



EUROPEAN FOUNDATIONS'  
INITIATIVE ON DEMENTIA

## EFID Awards 2017

Valuing the expertise of people living with dementia



EFID

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## **The European Foundations' Initiative on Dementia (EFID) European Awards: “Valuing the expertise of people living with dementia”**

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 (IE), the Fondation Médéric Alzheimer (FR), the King Baudouin Foundation (BE), the Robert Bosch Stiftung (DE), and the Genio Trust (IE). 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”.

In March 2017, EFID launched a new call for awards “Valuing the expertise of people living with dementia”. The EFID Foundations announce the decision to award 12 initiatives across 10 European countries aimed at valuing the expertise of people living with dementia as an acknowledgement of their work in respecting the autonomy, dignity and right to self-determination of people living with dementia. The importance of listening to the voice of people living with dementia to value their expertise is prioritized in informing all of these initiatives. It is further acknowledged this may need to take different forms across a person's journey but remains equally valuable throughout.

An independent Jury, together with EFID foundations, selected the 12 notable practices to prize during the official ceremony taking place in Sofia on 23<sup>rd</sup> January 2018, under the Bulgarian Presidency of the European Union

The initiatives selected for the prize are listed below.

## THE 2017 EFID AWARD WINNERS

### 1. Fontys University of Applied Sciences (NL)

Fontys University of Applied Sciences (Stichting Fontys) is a Dutch university that came into being in 1996 after a merger. Its mission is focused on providing education and conducting applied research. With the project “The Nursing Home of the Future is (a) Home”, the nursing home can be a place where people with dementia can live a good life, where people are recognized for who they are, and where visitors like to stop by. Through a systematic literature review and a large-scale field study, the phenomenon called ‘sense of home’ was investigated in four nursing homes in The Netherlands. Residents with dementia, members of staff and relatives participated in a photo production study and were interviewed about the visual material they provided. Because the home environment of people is often taken for granted, we invited people to take pictures of things that contribute (or don’t contribute) to a sense of home. A model of the experiential world of residents with dementia has been made, as well as an educational programme for nursing home practitioners.

### 2. Demenz Support Stuttgart gGmbH (DE)

Demenz Support Stuttgart (Dess) was established in 2002 with the intention to improve participation, self-determination and quality of life for people with dementia. The project “KuKuK-TV – Participation, Self-determination and quality of life” is a YouTube channel that gives voice to people living with dementia. It’s a platform that allows people with the condition to communicate their views on life and be active and creative on their own behalf. The programme features among other things reports, portraits, interviews and discussions. More information on [www.youtube.de/c/KuKuK-TV](http://www.youtube.de/c/KuKuK-TV) or [www.kukuk-tv.de](http://www.kukuk-tv.de)

### 3. Het Ventiel vzw (BE)

The objective of the project ‘Het Ventiel’, funded in 2015, is to encourage people with young onset dementia to break free from their isolation and engage in activities in a social context together with a buddy, who is also a volunteer. We look for new challenges and interesting alternatives to what is no longer possible. New challenges give new energy, confidence and self-esteem. People with young onset dementia can meet each other in an informal, casual atmosphere and find quality of life by discovering new activities. The condition has a significant financial impact on the families, so to make the project accessible to everyone, everything is free for the participants. The project also gives the partners of people with young onset dementia some breathing space and offers them the understanding of other partners going through the same experience.

More information: <http://www.hetventiel.be/> or [www.facebook.com/Het-Ventiel-874598159247257](https://www.facebook.com/Het-Ventiel-874598159247257)

#### **4. France Alzheimer Vaucluse and Alzheimer Gesellschaft München e.V. (FR and DE)**

«Meeting without Boundaries» is a programme created in 2011 by 2 associations sharing the same ethics in dealing with people living with dementia: France Alzheimer Vaucluse (France) and Alzheimer Gesellschaft München e.V (Germany). A common pursuit: promoting a more inclusive society while discarding the prevailing negative stigma around dementia. The involvement of people living with dementia in all stages of the project's elaboration and development was as high as that of relatives, volunteers and professionals. They shared their experience as individuals, as citizens and as European partners, which led to opening up the project to a European scale.

More information: <https://www.francealzheimer84.fr/> and <https://www.agm-online.de/agm-home.html>

#### **5. “Gondoskodás” Alapítvány (HU)**

The Gondoskodás Alapítvány (our Foundation) was established in 1998 with the aim of helping and supporting those people of Mosonmagyaróvár who have been using social services. The aim of the project “Dementia Friendly Community– phase 1” is to increase community awareness and understanding of dementia in Mosonmagyaróvár by creating Hungary's first dementia-friendly community. We would like to provide new opportunities for social participation and involvement within the community for people living with dementia. We will help ones with dementia to speak up for changes, which they feel could improve dementia care and benefit their lives. Our goal is to improve public perception of dementia and leverage decision-makers on both local and national level.

