Dementia-friendly community case studies across Europe

A MAPPING COMMISSIONED BY THE EUROPEAN FOUNDATIONS’ INITIATIVE ON DEMENTIA (EFID)
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Introduction

This collection of case studies or so called “mapping paper”, has been produced as a way of sharing information about ‘dementia-friendly community’ activities across Europe. It has been commissioned by the European Foundations’ Initiative on Dementia (EFID) and produced by a UK non-governmental organisation, the Mental Health Foundation. The aim of the paper is to map what it is commonly referred to as ‘dementia-friendly community’ work and inspire people to develop ‘dementia-friendly community’ activities in their own local areas, or within their area of particular knowledge or expertise, policy or practice.

The contents of the paper have been informed by an online survey, telephone interviews and literature review of ‘dementia-friendly community’ activities across Europe that were commissioned by EFID and undertaken by the Mental Health Foundation between May 2014 and May 2015. The report “Mapping dementia-friendly community across Europe: a study commissioned by the European Foundations’ Initiative on Dementia (EFID)” summarises the findings from the research. The report can be found on the website www.efid.info.

‘Dementia-friendly communities’

‘Dementia-friendly communities’ are a growing phenomenon across Europe and other parts of the world. The numbers of people with dementia continues to increase, mainly because of increased life expectancy and growing numbers of older people. There are many different types of dementia (Alzheimer’s disease is the most common) but they are all brain diseases affecting a person’s memory, perception, understanding, orientation, and communication. There is currently no cure or universally effective treatment for the condition and the concept of ‘dementia-friendly communities’ has developed as a collective approach to enable people with dementia to live as well as possible with the condition.

How the mapping paper is organised

It is organised under three main domain headings representing factors which the study “Mapping dementia-friendly community across Europe” identified as being fundamental to the development of ‘dementia-friendly communities’:

i) Raising awareness, providing information, education and training;

ii) Inclusion of people with dementia: involvement, participation, influencing; and

iii) Building partnerships, networks, collaboration.

In addition to these three factors, the importance of resources (financial, human, facilities, etc.) was also identified as being a crucial factor. While there are overlaps among the domains, all of the projects involved resources, so it was decided not to separate this out from the other domains but to have information about resources included in each entry, where such information was available. Furthermore, the availability of some resources, such as funding, was specific to the particular country where the project or activity was based, so including this detail was not so relevant to a European-wide mapping.
The findings from the survey and literature review also led to the creation of a taxonomy of ‘dementia-friendly community’ activity, called ‘DEM-FACT’, that described three different types of ‘dementia-friendly community’ activity taking place across Europe. This taxonomy is shown below and described in more detail in the report.

**Authorship**

This paper was compiled by Vicky Nicholls, supported by Toby Williamson, at the Mental Health Foundation, London, UK, on behalf of the European Foundations’ Initiative on Dementia.

Editing: EFID Secretariat
Diagram 1 - A taxonomy for ‘dementia-friendly community’ activity (DEM-FACT)

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

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

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

‘Community involvement’
Focus of DFC activity involves the wider community being supportive towards people with dementia

• Awareness-raising across community organisations, businesses, public services, etc.; is well resourced; includes the active involvement of people with dementia; results in positive activity to change attitudes and behaviours; remove barriers and to improve access; support inclusion and participation of people with dementia in the community; and is evaluated to assess impact.
• Active participation of people with dementia and other community members in all aspects of ‘dementia-friendly community’ activity, (as individuals and through groups, as equal citizens and valued members of a partnership), including awareness-raising and evaluations of impact.
• Democratic and accountable community partnerships and networks, that are co-ordinated by organisations with the ability to commit resources for community wide activity but who can also support and respect diversity, small, grassroots initiatives and the active involvement of people with dementia – most member organisations actively involved and there are resources and commitments to sustainability.

‘Whole community and citizenship’
Focus of DFC activity are community partnerships co-ordinating a comprehensive ‘whole community’ and citizenship approach with the active involvement of a range of organisations, resources, and people with dementia.
Examples selected for the paper

The mapping paper contains 48 examples of ‘dementia-friendly community’ projects, activities and initiatives. These include projects, videos, organisations, networks, campaigns and other form of initiatives. Both the authors of the paper and EFID wish to emphasise that the examples illustrate the diversity of ‘dementia-friendly community’ activity but have not been evaluated or chosen as examples of ‘best practice’. There are many other ‘dementia-friendly community’ initiatives within Europe: this mapping contains just a cross-section of those that were found during our information-gathering and there were many other examples identified that have not been included. Omission in no way reflects on the quality or contribution of other activities.

The criteria used to select examples included ensuring a diversity of projects, activities and initiatives:

- across a range of European countries;
- in different types of communities (e.g. urban/rural, large/small, geographical, communities of ‘identity’, etc.);
- reflecting a balance across the three main domains, and types of ‘dementia-friendly communities’ identified in the DEM-FACT;
- examples that had been referred to in the report describing the findings from the literature review and survey.

In addition to the survey and literature review, the paper is also informed by other work done by the European Foundations’ Initiative on Dementia, notably the awards that were given to outstanding ‘dementia-friendly community’ projects in 2012 and 2014. For full information about the EFID Awards “Living well with Dementia in the Community” see: www.efid.info. In total EFID rewarded 20 organisations in 11 countries.
Examples of ‘dementia-friendly community’ initiatives

(I) Raising awareness, providing information, education and training

The importance of raising awareness about dementia in communities, challenging stigma associated with it, and providing information, education and training to achieve these goals, was a consistently important theme from the survey and literature review.

The report “Mapping DFCs across Europe: a study commissioned by EFID” identified a wide range of activities under this theme, including:

- Awareness-raising sessions and training for a range of different audiences, often reflecting where ‘dementia-friendly community’ activity was focused. This could include family members and other carers, health and social care staff working in the community (as well as hospitals and care homes), school students, volunteers in local NGOs and churches, people working in shops, businesses, and public services (including emergency services and public transport), and the general public;

- exhibitions, displays, performances, talks, cultural events, etc. about dementia, involving people with dementia, or by people with dementia;

- community events, discussion groups, supporting people with dementia to have a visible, ongoing community presence, and participation in community life;

- ‘virtual’ and actual dementia information centres which are open to the community, can provide support to people with dementia and their carers, but also host events, exhibitions etc. about dementia;

- the use of symbols, leaflets, films, local and national media, etc. to communicate positive messages about dementia.

The rest of this section of the mapping lists all of the ‘dementia-friendly community’ projects that were identified across Europe, that come under the heading of raising awareness, providing information, education and training.
1. Entr’âges asbl (‘Intergenerational art’), Belgium

**Where:** Brussels, and other towns, Belgium

**Who is involved:** Entr’âges, non-profit organisation.

**Nature of activity:** For thirty years, Entr’âges has been facilitating intergenerational links. They promote the empowerment of older people, with an awareness of what this might mean in reality. The older person is supported to move to a position of active participation in social, cultural and even political life. Their approach is that when working with human beings, flexibility is essential. They strive to innovate and initiate new meetings between people. It’s no longer a case of a professional and a person with a known neurodegenerative disease. Here, a human meets a human. Another objective of Entr’âges is to recognize the status of resident actors-citizens, with rights and power to act.

One project of Entr’âges involved older people who experienced some form of disorientation (but not necessarily due to dementia) and lived in a local care home, ‘Le Val des Roses’ in Brussels, doing creative art workshops with young art students from ‘La Cambre’ once a week for nine months. Artworks were then exhibited in public spaces. You can see an inspiring video about this project here: [https://vimeo.com/38643425](https://vimeo.com/38643425). ‘Something more than the encounter is born out of the encounter’. The narrative is in French, but there are places where the visual is enough without the need for language. The video narrates the story of members of staff from Entr’âges, art students and residents from “La Val des Roses”. It is a story about building relationships, developing trust, identifying the concerns and being passionate about sharing skills and joys. On one occasion residents were asked to bring a treasured object with them, then they shared the story of why this object was important to them and what it meant; ‘we all felt the same – there were no more older people and young people – all the same’.

