

# FOTON: Together for a dementia friendly Bruges www.dementie.be/foton

# **Context/history**

Bruges (Belgium) has approximately 118,000 inhabitants of which, 25,000 of them are 65 years or older. The number of people living with dementia is estimated at 2,600, with 70% of them living at home. Founded in 1995, Foton is a centre of expertise in dementia. It is an initiative that was started by Familiezorg West-Vlaanderen, an autonomous and integrated non-profit homecare organisation in West Flanders, offering specialised care and support at home for people living with dementia. Care and support is provided by home health care workers who receive a four-day dementia training course. Foton also trains volunteers, dementia counsellors, as well as nurses and occupational therapists who provide specialised dementia services. The umbrella organisation Familiezorg (Family care at home) consists of 2,200 people (including 500 volunteers) that are devoted to providing personalised and specialised care and support to 10,000 people who are either directly or indirectly touched by dementia.

The vision, mission and values of Foton is captured in our name. A foton (Photon from Greek meaning light) is a little light-particle, almost invisible to the eye and the vision for the Foton service is to bring light to the people's lives and most importantly, find the lights present in all people and situations and find ways to connect them together.

### What this initiative is about?

#### Target pop:

People living with dementia, their carers and families, professionals working in dementia care services. Foton takes a whole-society approach: everyone can make a difference: schools, socio-cultural organizations.



socio-cultural organizations, cultural organisations, local economy.

#### Mission:

Foton strives to enable people living with dementia to have fulfilled and quality lives in the community they live in.

## **Description:**

The Foton concept is holistic as it not only promotes a dementia-friendly social care and health system and open culture of cooperation between organizations, but also proactively engages in influencing city initiatives resulting in citizens of Bruges gaining a better understanding of dementia. Foton is an open access service and embraces people who seek information, people with symptoms, carers, as well as health and social care professionals. A dementia diagnosis is not necessary to become part of the Foton family. Foton employs 7 dementia counsellors and is assisted by 25 volunteers without whom the activities and dementia resource library would not be possible.



# **About / Aims**

The aim of this initiative is to eliminate the existing stereotypical views of dementia by raising awareness through actions that present and promote dementia, the people living with it, and their families, in new and different ways.

The main objectives of Foton are:

- To provide day-to-day social interaction for people living with dementia and wider society
- To maintain the highest quality of life possible through active involvement,
   consultation and participation of people living with dementia and their families
- To motivate, inspire, advise and support organisations and individuals to set up or continue their own dementia-friendly actions, with a special focus on cross-sectorial partnerships and intergenerational initiatives.
- To provide long-term, structural support and attention to the needs of persons with dementia and their informal carers through the development and implementation of concepts such as 'dementia-friendly business', 'dementia-friendly socio-cultural organisation' and 'dementia-friendly neighbourhood'.

To help provide long-term structural support to people living with dementia Foton focuses on:

<u>Creating more dementia-friendly home care services:</u> through providing a range of training for GPs, physiotherapists, dietitians, volunteers, nurses, occupational therapists, family carers with a particular focus on a goal-oriented care by Care-Esperanto approach.

<u>Providing specialist care:</u> all people living with dementia and their families are introduced to their own specialised dementia counsellor from the first moment dementia symptoms are observed. Dementia counsellors are trained in Nagy's (1987) contextual approach to family therapy and individual psychotherapy. They offer more than mere information and advice on dementia. They assess on-going family dynamics and relational issues and adjust their interventions with preventive means. The aim is to assist people to manage dementia constructively, leading to freedom to live.



# **About Foton/Aims (cont'd)**

#### **Creating a space where everyone can come together:**

since 2005, FotonHouse has been a place for where everyone can connect and talk about dementia, including people living with dementia, their carers and families, citizens familiar or unfamiliar with dementia, professionals providing carefor people with dementia in public and private organisations (homecare, residential care, hospitals), and civil society (restaurant owners, shop-keepers, socio-cultural organisations, educational and cultural institutions). FotonHouse organises in-house cognitive stimulation. Once a month, musicians fill FotonHouse with wonderful sounds and people with dementia and their carers can relax with a cup of coffee, enjoy the music and meet other people. The choir is led by a dementia counsellor and two volunteer musicians.