#### **6. The Alzheimer Society of Ireland (IE)**

The Alzheimer Society of Ireland works across the country in the heart of local communities providing dementia specific services and supports and advocating for the rights and needs of all people living with dementia and their carers. The Alzheimer Society of Ireland (ASI) established the Irish Dementia Working Group (IDWG) in early 2013. The IDWG is a national advocacy group made up of people with dementia. The IDWG wish to run an advocacy campaign in 2018 “Forget the Stigma of Dementia – Learn Listen Link”. The campaign is an opportunity for the IDWG to engage in local advocacy work through their national and regional groups, while also raising public awareness about dementia. The members of the IDWG will take responsibility for the planning, development, delivery and content of the campaign, ensuring the voice of people with dementia is at the centre.

More information: <http://www.alzheimer.ie>

#### **7. Associazione Novilunio Onlus (IT)**

Founded in 2014, Novilunio is a non-profit association dedicated to inspiring a culture of positive change based on dignity and empowerment of individuals living with dementia and their carers. In 2017, Novilunio launched four online peer support groups for care partners of people with dementia (i.e. frontotemporal, Lewy body, Alzheimer's and vascular). Encouraged by this positive experience, the association is now working on the launch of the first online network of peer support groups exclusively dedicated to Italians living with dementia. The group

participants will convene from across the country in video chat rooms to exchange personal stories, tips and advice, as well as mutual support to better cope with their life changes and live a good quality of life beyond their diagnosis. To this end, the members of the first pilot group will meet on a weekly basis with the support of two Novilunio's advisors who will facilitate their interactions, empower their viewpoints, and assist in case of any issue affecting their participation. The first pilot group will also define the guidelines that will be shaping the values and operations of future peer support groups dedicated to specific types of dementia, which will be launched starting from the second half of 2018.

More information: <https://novilunio.net/>

## **8. St James's Hospital (IE)**

St James's Hospital in Dublin has been in existence since 1727. St James's Hospital, Dublin are involved in a large initiative 'DemPath' and within this undertook a project to improve the experiences of people with dementia within the hospital setting. The project "Wayfinding for people with dementia in a Dublin hospital" included making environment changes to make it more dementia-inclusive. This has covered a number of different areas including improved wayfinding. A wayfinding audit was undertaken involving people with dementia and all found the environment confusing but highlighted specific changes. Drawing on best practice examples environmental cues, including specially designed signage, have been introduced to help orientate people within a new building on the hospital campus. The aim is to extend this exemplar to key parts of the acute hospital.

## **9. University of Salford & University of Manchester (UK)**

The Neighbourhoods: Our People, Our Places project is part of an international research programme called Neighbourhoods and Dementia funded by the ESRC and NIHR (UK). The aim of the research project is to investigate: 1) how people living with dementia and their care partners experience their neighbourhoods and 2) the forms of support and help that are available (and not available) locally. With the support and input of people living with dementia we are developing an innovative dissemination and knowledge exchange programme to inform others of the findings from the research. By disseminating the findings in diverse and creative ways the work is informing public understandings of dementia as well as improving the everyday lives of people living with dementia.

## **10. Foundation Compassion Alzheimer Bulgaria (BG)**

Foundation Compassion Alzheimer Bulgaria is a non-governmental organization established by people living with dementia and their families in 2004. The organisation won an EFID Award in 2012. The project "Together we respect, promote and act - Inclusive society for all ages and all stages of Dementia" aims to study, promote the respect to the needs of people with dementia and enhance a model for inclusion through the following activities in Sofia and Varna:

1. Create local support networks – through building connections with the social services, police, care homes, other related institutions and local community
2. Groups for self-help (support)
3. Research and focus-groups

4. Cultural and public events: exhibitions, inclusion of the local schools (essay contest)
  5. Public Campaign – conferences, publication of the study and project report, etc.
- The project impact is based on the needs of people with dementia to be respected and integrated by the community and the society.

### **11. Norwegian Health Association (NO)**

Norwegian Health Association (NHA) is a voluntary organization funded in 1910. The project “Dementia-friendly hospitals: improving the experience of people with dementia in hospitals” will work together with hospitals to explore how they could become more dementia-friendly. The aim is to improve the experience of people with dementia in hospital. There is recognition that people with dementia face difficulties when they go to hospital. Our project will focus on: how the hospital is organized; hospital staff knowledge of dementia and universal design.

### **12. Upstream (UK)**

Upstream works with people living with dementia to understand their travel challenges and explore their ideas for more inclusive, enabling services. The project has developed a training and design programme for transport service providers based on these insights, to build staff awareness and a deeper understanding of living and travelling with dementia. The programme brings service provider staff together with people living with dementia to experience travel services together, to develop a shared understanding and to co-design solutions that reflect the needs of people travelling with dementia. The Upstream approach ensures that people living with dementia can participate throughout the process, leading to truly inclusive design. More information at [www.upstream.scot](http://www.upstream.scot) or follow @upstreamscot