Another recent project (‘Wink’) has been around taking photos [http://www.entrages.be/site/portfolio/animation-et-exposition-clin-doonil-terrasse-des-hauts-pres-et-entrages-mai-2015/](http://www.entrages.be/site/portfolio/animation-et-exposition-clin-doonil-terrasse-des-hauts-pres-et-entrages-mai-2015/). This is a pilot project that is part of a reflection on how intergenerational relationships can develop with people with problematic cognitive ageing who live in ‘Terrasses des Hauts Prés’ care home in Uccle, a municipality of Brussels. In 2015, Entr’âges organised a series of meetings between six members of staff and six residents from this home who volunteered to take pictures together.

**Website:** [http://www.entrages.be/site/](http://www.entrages.be/site/)
2. Dementia friends, United Kingdom

Where: United Kingdom

Who is involved: Alzheimer’s Society and Alzheimer’s Scotland.

Nature of activity: ‘Dementia Friends’ is an awareness-raising initiative developed by the Alzheimer’s Society. It involves a 45-minute information session given to any group of individuals who may have contact with people with dementia in the community (e.g. shop staff, public transport workers, volunteers in civil society organisations and faith communities, etc.). It provides basic information about dementia and suggests helpful responses that people can give in encounters with people with dementia. People who have participated in a Dementia Friends session (including people with dementia) can become Dementia Friends Champions and deliver the session themselves. An alternative way to become a dementia friend is to watch online videos that show the world from the point of view of someone with dementia, and are tailored to people who might interact with people with dementia in different environments.

There are dementia friends’ initiatives in other UK countries. You can find out about Dementia Friends in Wales and Northern Ireland via the main Dementia Friends website and for Scotland in http://www.dementiafriendsscotland.org/.

The Dementia Friends websites contain inspiring ‘dementia stories’ and videos, like Gina Shaw’s story. Gina is 61. She used to be a children’s nurse. She was only diagnosed in 2014 with dementia and is still coming to terms with it. She uses the metaphor of a couple of lightbulbs on a Christmas tree that aren’t working to explain what dementia is. For her, being around other people is all about them being kind, patient and waiting. She has family and friends who help her and “I don’t know what I would do without them”. She explains that people with dementia sometimes see things that aren’t really there, like a reflection in a mirror. The hardest thing for her was telling her children as she is their mother and wants to carry on being a good mum. Her friend has had dementia friends training. She says that if Gina seems to go off into a world of her own, as she sometimes does, she asks gently if she’s gone to the Palace (a live music venue) which is somewhere they used to enjoy going to when they were younger. Gina finishes by saying that with help people with dementia can lead a full and active life. She spearheaded a 2015 Alzheimer’s Society promotion campaign which led to establishing Dementia Friends in Australia.

Website: https://www.dementiafriends.org.uk/
3. Missing persons services, Belgium

Where: several Flemish police areas, Belgium

Who is involved: Police in the Hekla district (Hove, Edegem, Kontich, Lint and Aartselaar – all in the area around Antwerp) have been supported by the King Baudouin Foundation and the European Foundations’ Initiative on Dementia (EFID) to improve the systems used to find missing persons who have dementia. The Jury of the EFID Awards highly valued the fact that the project methodology and tools could easily be adopted in other geographical areas and by other local police forces.

Nature of activity: The federal police in Belgium has a Missing Persons Unit that has set up a protocol with Foton (a Bruges charity aimed at promoting specialised dementia care, support and awareness across Bruges), institutions, police forces, and the Public Prosecutor’s department, in order to improve responses from each when someone with dementia goes missing. These protocols are intended to facilitate safe, autonomous movement around the community for people who have dementia, as well as promoting a more cohesive, dementia-aware community.

An example of a protocol is in the Hekla police zone where police collaborated with the care sector to find wandering people. The protocol provides care givers with an information sheet and a guided response on what to do should a person with dementia goes missing. The information sheet contains a personal description, contact details of family and friends, former addresses, places of interest etc.

This idea, which has been picked up and adopted by eight other areas, has reduced pick up time for lost people with dementia to two hours.

On the website www.efid.info you can find a presentation given by Chief Inspector Patrick Crabbe (since retired), about how the protocols were developed. The presentation includes 15 tips to help family members in their search for answers and overcoming feelings of shame. They provide tips to prevent people from going missing, including: seeking advice from a healthcare professional; finding out if there are local protocols with the police; taking a note of important 'anchor points' in the life of the person with dementia (these are places they often talk about or frequently visit, such as the place where they grew up or used to work, cemetery, etc.); making sure that the persons themselves have a way of making contact in an emergency and carry information about who they are; advice if the person goes missing.

Website: www.hekla.be/
4. Foundation Compassion Alzheimer, Bulgaria

Where: ‘Bureau of complex social services’ in Varna, ul. Pop Hariton 4 and mobile services for small settlements in the Sofia region (Buhovo and Kremikovtzi), Bulgaria

Who is involved: The Foundation Compassion Alzheimer, a non-governmental organisation, was created by people with dementia and their families in 2004 to help and support older people with Alzheimer’s disease and dementia and their families and friends. Thanks to a 3-year twinning grant from Alzheimer’s Disease International, a programme that provides support for core activities of ADI members, the Foundation was able to expand its activities. In 2012 the Foundation won an EFID award for engaging in a robust programme to sensitise the general public, and creating the first primary services for people with dementia and their families.

Nature of activity: The Foundation aims to improve the quality of life for people with Alzheimer’s and dementia by changing attitudes and practices towards them and providing access to treatments and social support. Activities include: provision of innovative social services (legal, psychological consultations for people with dementia and families), art-therapy, non-pharmacological methods of prevention, an Alzheimer’s café, information campaigns for prevention of dementia, awareness-raising and lobbying for improved services, accessible treatment and other services and policies. Training for the staff in residential homes for people with dementia is also provided. The twinning of the Foundation with an organisation in another country facilitated the transfer of expertise in the fight against exclusion experienced by people with dementia.

As well as psychological, social and legal advice to people affected by Alzheimer's disease and their families with opportunities for referral to other specialists, the Foundation supports people directly involved with the care of the person with Alzheimer's through individual counselling to deal with stress and depression.

Website: http://www.alzheimerbulgaria.org/
5. Oficinas Terapêuticas (‘therapeutic workshops’), Portugal

Where: Associação ProfundaMente, Lisbon

Who is involved: ProfundaMente is an association recognised as a private social solidarity institution which aims to study and support older people. In 2012 the organisation won an EFID award, for giving value to the capacities of those diagnosed as having dementia through various activities. The Jury of the EFID awards recognised the value of its twofold objective: firstly to enable people diagnosed with dementia to regain their self-esteem; and secondly to change the representation associated with dementia. Partnerships with the museums and gardens of Lisbon were seen as particularly encouraging in achieving the second objective.

Nature of activity: The main project focuses on the loss of identity that can occur when someone is given a diagnosis of dementia. The person themselves can develop low self-esteem. Rebuilding self-esteem is the overall aim of the organisation, by providing more autonomy and developing old and new capabilities, even if the person’s thinking is less clear.

Oficinas Terapêuticas is a project that began in 2004, in a private institution in Lisbon. Oficinas Terapêuticas, or therapeutic workshops, are small units of therapeutic intervention based in the community, that use community structures, preferably linked to primary health care, and develop programmes for people with Alzheimer’s disease or related diseases. The work of the project is carried out with the therapeutic intervention of a number of artists and artisans and with the collaboration of community organisations.

Website: www.profundamente.pt
6. Dementia-friendly Community Pharmacy, Austria

Where: Graz in southern Austria

Who is involved: The Institute of Palliative Care and Organisational Ethics at Universität Klagenfurt, Wien Graz. A steering committee consisting of Alzheimer Austria, the Austrian Chamber of Pharmacists and researchers from the Institute for Palliative Care and Organisational Ethics manages this project. It is funded by Fonds Gesundes Österreich, Gesundheit Österreich GmbH, Wiener Gesundheitsförderung WIG, Niederösterreichischer Gesundheits und Sozialfonds NÖGUS, and financially supported by Österreichische Apothekerkammer ÖAK. The project received a special nomination by EFID in 2014.