The counsellor encourages channelling of emotions through music. Other activities include seasonal celebrations (Easter and Christmas), memory-clinics, literary evenings, a library, workshops, art projects and a café. For people with young onset dementia, FotonHouse works together with Regina Coeli, a combined day care centre, residential home, and short stay for people with young onset dementia. The role of mediator is very important in ensuring interactions are dementia and age appropriate, and that the settings are physically and emotionally comfortable for all involved.

Meeting group for people living with dementia: The primary goal is to offer people living with dementia a context of safety and comprehension where rather painful experiences as well as 'new discoveries' can be discussed. A rather stable group of eight persons gathers every three weeks. Each session starts with some psychomotor exercises that give people the opportunity to carefully discover the boundaries of their body and of themselves. These are followed by a coffee-break. The group discussion lasts one hour. The exploration of the concept and the experiences of this meeting group are shared in a book: "A pebble in one's hand: bringing dementia into the forum." (Deltour et al. 2008). A pebble, that is carefully chosen by each participant, is used as a connecting ritual object.





# **About Foton/Aims (cont'd)**

In terms of creating a dementia-friendly society, the initiative "Together for a dementia-friendly city" is a partnership between:

- Primary Care Zones Bruges, Oostkust, Houtland & Polder and WE40 (Primary healthcare network of Northern West Flanders)
- Dementia Platform of Bruges-East Coast (OverlegPlatform Dementie Brugge-Oostkust) City of Bruges
- The Foton Dementia Expert Centre and home care support

The aim of the partnership is to make the best use of all existing expertise. The commitment of the Mayor and the City Council is an important added value for the success of the initiative. Projects include:

- Leisure and cultural activities, including exhibitions and guides at museums in a project called 'Memorable'
- In 2013 'Klant blijft Koning' (Customer remains King, Dutch expression) was introduced, and currently the fourth sensitisation of local businesses is underway. Shops and other businesses display the sticker that indicates dementia-friendliness and that people with dementia are most welcome.
- A missing persons project with police and city guards, among many others.

# How does Foton exemplify integrated community care?

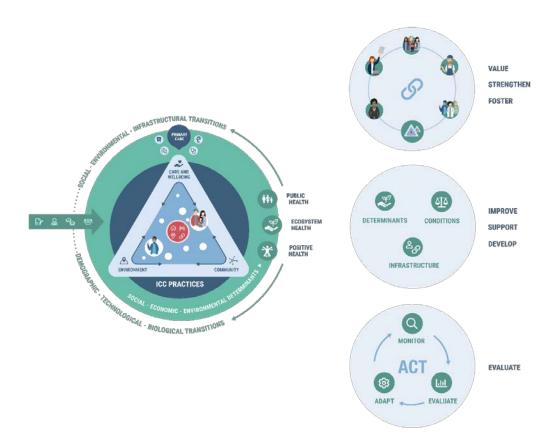
Foton joins together health and social care professionals from multiple disciplines and sectors through a dementia-platform (forum). Foton provides training and introduces new projects, discussing people's desires, goal and needs and how to translate the theory and learning into practice.

Foton has created a network of over 200 partners:

- 6 Hospitals
- 6 City Councils
- 25 residential facilities/day centres
- 4 insurance companies
- 9 regional dementia expertise centres
- Nursing organizations, cultural centres, neighbourhood committees, patient associations, universities, and high schools



# Implementation of the 7 ICC Effectiveness principles



The effectiveness principles [1] have been developed to guide action in a complex transition and turn Integrated Community Care from aspiration into reality. Each one is a clear and actionable statement that provides guidance for thinking and behaving toward some desired result. Building on the typology (introduced above) and the effectiveness principles, Foton is a practice that can be seen as embodiment of Integrated Community Care.

Foton exemplifies the effectiveness principles:

#### **Co-develop health & wellbeing and enable participation** by:

- Maintaining as many actors as possible actively involved in the development, implementation and management of their initiatives;
- Fostering community spirit and collaboration. Through multi-disciplinary and crosssectoral partnerships, forums and platforms;
- Realising co-design and co-development of health and wellbeing programs for families living with dementia;

