. These experiences can be applied to any other city.
In 2012 and 2014 EFID honoured 20 organisations in 11 countries with the Award “Living well with dementia in the community”.

Find more information online:

www.arnsberg.de/zukunft-alter
www.familiezorg-wvl.be/foton
www.efid.info