Nature of activity: The project aims at promoting health and well-being for families, informal caregivers and people living with dementia via fostering the implementation of needs-based, person-centred care in community pharmacies, thereby developing a health-promoting community pharmacy environment. People living with dementia and their caregivers are regular users of community pharmacy services, which are an easily accessible health care setting within the wider community. The project is based on principles of health promotion and palliative care and offers specific opportunities for health-promoting interventions. Active participation and empowerment of people are basic principles in such an approach, thus fostering dignity and quality of life and reducing stigma. It fosters person-centred care in pharmacies via participatory health research. Applying the principles of participatory research (i.e. involving caregivers and people with dementia) is one major goal as is working in cooperation with Alzheimer Austria, (a self-help group), the Austrian Chamber of Pharmacists, and with other partners from palliative care and health promotion in Vienna and Lower Austria. Forty staff from 18 community pharmacies were consulted and took part in a series of workshops to further develop their knowledge in dementia care. Subsequently, via ‘practice-based projects’ developed by community pharmacies, interventions in the community setting were tested. Successful interventions encompassed issues around pharmaceutical care and building networks of care, spreading information on dementia via lectures and in designated counselling spaces in pharmacies, and organising and participating in community-wide activities such as ‘dementia-days’. The pharmacies were thus adapted to be welcoming and inclusive of people with dementia via delivery of specific interventions. Those staff who took part in the project improved their competence in counselling.

Website: a poster presentation [http://www.uni-klu.ac.at/pallorg/downloads/Poster__AlzheimerEurope_2015_END.pdf](http://www.uni-klu.ac.at/pallorg/downloads/Poster__AlzheimerEurope_2015_END.pdf)
7. Foundation Mental Health Care Centre, Estonia

Where: Tartu, Estonia

Who is involved: The Centre has received much support in developing and improving the quality of the services from Sopimusvuori ry (Finland); the Psychiatric Service of Malmö University Hospital (Sweden); the Community Residence National Association (Netherlands); the Hamlet Trust (Great Britain), Visby Hospital (Sweden); the Toronto Mental Health Centre (Canada); and specialist-, clients- and family members’ organisations in Estonia (EPRA, Independent Life, EGGA, Association of Estonia Alzheimer Disease, Davy, Estonian Association for Supporters of People with Mental Disorders etc.).

Nature of activity: The Foundation provides help for people with dementia at their home, at a day care centre and at Nõlvaku Care Centre (24 hour care). They work closely with relatives of clients and also with people involved in dementia care. They are developing respite care at person’s home to enable relatives to continue living their own life and continue working. They are trying to be very flexible in the way they provide their services.

The organisation highlighted the importance of amplifying awareness about dementia among the general public to promote improved attitudes and understanding towards people living with dementia. A lack of resources to enable adequate service provision was cited as the biggest factor impacting on the feasibility of developing ‘dementia-friendly communities’ in Estonia.

“Usually people don’t think about dementia before they themselves need help. That’s why the information is the most important.”

Website: [http://www.tartuvthk.ee/keel_englise/](http://www.tartuvthk.ee/keel_englise/)
8. Act and React for Dementia, Cyprus

Where: Cyprus

Who is involved: Ske Kouri Ksilourikou, a Council of volunteer community care addressed to a complex of 12 communities/villages. In 2014 the organisation won an EFID award.

Nature of activity: There is an urgent need for improving the awareness and understanding of dementia across society in order to enhance the quality of life for people with dementia and their caregivers. The Cyprus organisation has been trying for several years to offer people with dementia an independent and active life. The organisation exercises direct contact with the residents of the 12 communities/villages, in order to identify community needs and gaps that exist and to search for viable solutions, solutions designed for residents themselves based on their own needs.

The organisation ran awareness workshops on dementia in primary and high schools, in order to educate young children of all communities on the facts of ageing and dementia, in collaboration with the training and research centre LCEducational.

Website: https://www.facebook.com/Act-and-React-4-Dementia-275072549355097/
9. ‘The customer is always right’ video, Belgium

**Where:** Bruges, Belgium

**Who is involved:** The video was made by Foton with funding from EFID and the cooperation of Family Care West-Vlaanderen, an autonomous and integrated home care service, working in West Flanders and in the border areas of East Flanders (website: [http://www.familiezorg-wvl.be/](http://www.familiezorg-wvl.be/)). It was made with the participation of people with dementia and their spouses or child(ren), the local authority, the Smedenstraat trade cooperative and local traders.

**Nature of activity:** a short film, set in Bruges, entitled ‘The customer is always right’ was made to show how having people trained in dementia awareness working in local businesses such as shops, pharmacists and hairdressers, can make a big difference to the lives of people living with dementia. The video can be viewed on the website [www.efid.info](http://www.efid.info). The traders show kindness and patience in prompting someone with dementia (played by an actor) as to what day of the week it is, and recognising the things that the customer with dementia does know, such as the word for newspaper, and how to get home again, with gentle prompting. One shopkeeper said:

‘It’s a matter of trust and building that relationship with my customers.’

**Website:** [http://www.efid.info/eng/resources/video-the-customer-remains-the-king/](http://www.efid.info/eng/resources/video-the-customer-remains-the-king/)

![Image of a shopkeeper and customer discussing](image-url)
10. Dementia-friendly churches, England

Where: Oxfordshire and elsewhere, England

Who is involved: Diocese of Oxford, Spiritual Concern for Older People (SCOP), local parishes and other church organisations.

Nature of activity: The Diocese of Oxford (Church of England) runs dementia awareness training and other initiatives to increase understanding of dementia amongst churchgoers. Their website lists include good access, signposting, and welcome; accessible toilets; help with transport needs; convenient service times; user-friendly service sheets; familiar words and music; low-demand community activities, for example singing or coffee mornings; services or other events to celebrate care-giving; links with local care homes; involvement with local community initiatives on dementia; key congregation members having completed some dementia awareness and adult safeguarding training.

In the autumn of 2015 they are focusing on pilot projects in individual churches which they hope can act as beacons of good practice across the diocese. So, for example, one church has invited the advisor for spiritual care for older people to preach on spirituality and dementia at one of their Sunday services aimed at adults, and then return the following week to facilitate an all age service in which the congregation will construct memory boxes together.

A book on the subject of worship in care homes is due to be published in late 2016 by BRF (Bible Reading Fellowship). It will be based on materials used in a presentation produced by the Rev Collicutt which includes guidance on community building; setting the scene; the act of worship; how to dress; the use of visual resources such as slides; and seasonal prompts.

Other Church of England dioceses across England are involved in dementia-friendly activities. Also Catholic and other Christian denominations in various parts of Europe are taking action. For more information on any of these, contact your local parish or comparable organisation.

Website: http://www.oxford.anglican.org/dementia-friendly-churches/
11. The Birches Alzheimer’s Day Centre, Ireland

Where: Louth, Republic of Ireland

Who is involved: The Birches is partially funded by the Department of Health, supported by the Health and Safety Executive North East branch (HSENE) and The North Louth Branch Dundalk fundraise the balance. There is a Management Committee responsible for the day-to-day management of the Day Centre. All branch members work in a totally voluntary capacity.

Nature of activity: Six day services for people with dementia, and a weekly outreach day service in a rural coastal community. It provides a family support group, training to family carers, and is organising an advocacy programme for family members. It is described as ‘a mixed model of care and encompasses all the current models medical/social/and rights model of care’. It is involved with a local age friendly forum which is part of the World Health Organisation’s age friendly city programme to include dementia-friendly aspects to the area plan.

It plans to organise monthly dementia-friendly events to raise dementia awareness, interact with the older people’s forums to engage with local businesses and government agencies about becoming dementia-friendly, reminding everyone that the person with dementia is part of the community and together with their family should have their rights respected.

Website: http://www.thebirches.ie/
12. Beauraing Centre for Social Action, Belgium

**Where:** Beauraing, Belgium

**Who is involved:** Beauraing Centre for Social Action.

**Nature of activity:** This is a centre for people aged 60 or over during the day in order to combat isolation. Activities are adapted to the needs of people with dementia (e.g. musical workshops, massages, gentle exercises, craft, games). Participants enjoy being with others who are less dependent and thrive during these precious moments in groups. They organise joined-up activities with a care home or with services such as libraries and cultural centres, in order to engage participants through different events. For example, a project was organised around remembrance of the First World War. A member of staff commented:

‘It all depends on resources. It is crucial to engage a minimum number of participants in order to organise meetings, coordinate activities and supervise people. Infrastructure such as the Community Centre ‘La parenthèse’ couldn’t have happened if it hadn’t been for subsidies we received. Financial resources such as the ‘Alzheimer’ grant enable us to improve the quality of the activities and offer diversity. Unfortunately, the grant was for a fixed period and does not allow long-term planning.’