[1] See TransForm Strategy Paper



# Implementation of the 7 ICC Effectiveness principles

#### Strengthening community-oriented primary care by:

- Raising awareness, providing education/training and information to all participants of
  society. Foton offers long-term, structural support and attention for the needs of people
  with dementia and their informal care through the development and implementation of
  concepts such as 'dementia-friendly business', 'dementia-friendly socio-cultural
  organisation' and 'dementia-friendly neighbourhood'. The strive toward maintaining a
  shared vision and shared goals enables the participation of people living with dementia and
  highlights and confirms their continued abilities to partake in society; and
- Taking **people's life goals as the starting point** to define the desired outcomes of care and support. (Goal-Oriented care by Care-Esperanto)

#### **Building resilient communities** by:

- Offering social care and support at home, and in their own facilities, that join people
  together. Through these channels, Foton addresses social determinants of health such as
  health, environmental and economic inequalities, and sustains the promotion of health and
  prevention.
- Supporting a healthy and inclusive community by providing opportunities to bring people together and by investing in both dementia-friendly social care and dementia-friendly communities.

However, Foton continues to struggle with achieving the legal and financial conditions enabling the co-creation of care and support at the wider community level.

#### Foton has embedded 'a learning by doing' approach to its governance by:

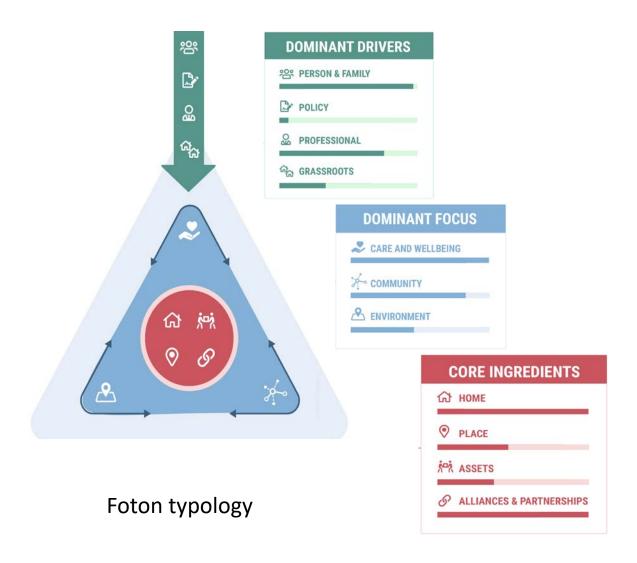
- Helping the voices of people with dementia and their informal carers to be heard
- Co-developing a toolkit for planning, reflection and learning within the European
  Foundations' Initiative on Dementia. The Toolkit (available for download <a href="here">here</a>), constitutes a
  collection of ideas, concepts and examples for reflecting upon and learning from projects
  addressing the social side of dementia.





# **Typology**

The TransForm project developed three main dimensions (drivers, focus and ingredients) that characterise the ICC practices. The assessment of these dimensions is visualised in a slider model. The slider bars illustrate how the various practices of ICC can be positioned on these core dimensions.





# **Funding**

Foton relies on structural financial support, which covers approximately 70% of the funding requirements:

- Yearly subsidies from the Flemish Government, nearly €260,000
- Yearly funding from the City of Bruges with an amount of €5000
- 30% is sourced directly by Foton income generating activities.

# **Governance & Management**

In order to realise the ambitions of Foton, Familiezorg West-Vlaanderen has opted for a participatory governance model which includes policymakers, stakeholders and people living with dementia as follows:

- Primary care network of Northern West Flanders
- Dementia Platform of Bruges-East Coast
- City of Bruges
- Foton Dementia Expert Centre and home care support
- Dementia ambassadors, coming from working groups of people with dementia
- The Flanders Centre of Expertise on Dementia and the regional centres of expertise on dementia

The aim of the partnership is to make the best use of all existing expertise. The commitment of the Mayor and the City Council is crucial for the success of the initiative.

The daily management is led by the umbrella association: Familiezorg West-Vlaanderen npo:

The director care of Familiezorg West-Vlaanderen, Bart Deltour, has the end responsibility about the Foton-initiative together with the management team of the umbrella-organisation.

Bart is the liaison person for Hilde Delameillieure, the coordinator of the Foton-team. Foton can rely on the Network of Centres of Expertise on Dementia in Flanders.

Foton employs 7 dementia counsellors and is assisted by 25 volunteers without whom the activities and dementia library could not be possible.





# **Outcomes & Impact**

Between 2010 and 2019, 24,879 persons received information and training in 974 sessions (approximately 3168 training hours). This includes health care professionals, students, caregivers, people with dementia and people of the wider urban community.