**Website:** [http://cpas.beauraing.be](http://cpas.beauraing.be)
13. Us with you – ambassadors for Alzheimer’s, Italy

**Where:** northern Italy

**Who is involved:** Rifugio Re Carlo Alberto, Diacona Valdese. In 2014 the project won an EFID award.

**Nature of activity:** This project aims to provide education about dementia, as well as advocacy services. Through this project people living with dementia can become ambassadors who campaign on behalf of others who are living with dementia. Training, support and information workshops are also provided as part of the project, as are social engagement and community outreach opportunities within community settings, such as local coffee shops.

The idea is to integrate the local community with the residents of the refuge. Residents are encouraged to participate in the daily activities offered by the area, such as markets, village festivals, restaurants, and bars; there is a drop-in at a local coffee shop; community and socio-pedagogical activities for people with and without dementia within and outside the Refuge; awareness-raising activities such as conferences, seminars, and cinema screenings; and a meeting between the residents and the regional municipalities for a confrontation between citizens and politicians.

The project is based on creating relationships of reciprocity, in which those who help and who are helped collaborate to achieve a common goal, making the most of the contributions that each can make, respecting desires, wishes and inclinations. It is about “celebrating the possible”.

**Website:** [http://www.diaconiavaldese.org/linea287/A28700.php](http://www.diaconiavaldese.org/linea287/A28700.php)
14. Alzal House, Italy

Where: Lamezia Terme, Calabria, southern Italy

Who is involved: Associazione per la Ricerca Neurogenetica o.n.l.u.s. In 2012 Alzal House won an EFID award. The Jury of the awards appreciated the strong network approach of the project that strengthens the natural networks formed by the family, community, parish, friends and colleagues and also gives special emphasis to integrating the younger generation. They stated that by involving the community, people with dementia remain part of it so that the isolation and stigma of those with dementia and their families, can be reduced. Stigma is still a day-to-day reality in many regions of Southern Europe.

Nature of activity: Alzal House is a community day-care home for people with Alzheimer’s disease and their families, situated in Lamezia Terme, Calabria, in the very south of Italy. It opened in 2002 as the first adult care home in Lamezia Terme and offers a wide range of creative activities such as handicrafts, self-management activities, organised day trips and short vacations, as well as group meetings and support for families.

The daily running of Alzal House is purposely shared with families, young civil service volunteers and students to encourage the dissemination of good social practices and assistance within the community. Encouraging the participation of people from all age groups fosters effective intergenerational communication – between young people, adults and older people – and narrows the generation gap, whilst ensuring stronger integration of the person with dementia in the community.

Website: [http://www.arn.it/it/home-it/](http://www.arn.it/it/home-it/) and a lively Facebook page.
15. Au Fil de L’Age (‘In the Course of Age’), France

**Where:** Saint Sauvent in the Maine et Loire region of France

**Who is involved:** Multidisciplinary team in the Champtoceaux community. Authorised by the Regional Health Agency and the General Council.

**Nature of activity:** ‘Au Fil de l’Age’ is a mobile day care service centred on people rather than buildings. This means that they welcome people with dementia in different locations according to the day of the week, and above all, locations that are public and accessible to all. They describe themselves as being mobile due to the fact that the day care service moves around different sites.

The venues are made available to individuals and groups, and therefore are not linked to medical services. This makes it easier for many people and their carers to access the day centre, as being in a neutral environment reduces anxiety linked to medical structures and makes processes easier.

They work closely with local authorities in order to identify the sites. They organise daily trips to business to purchase food for dinners, therefore establishing strong links with businesses and their customers. They want to foster social links and are also working with the area’s cultural centre. They see it as very important to maintain this link. They believe that they can change people’s perception of the condition through their work. For example, they participate every year in a poetry contest organised by an association. It is important for them to participate in local public life.

Having people with dementia occupying ordinary public spaces promotes a positive image of the condition.

**Website:** [http://www.cc-cantonchamptoceaux.fr/pageLibre00010a6f.aspx](http://www.cc-cantonchamptoceaux.fr/pageLibre00010a6f.aspx)
16. Urbach dementia resources, Germany

**Where:** Urbach, Stuttgart, Germany

**Who is involved:** Online resource managed by Urbach municipality authorities.

**Nature of activity:** Urbach is a municipality in Germany. A collection of dementia relevant literature was distributed to 28 libraries, including books and DVDs which offered introductory information about dementia. A range of books and resources have also been made available online and includes short stories, first-person accounts of people living with dementia, novels and books for children.

Their remit is to inform and educate.

**Website:** [http://www.urbach.de/servlet/PB/menu/1347765_l1/index.html](http://www.urbach.de/servlet/PB/menu/1347765_l1/index.html)
**17. Bishopbriggs Academy community action project, Scotland**

**Where:** Scotland

**Who is involved:** Bishopbriggs Academy and East Dumbartonshire dementia network.

**Nature of activity:** This project enables school pupils to undertake dementia informed training and encourages them to participate in intergenerational initiatives within Bishopbriggs supported by a local dementia action team. Pupils who have been trained have shown a real understanding of some of the issues older people and people with dementia face including losing touch with their community and now help to run a monthly community café.

18. Tea House Reminiscence®, Merseyside, England

Where: Liverpool, Merseyside, England

Who is involved: Chinese Wellbeing organisation.

Nature of activity: A pilot Black, Asian and minority ethnic (BAME) and Faith Communities Dementia Champions project funded by Merseycare National Health Service Trust aimed to raise awareness of dementia within five communities, improve knowledge and understanding of dementia, and reduce social stigma. The initial pilot was successful in achieving its aims and the project was continued. Chinese Wellbeing, a registered charity which delivers culture and language-specific health and social care services within the Chinese community, was one of the beneficiary organisations. Chinese Wellbeing had already begun to explore ways to respond to the needs of their service users through a Winter Survival Project called ‘Soup and a Movie’ which was delivered across a number of sheltered housing schemes. This work highlighted the need for more language and culturally aligned reminiscence activities to cater for the specific needs of the Chinese community, which could not be met by mainstream Memory Cafes. Memory box and reminiscence activities were developed and became the pilot for ‘Tea House Reminiscence’, something that is meaningful and has cultural resonance for Chinese people. The sessions are not currently exclusively for people living with dementia, and are open for those who are at risk of developing dementia and their carers. Tea House Reminiscence is unique in Liverpool and provides a safe haven for the Chinese older people to socialise. Chinese Wellbeing’s very own chef prepares a traditionally cooked lunch including a tasty and nutritious soup which often evokes memories from the past. Chinese Wellbeing’s success in reducing social stigma is perhaps evidenced by the fact that people living with dementia are now joining the sessions; they are able to be more open about their dementia as it is less stigmatising in this environment.

Tea House Reminiscence® is run by Chinese Wellbeing’s Mental Health Lead Rita Lee with assistance from the Dementia Champion and support workers who are all bilingual and can speak a number of local dialects. Service users from all walks of life certainly enjoy Tea House which has generated a very positive response from the community as a whole. Chinese Wellbeing was encouraged by the Dementia Engagement and Empowerment Project (DEEP) to develop a service user-led network which began with the creation of the Liverpool Chinese Dementia Support Network. With the aim of creating a sustainable user led network the group set out to establish the priorities for those members living with dementia. A dementia-specific Tea House was top of the list. Chinese Wellbeing is now in discussions with the Liverpool Clinical Commissioning Group which has recently agreed to the development of this much needed service.

Website: http://www.chinesewellbeing.co.uk
(II) Inclusion of people with dementia; involvement, participation, influencing

The second essential factor in developing ‘dementia-friendly communities’ was the inclusion and involvement of people with dementia. In some ways this seems obvious; how can a community be dementia-friendly if people with dementia are not included and involved? The importance of supporting people to remain autonomous, independent and self-determining for as long as possible was a particular theme in the literature from England, Germany and Belgium, as identified in the literature review.

It was clear from an analysis of the survey findings that inclusion and involvement could be defined in many different ways. These included ensuring people living with dementia:

- were not excluded from receiving care and support provided to groups with other disabilities or health conditions in the community;
- were able to access to ordinary community activities so people living with dementia could continue with their day to day lives (shops, theatres, cinemas, galleries, museums, libraries, parks, restaurants, cafes, public transport, leisure services, churches and faith groups, community groups, etc.);
- were actively involved in ordinary community activities (e.g. volunteering, choirs, outdoor activities, etc.);
- were actively involved in activities specifically aimed at developing ‘dementia-friendly communities’ (e.g. giving talks, planning activities, speaking to the media, checking on how dementia-friendly a community was, etc.);
- had opportunities to be active citizens and campaigners (through empowerment groups actively involving or led by people living with dementia).

The report also noted that inclusion and involvement was sometimes defined as including the whole community, not just people with dementia. Although this section focuses on the inclusion and involvement of people with dementia it is recognised that a ‘whole community’ approach is also important and supports the development of ‘dementia-friendly communities’ – a number of examples in this paper illustrate this.

The rest of this section of the mapping paper lists all ‘dementia-friendly community’ projects that were found across Europe, that come under the heading of ‘inclusion of people with dementia: involvement, participation, influencing’.
19. Konfetti im Kopf eV (‘Confetti in the Head’), Germany

Where: Hamburg, Stuttgart, Berlin and elsewhere, Germany

Who is involved: Sometimes big actions start with the commitment of an individual, who then manages to inspire other people with their ideas. The Hamburg-based photographer Michael Hagedorn had been following the lives of people with dementia for a long time, then had the idea of initiating a large, open-air photo exhibition. He joined forces with other passionate creative people, then in 2009 the company VIA composite gGmbH took the campaign into their own hands and implemented it enthusiastically in Berlin, making the dream a reality. Konfetti im Kopf has received an EFID award in 2014.

Nature of activity: The project develops events and activities to bring together people with and without dementia in their local community. In using music, visual arts, theatre and humour they create meeting spaces, where people connect and gain new perspectives through social contact and information. The project puts emphasis on building a network of local institutions dealing with dementia care. There is a plan to establish a Music & Arts Studio, where music and art therapists encourage people with and without dementia of all ages and backgrounds to experience the fun of creating and an increase in self-esteem.

This project is about blowing up the gloomy stereotype that dementia patients are confused people whose personality gradually disappears with their memory. They celebrate radiating joy, wonder, dignity, individuality, exploring how dementia affects everyone. The centrepiece of the campaign is a large open-air photo exhibition - a place of many creative and informative activities related to dementia.

The project has also established KONFETTI cafes for the inclusion of people with dementia and their families in Hamburg. The KONFETTI cafes creative meeting spaces are currently generated that appeal by an unusual and diverse program to all people in the district, and merge in cultural activities. The moto is “come and be surprised!”.

Website: www.konfetti-im-kopf.de
20. The European Working Group of People with dementia (EWGPWD)

Where: Europe-wide

Who is involved: EWGPWD was established in 2012 following a meeting in Glasgow jointly organised by Alzheimer Europe, Alzheimer Scotland and the Scottish Dementia Working Group that was attended by nine people with dementia, their carers and 20 delegates from the national Alzheimer associations of Austria, Bulgaria, Norway, Slovenia and Spain.

Nature of activity: The EWGPWD is composed of people with dementia. They work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. The group operates independently, with its own Board and agenda of activities. The Chairperson of the EWGPWD also sits on the Board of Alzheimer Europe.

Website: http://www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia

![Image of the European Working Group of People with dementia (EWGPWD)]
21. Dementia Engagement and Empowerment Project (DEEP), England

Where: United Kingdom

Who is involved: The Dementia Engagement and Empowerment Project network (DEEP) is supported and coordinated by Innovations in Dementia (iD), in partnership with the Mental Health Foundation. iD is a community interest company that works nationally with people with dementia, partner organisations and professionals with the aim of developing and testing projects that will enhance the lives of people with dementia. The Mental Health Foundation is a UK social research and development non-governmental organisation.

Nature of activity: DEEP is a network of independent groups led by or actively involving people with dementia. DEEP groups are involved in activities aimed at influencing services and policies affecting the lives of people with dementia, and the communities where they live. There are over 60 groups that are part of the network, ranging from small local groups up to national groups (such as EDUCATE and the Scottish Dementia Working Group). Examples of activities include consultations on national policies, training staff, speaking at conferences and through the media. Some groups employ people with dementia to help raise awareness and provide support to others.

“Dementia Diaries” is a project that brings together people’s diverse experiences of living with dementia as a series of audio diaries. Some diaries are produced by DEEP members. Wendy from York found “nothing more comforting than for someone else saying that they are experiencing the same symptoms”. Gina from Liverpool thought it is “so important to keep those links, keep yourself motivated and active”. You can find the diaries on the website http://dementiadiaries.org/

Website: http://dementiavoices.org.uk/
22. EDUCATE (Early Dementia Users Cooperative Aiming To Educate), England

Where: Stockport, England

Who is involved: The project is run by people with dementia who use their own experience to raise awareness about dementia. In 2014 EDUCATE won an EFID award.

Nature of activity: Participants give talks to businesses, community and faith groups, health and educational establishments about living with dementia. They help deliver training to staff supporting people with dementia and act as consultants in matters of dementia policy. The Coming Together project hopes to help people with dementia develop their own groups in surrounding boroughs. EDUCATE is a DEEP group (see case study n.21).

Website: www.educatostockport.org.uk
**23. Service for people with young onset dementia and their families, YoungDementia UK**

**Where:** Oxfordshire, England

**Who is involved:** YoungDementia UK is an NGO based in Oxfordshire. The charity comprises a dedicated, knowledgeable, lively team of trustees and staff, volunteers and inspirational, amazing members whose lives have been changed by young onset dementia. Those involved learn from each other and seek the best ways to make the most of life with young onset dementia. In 2012 YoungDementiaUK won an EFID award. The Jury commented that thanks to their specific and individual support, YoungDementia UK significantly improves the quality of life of the families they serve and empowers local communities to take initiatives for a more inclusive community. It is tailored to the situation of people aged 30 to 65 and their families, helping them to live as well and as fully as possible with dementia.

**Nature of activity:** YoungDementia UK offers integrated services to meet the complex needs of people with young onset dementia and their families from diagnosis to post-bereavement. A trained support worker partners the person with dementia, developing a trusting relationship, sharing chosen activities within their local community and ensuring the present is fully lived. Flexible support is tailored to the family’s circumstances, including information, practical and emotional guidance. To combat the isolation, a lively monthly café encourages a welcoming community for all.

Other services include a monthly coffee and chat; Creative Minds, a monthly arts and crafts group for people with young onset dementia; and Like Minds, for people with young onset dementia who are interested in coming together to share time, experiences and ideas. It provides an opportunity for members to build new friendships with people in similar situations, and meets monthly in four locations across Oxfordshire. Another opportunity to enjoy activities together is Walk and Talk, a monthly opportunity to enjoy fresh air, the wonders of nature and good company.

**Website:** [www.youngdementiaku.org](http://www.youngdementiaku.org)
24. Promoting awareness of and support for dementia for people from Black, Asian and minority ethnic populations, England

Where: Bradford, England

Who is involved: Bradford & District Older People’s Alliance (BOPA).

Nature of activity: Individuals with dementia from Black, Asian and minority ethnic (BAME) populations are currently under-represented within services. This is due to lack of awareness among the BAME population regarding the nature of dementia, a lack of understanding in many health and social care services of the needs of BAME communities, and appropriate support and services being available. BAME communities are not homogeneous and so specialist knowledge is needed to work with ‘communities within communities’. The project received a special nomination by EFID. Their remit is to: (a) extend an ongoing project by delivering five further dementia awareness roadshows tailored to specific BAME groups; and (b) produce a culturally appropriate DVD to raise awareness.

Their activities included 5 community engagement road shows to raise awareness and reduce stigma in BAME communities, including a presentation on “how to live well with dementia”.

Website: www.bopabradford.org.uk
25. Dementia Support Stuttgart gGmbH, Germany

**Where:** Stuttgart, Germany

**Who is involved:** Core funding was secured for the organisation via the Eric and Griselotte Gradman Foundation in 2002.

**Nature of activity:** Dementia Support does practical research, project development, events, publications, symposia with the guiding principles of inclusion, self-determination and quality of life for people with dementia. It is committed to the genuine involvement and participation of people with dementia in its work to make communities more dementia-friendly, inclusive of people with dementia, and “overcome the purely medical idea of dementia as a deficit”.

**Website:** [http://www.demenz-support.de/home](http://www.demenz-support.de/home)
26. Generation Treff, Enger, Germany

**Where:** Enger, Germany

**Who is involved:** Generationen Treff Enger, a communication platform for community-oriented work with older people. In 2012 the Enger Alzheimer’s Counselling Centre won an EFID award.