The dementia counsellors undertake an average of 1500 interventions in approximately 350 families a year. FotonFoton is one of the 32 organisations that won the European Foundations' Initiative on Dementia (EFID) Award acknowledging the work on improving the lives of people living with dementia in the community. Foton co-developed the EFID "Toolkit for Planning, Reflection and Learning" aimed at helping professionals and practitioners think through their approach to planning, implementing and reflecting on their work/project.

Foton developed a dementia guide to serve as an instrument for empowering people about their health/social needs. Like a colour guide for choosing paint, the dementia guide helps navigate through the world of dementia in a clear and simple way. It consists of a simple social map and straightforward communication hints. More than 7.000 dementia guides have been distributed.

People involved in the FotonHouse initiative believe their activities delay the move to residential institutions, decrease isolation, and increase the quality of life for people living with dementia and their families/carers.

# **Lesson learned & Insights**

- Foton started as a locomotive for change and action. There was a lot of coordination work
  required. It took a long time to create a culture of open collaboration. The move towards Bruges
  as a dementia-friendly city started with a meeting in 2010 everyone was invited, not just
  dementia organisations. It was very informal, dynamic and bottom-up. The City of Bruges aims
  to continue along this path and is leading an initiative to become a compassionate city.
- Foton is successful because everyone involved knows and listens to each other and meets regularly (2 or 3 times every year) to exchange stories of challenges being faced, potential solutions and new ideas. Professionals are able to tri-angulate between the goals of the patient, the requirements of professional standards and their individual penchant for beauty, sympathy and sense (Van Ewijk, 2018). Care-Esperanto enables this process. Care-Esperanto has been developed by Bart Deltour and his collaborators at Familiezorg West-Vlaanderen and is finding its way into the wider care community. Care-Esperanto is, as the name suggests, a 'language', a heuristic framework that supports care providers, informal carers and patients in the collaborative process of finding out what 'good care' means (Deltour, 2018).



# Lesson learned & Insights cont'd

- Learnt from people with dementia that time is too short, and it is better to work together.
- One of the most important but most difficult challenges to create a dementia-friendly city is
  to change the negative perceptions about dementia. After nearly 25 years of efforts to
  realize this change Foton knows that this work will be an ongoing journey not a destination.
- Beside the awareness-raising initiatives which try to influence this negative perception to a
  more nuanced perception, Foton thinks that creating meeting places is very important.
  Direct contact and shared experience with people with dementia is necessary to
  demonstrate and promote 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 inclusive way and not a way which excludes or infantilizes people
  with dementia.

# **Covid-19 Impact**

Foton was impacted by Covid-19 primarily in our essential method of interaction: in-person contact.

Group sessions were cancelled, and video calls were introduced. This virtual method was successful amongst teams of professionals, but less so with families. In fact, Foton continued to visit families in person, respecting physical distancing measures, because in-person interactions are vital for families living with dementia. Wearing masks made face-to-face interactions more complicated as they created a barrier to communication.

Video calls provided an alternative channel for communication and this is expected to be continued, assessing continuously to improve the effectiveness and sustainability of this service. Covid-19 led Foton to evaluate the need for webinars and online training modules to preserve the educational efforts on changing perceptions on dementia and communication with people living with dementia.

The most valuable lesson was the fundamental roles that the neighbourhood and informal networks have in the lives of families of people living with dementia and also the primary care at home like the professional caregivers, nursing people and the volunteers



### **Further resources & Contacts**

- Deltour, B. (2018). Care-Esperanto: the power of simplicity. Gompel & Svacina. First edition. Antwerp.
- Boszormenyi-Nagy, I. (1987). Foundations Of Contextual Therapy. New York: Brunel/Mazel Inc.
- Deltour, B., Meire, C., Lemey, L., Huys, D., Huys, H. (2018) Een steen in je hand: dementie bespreekbaar maken. Garant Uitgevers. Belgium.
- Boeckxstaens, P., Vandenbroeck, P. et al. (2020). Goal-oriented care. A shared language and co-creative practice for health and social care, Brussels: King Baudouin Foundation.

#### **Contacts:**

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- Lieve Vermeulen, responsible for the documentation centre, reception and administration (Fotondoc@dementie.be)
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