**Nature of activity:** Learning with and from each other in order to deal with each other is what some of the senior experts intended for this project. This guiding principle set out to strengthen the various networks in the town of Enger and to offer young and older people the possibility of taking part in social development. This project enables people with dementia to actively participate in life and to come into contact with people without dementia. Such a project was only possible in the town of Enger with the support of the local community, its shopkeepers and the local authority. The programme offers help from senior experts for others wanting to build similar initiatives in their local area. It attempts to create a culture of cooperation and interaction among people with and without dementia in a project called “Dementia touches with many faces”.

27. Demen Talent (‘dementia skills’), Netherlands

**Where:** Netherlands

**Who is involved:** Care Innovation Agency DAZ coordinate and foster the nationwide rollout and 'guard' the concept. The philosophy behind this coordination is that local Demen Talent projects are independently run, supported by local organisations with local project management. The start of each project is supervised by DAZ, who work in cooperation with local organisations and people. In 2014 Demen Talent won an EFID award.

**Nature of activity:** Demen Talent aims to empower people with dementia. To focus on their strengths (or talents) and abilities, and use these strengths in society by putting in people with dementia as volunteers. This allows people with dementia to feel valuable and useful, which improves their emotional wellbeing. By making use of their talents this preserves the connection with society and they can continue to operate independently for longer.

Demen Talent projects, which are being rolled out across the Netherlands, recognise the skills of people with dementia and focus on what they can do rather than what they cannot do. The aim of any Demen Talent project is to support a cultural shift in attitudes towards dementia, which means that substantial out-of-the-box thinking and action is required.

The Zorggroep Apeldoorn e.o. is the first Demen Talent project initiated by Zorggroep Apeldoorn (a care group in the municipality of Appeldorn) and the Forestry Commission. Volunteers with dementia work outside in the woods, maintain the buildings and help to organise events. The protected environment, strong supervision and peer support are crucial to this.

**Website:** [http://www.dementalent.nl/](http://www.dementalent.nl/)

Very friendly website with lots of visuals that make it easier to look at. You can view several short films about the work of Demen Talent on the website (Dutch language only).
28. Dementia is Everyone’s Business – North Lanarkshire Partnership, Scotland

Where: Motherwell town centre, north Lanarkshire, Scotland

Who is involved: Alzheimer Scotland. In 2014 ‘Dementia is Everyone’s Business’ won an EFID award.

Nature of activity: Shops, businesses and organisations are committed to learn about dementia and to do simple, practical things that make an enormous difference to people with dementia, so as to help them remain a part of their community. The project proactively engages with shops and businesses and opens not just doors, but hearts and minds, and raises awareness of dementia, its impact on people, families and carers and the importance of citizenship and community connections.

Website: http://www.alzscot.org/dementia_friendly_communities

Where: Bradford and York, England

Who is involved: Joseph Rowntree Foundation.

Nature of activity: In September 2015 the Joseph Rowntree Foundation (JRF) published its evaluations of activity to develop York and Bradford as dementia-friendly cities. The evaluation used a framework based upon the JRF’s ‘Four Cornerstones’ model (place; people; resources; networks) for developing ‘dementia-friendly communities’; it involved online surveys and interviews with key local stakeholders (including people with dementia).

Key findings in the reports included that local approaches have encouragingly led to a range of small initiative springing up, influenced by people with dementia and carers, though it remains difficult to engage some smaller groups marginalised by economic, social or environmental situations. What most people want is the right to live as normal a life as possible for as long as possible. In the words of a participant with dementia at the York workshop: “People treat you differently after diagnosis even though you might not have changed”.

30. Dementia Services Development Centre – Scotland

**Where:** International (Scotland, the Netherlands, England)

**Who is involved:** The Dementia Services Development Centre (DSDC), is an international centre based at the University of Stirling and guided by an International Advisory Board.

**Nature of activity:** The Dementia Services Development Centre (DSDC) at Stirling University is world-renowned for its work on dementia-friendly design, environments and housing (see also Mitchell L 2012 in the literature review for dementia-friendly housing)\(^1\). In partnership, the Eindhoven University of Technology in the Netherlands brings in its knowledge on intelligent lighting systems which can improve the physical and mental wellbeing of people with dementia and their (informal) care providers and knowledge on how dementia lighting innovations can create sustainable business. Further, in collaboration, a guide on how to do dementia-friendly ‘access audits’ of buildings has been produced by an NGO in England, “Innovations in Dementia”.

At DSDC, which champions sharing of information and resources, an online Innovation Wall is hosted for anyone to register their ideas, simply sharing the aim of getting the best ideas which help people with dementia.

**Website:** [http://dementia.stir.ac.uk/](http://dementia.stir.ac.uk/).

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\(^1\) The literature review is in the appendices of the study “Mapping dementia-friendly communities across Europe”. The study is available on the EFID website [www.efid.info/resources](http://www.efid.info/resources)
31. A reminiscence promenade in Aalbeke, Belgium

Where: Aalbeke, Belgium

Who is involved: The project is run by OCMW Kortrijk. In 2014 the Aalbeke project won an EFID award.

Nature of activity: The project consists of four walks with reminiscence points on them, for people with dementia who are residents in the De Weister nursing home. The walks are open to anyone to take part, which is seen as encouraging intergenerational dialogue. The aim is for people with dementia to become part of local daily life. An educational programme is being organised so that people will understand the symptoms of dementia and the promenade. Four walks take place on slow roads with two or three stops where benches are available, and there is information about buildings or monuments nearby linked to events that happened in the past, so that people with dementia can relive that event and talk about it. The walks start and end at the nursing home, to encourage it to be more integrated into the local community. Work on accessibility for people with disabilities and families using buggies has included a wheelchair/buggy screening to identify bottlenecks such as narrow paths and the need to lower curbs. The promenade is built around four principles: reminiscence work; intergenerational work; improving mobility and accessibility; and integration into village life. The Aalbeke signs were made by local unemployed people wanting to develop more skills and contribute to the community.

Website: http://www.afeinnovnet.eu/news/%E2%80%9Cgo-back-time%E2%80%9D-reminiscence-promenade-belgium
32. Bistrot Mémoire, Rennes, France

Where: Rennes, France. There is also a network of Bistrot Mémoire across France.

Who is involved: Bistrot Mémoire Rennes was jointly developed by a group of institutions and volunteers. Later, a board of governors was appointed which included people with dementia as well as carers. The first Bistrot Mémoire was set up in Rennes in January 2004. Since then, the concept has been implemented in more than 50 communities in France. The national network of Bistrot Mémoire is supported by ‘L’Union Nationale des Bistrot Mémoire’ which was set up to promote the concept and encourage new Bistrots across France. In 2012 Bistrot Mémoire won an EFID award. The Jury stated that Bistrot Mémoire creates a special environment where people with dementia are able to express themselves whilst still being part of the community.

Nature of activity: The Bistrot Mémoire is located in a popular bistrot in the city and welcomes people with dementia and their carers once a week. In Rennes, some 25 people attend each week, including both professionals and volunteers. The Bistrot Mémoire is a place where people share feelings and experience and develop social ties. It is not an information centre, though information is available. The mission is to provide a pleasant location for people with dementia, develop tolerance, change the public’s views about dementia, support carers, prevent crises in the family network and change professional practice.

Website: http://bistrot-memoire.com/
33. Pact Ateliers (‘Artistic Forum’), Pacheco Institute, Belgium

**Where:** Brussels, Belgium

**Who is involved:** Under the auspices of Brussels volunteer bureau.

**Nature of activity:** The project develops artistic projects involving people of all ages but linked with a care institution. The aim is to promote cultural participation, social cohesion, social resistance and empowerment of older, more disabled people and the promotion of intergenerational collaboration. Workshops include batik, sewing, jewellery design, modelling, art therapy, theatre, graffiti, and screen printing and can be based upon experiences and memories of the institution focusing on people’s creativity and imagination, but also their political and social agency. The project is evolving into a collaboration with other care homes, schools, associations and community centres in Brussels.

**Website:** [http://www.vrijwilligerswerk.be/node/organisaties/2723](http://www.vrijwilligerswerk.be/node/organisaties/2723)
34. Dementia – Community Intervention, Greece

Where: Urban and remote rural areas and islands throughout Greece.

Who is involved: This programme is run by the Athens Association of Alzheimer’s Disease and Related Disorders in collaboration with the Association For Regional Development And Mental Health and CMT Prooptiki consultancy. It is funded by EEA Grants and the Bodossaki Foundation.

Nature of activity: This programme looks at raising awareness about dementia in the community. It is establishing 13 Consultancy Stations, 23 Memory Clinics and 16 Day Centres. In January 2016 an eLearning dementia awareness platform was launched. The programme is particularly sensitive at reaching patients in remote rural areas.

Website: http://dementia-community.gr/
(III) Building partnerships, networks, collaboration

The third essential factor in developing the so called ‘dementia-friendly communities’ involved building partnerships, networks and collaborations. Communities are made up of many different groups, organisations and services and clearly no one organisation can initiate the development process of a ‘dementia-friendly community’ on its own. Collaboration, both through formal and informal processes is essential.

In most countries where the study\(^2\) identified significant activity developing ‘dementia-friendly communities’, partnerships, networks and collaborations existed at regional, municipal or local levels, involving public services and officials (e.g. mayors), NGOs, businesses, public authorities, community groups, faith organisations, people living with dementia and their families. In some countries they also existed at a national level, most notably England, with its National Dementia Action Alliance. These partnerships had many functions including sharing information, learning and resources, monitoring progress and impact, supporting members and promoting ‘dementia-friendly communities’, and enabling community development and cohesion.

Examples of partnerships and networks included:

- Informal support networks of organisations
- Networks co-ordinated by a dedicated team or individual
- Formal stakeholder steering groups or governing bodies

The rest of this section of the mapping lists all ‘dementia-friendly community’ projects that were found across Europe, that come under the heading of building partnerships, networks and collaborations.

\(^2\) The study « Mapping dementia-friendly communities across Europe » is available on the website www.efid.info/resources
35. Dementia action alliances - England, Germany

Where: The below activities in England and Germany are examples of Dementia Action Alliances. There are a number of other European countries that have both local and national Dementia Action Alliances – non-inclusion in the mapping is not a reflection on the quality of these organisations or their work.

Who is involved: In England the National Dementia Action Alliance is supported by a Secretariat funded through voluntary financial and in kind contributions from members. It is hosted by the Alzheimer’s Society and works according to the programme agreed by the whole membership and people living with dementia and their carers who attend their sessions.

In Germany, the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth, and the Federal Ministry of Health, plus representatives of the countries, associations and organisations, who are responsible for people with dementia at the federal level, such as the German Alzheimer Association - self-help Dementia - the German Nursing Council and the German Medical Association.

Nature of activity: In England, the National Dementia Action Alliance (DAA) is working towards bringing about a society-wide response to dementia. At a national level the DAA has begun to shape policy and attitudes. Locally they galvanise action by coordinating and supporting Local Dementia Action Alliances. There are local DAAs across England and you can access information about them and links to the local websites via the main DAA website.

In Germany, on the occasion of World Alzheimer’s Day on 21th September 2012 a new ‘Allianz für Menschen mit Demenz’ (‘Alliance for People with Dementia’) was founded by the German governments in partnership with the German Alzheimer Association, Deutsche Alzheimer Gesellschaft (DALZG), as a central component of the demographic strategy of the government. The aim is to develop tools to benefit people living with dementia and to raise awareness in order to counteract social exclusion. As well as the national alliance, 26 local alliances have been launched in multigenerational houses – financed by the national government. By 2016, 500 of these nationwide local networks will develop. In September 2014 the Alliance launched an agenda to implement the foundation of a national dementia strategy for Germany.

Website: [http://www.dementiacao#ln action.org.uk/](http://www.dementiaaction.org.uk/) And [http://www.allianz-fuer-demen#ln.de](http://www.allianz-fuer-demenz.de)

Where: United Kingdom

Who is involved: The guidance was developed in conjunction with the Alzheimer’s Society and the Department of Health. It had collaborative input from organisations including Age UK, the Dementia Action Alliance (DAA) and Public Health England, and included input from people with dementia and their carers. One of the members of the Steering Group was a person living with dementia.

Nature of activity: BSI is a national and international standards organisation. It has produced a national standard to support the recognition process for ‘dementia-friendly communities’. Publicly Available Specification (PAS) 1365 will support the continuous development of communities in accordance with the behaviours and characteristics defined by the Alzheimer’s Society. The PAS covers who should be involved, how to engage stakeholders, and areas of or action to develop a ‘dementia-friendly community’. It is aimed at local government, business, health and social care organisations, and NGOs. The development process included a public review where comments were received from a variety of organisations in the sector, including care homes for people living with dementia, carers’ associations and residential care organisations.

37. Aktion Demenz (‘Campaign Dementia’), Austria

Where: Vorarlberg, Austria

Who is involved: Connexia – Gesellschaft für Gesundheit und Pflege – gGmbH. In 2012 Campaign Dementia won an EFID award.

Nature of activity: Campaign Dementia aims to create conditions in Vorarlberg that enable people with dementia to participate in public and social life. They support communities that wish to create a friendlier environment for people with dementia and their families. Twenty-three example or model ‘dementia-friendly communities’ (out of 96 possible districts, and almost 60% of the inhabitants of Vorarlberg) have joined them since 2008. Countrywide, they also want to sensitise the general public and increase awareness of dementia by informing (e.g. through press relations and conferences, brochures, events, movies, art exhibitions, lessons in schools and kindergarten) and educating (e.g. neighbourhood assistants, policemen, salespeople, bus drivers, bank employees).

In Bludenz, for example, the city has made health a priority and Dementia Action complements this. There is a recognition that people with and without dementia encounter one another on a daily basis whether in the family, in the supermarket, on the street, in the neighborhood, or in public institutions. The aim is to draw up a joint project to develop a dementia-friendly city, with the involvement of people with dementia, professional experts, policymakers and civic volunteers.

Website: http://www.aktion-demenz.at/modellgemeinden-vorarlberg.html

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38. Together for a dementia-friendly Bruges, Belgium

**Where:** Bruges, Belgium

**Who is involved:** Foton, the Centre of Expertise for Dementia, leads and coordinates the project. They work in partnership with SEL North West Flanders primary health care cooperation initiative; the consultation platform for dementia, an open and pluralistic dialogue forum; and the City of Bruges. In 2012 Together for a dementia-friendly Bruges won an EFID award.

**Nature of activity:** The aim is to create a dementia-friendly Bruges. This comprises a wide range of activities including working with partners across health and social care and the local business community to raise awareness of dementia. One of the aims has been to make dementia visible in the city, and this can be reflected by merchants and others showing the red knotted handkerchief logo in their windows. Merchants doing this show their solidarity with people with dementia and their family members. The logo indicates: dementia can be discussed here and you will receive good help. In September 2015 the Bruges Concert Hall was presented with the Solidarity logo of the knotted handkerchief in recognition of its commitment and efforts to create a vibrant art and dementia-friendly place.

The ‘dementia-friendly Bruges’ website contains a wealth of information about all of the activities that are taking place in Bruges and beyond, including information about films (e.g. ‘Still Alice’ and ‘Do Not Forget Me’) and about a golden gnome award presented to an innovative project bringing together many organisations to create comprehensive care for early onset dementia. Further, in March 2015 the Golden Falcon Seagull Theatre festival included an inspiring play about the role of laughter in alleviating the misery of loss.

**Website:** [www.dementievriendelijkbrugge.be](http://www.dementievriendelijkbrugge.be)
39. ‘Continue taking part in community life through Dementia’, Germany

**Where:** Germany

**Who is involved:** Nachbarschaftliche Unterstützung und Zeitvorsorge (NUZ) e.V. (‘Neighbourly Assistance and Time Pension’), Germany. In 2014 the ‘Continue taking part in community life through dementia’ initiative won an EFID award.

**Nature of activity:** The community is stimulated through public awareness and political activism. Regular meetings and joint actions are organised to enable a space for networking of the boroughs with the professional service providers. The aim of the project is to enable people with dementia to remain in their homes for as long as possible. People with dementia and their family carers are supported through neighbourhood assistance, organised and implemented by the Association of NUZ. Moreover, training and support are provided to citizens who are willing to engage themselves in the neighbourhood assistance on a voluntary basis and against time credit, especially for people with dementia. Time credits are a creative way of rewarding people for giving up time to support the local community. For every hour that a person gives, they are given a time credit that can be redeemed against a variety of public services and activities such as sports or leisure, provided that the organisation is part of the scheme. Time credits recognise the time that individuals give to support the local community and aims to encourage more people to get involved and give their time.

**40. Arnsberger dementia ‘learning workshop’, Germany**

**Where:** City of Arnsberg, Germany

**Who is involved:** the Special Department for Future and Old Age, plus professional and civil society services supporting people with dementia. In 2014 the ‘learning workshop’ won an EFID award.

**Nature of activity:** Arnsberg addresses the challenges of demographic change with its concept ‘Living a Long and Good life in Arnsberg’. This includes bringing services supporting people with dementia together in the ‘Arnsberger Dementia Learning Workshop’ to create a tight-knit support network for people with dementia and their environment. This involves establishing networks of professionals (medicine, nursing, etc.) and civil society partners (kindergartens, schools, cultural and economic institutions, etc.) who share the aim of improving the quality of life of people with dementia and their relatives. The main focus is on projects to connect generations, generate ideas, raise awareness, network, develop support and promote projects.

In 2011 a manual was published which reports on the experience of more than three years working on the ‘learning workshop’ pilot project together. It is aimed at decision makers and practitioners from cities and towns, as well as civil society initiatives. You can access the handbook from the online version of this mapping paper at [www.efid.info/resources](http://www.efid.info/resources).

**Website:** [http://www.projekt-demenz-arnsberg.de/](http://www.projekt-demenz-arnsberg.de/)
41. Living Well with Dementia Stillorgan-Blackrock, Ireland

Where: Blackrock, Co. Dublin, Republic of Ireland

Who is involved: Each project is comprised of a consortium of people and organisations. It is supported by Genio Trust.

Nature of activity: Living well with Dementia Stillorgan-Blackrock is one of four pilot projects that are developing new services and supports to people affected by dementia. These projects, representing four different geographical locations, are working to identify, mobilise and develop community-based supports with the aim of enabling people with dementia to remain at home living full lives. The other projects are in Cork, Tipperary and Mayo.

Living Well with Dementia is a community-based project supported by the Health Services Executive. As well as activities such as community support, advice and information, training for carers, the project includes public awareness information events, education in schools and the retail sector, and people with dementia participating and re-connected with social activities in their community (e.g. choirs, physical activities, golf, playing cards, creative writing etc). The project’s vision “is of a community that respects, supports and empowers people with dementia, a community in which people with dementia are culturally & socially valued, a community where people with dementia actively participate in a safe environment”.

Website: [http://livingwellwithdementia.ie/about-us/](http://livingwellwithdementia.ie/about-us/)
42. The PG-raad [Programme Council Care Renewal in Psychogeriatrics], The Netherlands

Where: The Netherlands, Germany, Belgium

Who is involved: Municipalities in Brabant in collaboration with Flanders, Belgium, and Limburg, Germany.

Nature of activity: The PG-raad started in 2012 through inter-regional collaboration, creating and supporting four local networks in Brabant, in the lead municipalities, to create dementia-friendly municipalities. A lead municipality starts by forming a local network consisting of a group of stakeholders that is as diverse as possible. With the lead municipalities of Brabant, the PG-raad has signed a declaration of intent in which the role and the tasks of the municipality in the project are described. These lead municipality networks receive support and project guidance from the PG-raad over four years consisting of:
  • Support in setting up the local network Dementia-friendly municipality (DVG network).
  • Project guidance and advice in developing plans.
  • Offering substantive expertise in the development of trailblazer actions.
  • Input of expertise from other provincial networks

Website: http://dementievriendelijk.nl/bladel/
43. West Dunbartonshire Partnership, Scotland

Where: West Dunbartonshire, Scotland

Who is involved: West Dunbartonshire CVS, West Dunbartonshire Community Health and Care Partnership, Scottish Care, West Dunbartonshire Council and RNIB.

Nature of activity: The Partnership has developed a local Dementia Strategy; with commitments for the creation of Dementia-friendly West Dunbartonshire (WD) as well as supporting the development of neighbourhood services to meet the needs of all citizens locally including those with a diagnosis of dementia. This has begun with specific work within its 22 identifiable neighbourhoods. WD is working with local schools and nurseries to create unique identifiers and branding for each area. They are using ‘Promoting Excellence’ as their preferred education approach to create and deliver cultural and behavioural change within each community to the benefit of those with dementia. They are evaluating progress using the ‘Individual, Social and Material’ tool (ISM) and taking pledges from each participant which lays out their commitment to make professional and personal change to their practice.

The longer term aims of the ‘Dementia-friendly Community’ initiative are to: build general dementia awareness in the community; develop a Dementia-friendly shopping area involving local traders and retailers; establish a network of Dementia Awareness trainers throughout the statutory, private and third sector partners in the area; and support individuals and organisations to pledge service improvements and enhancements which could improve the quality of life for those living in the area.

Website: http://www.wdhscp.org.uk/mental-health-services-for-cyp-adults/dementia-friendly-west-dunbartonshire/
44. Muistillitto: Influencing and inclusion, Finland

**Where:** Finland

**Who is involved:** The Alzheimer Society of Finland in partnership with public, private and third sector actors.

**Nature of activity:** The Alzheimer Society of Finland described their work to develop a memory friendly Finland. The organisation coordinates the involvement of NGOs, statutory service and private businesses in developing DFCs, while providing guidance and support to encourage the involvement of these community groups.

Guidance and support is delivered via the Society’s Intranet in the form of slideshows, checklists, letterforms, a range of guidance documents and ideas for workshops. The National Memory Programme committee has proposed actions for communities to become dementia-friendly. These proposed actions were collated to develop tools to support collaborators in checking aspects of their programmes and identify where their work links in with third/other sectors, in line with good practices gleaned from dementia care.

Crucially, The Alzheimer Society of Finland has developed and continues to support a working group made up of about 10 individuals who are living with dementia and family carers. This working group meets on a bi-annual basis to voice their opinions in public forums - the opinions of the working group are sought in relation to issues highlighted by national and local associations, advising on national decision-making and planning the Society’s Memory Magazine and local action plans.

This influencing and involvement work has thus far culminated in a reformed Bill of Rights and a reformed workbook for good quality care and practices, which supports service providers’ ongoing development of knowledge and competence in providing supportive care.

45. Wicklow Dementia-friendly, Ireland

**Where:** Co. Wicklow, Ireland

**Who is involved:** Co. Wicklow Network for Older People. Membership of the Network is open to groups, organisations and individuals committed to improving the quality of life of older people.

**Nature of activity:** Co. Wicklow Network for Older People was set up in 2007 to give older people in Co. Wicklow a voice in decision-making processes at local, regional and national levels. By creating a dementia-friendly Wicklow, this project aims to remove the barriers people face around the lack of knowledge within communities through targeted awareness raising activities. An extensive, countywide programme of educational workshops for retailers, doctors, Active Retirement Associations and Citizen Information Centres has been delivered. Awareness workshops have also been delivered to the police (Gardai). The project has also developed a number of useful resources for businesses, Gardai, emergency service providers, libraries and financial services. The project is also working towards creating a dementia strategy for the county involving key stakeholders and mapping services available to people currently. A booklet outlining services and supports for people with dementia in the community was developed in partnership with one of the local Citizen Information Centres.

County Wicklow is one of several counties across Ireland that are involved with the Alzheimer’s Society of Ireland’s ‘dementia-friendly communities’ initiative (see: [http://www.alzheimer.ie/Get-Involved/Dementia-Friendly-Communities.aspx](http://www.alzheimer.ie/Get-Involved/Dementia-Friendly-Communities.aspx)). The other counties and areas with ‘dementia-friendly communities’ initiatives are Galway, Ballina Killaloe, County Mayo, Boithrin na Smaointe, Kilkenny and Mallow in County Cork. This mapping also includes an entry about the Crystal Project in Mallow (case study n. 48).

Most importantly, Wicklow Dementia-friendly aims at looking at ways in which communities – neighbours, friends, everyday service providers – can support people with dementia to carry on, as normally as they can, for as long as possible.

**Website:** [www.wicklowdementiafriendly.ie](http://www.wicklowdementiafriendly.ie)
46. Dementia-friendly Brecon, Wales

**Where:** Brecon, south Wales

**Who is involved:** In June 2013, a group of like-minded individuals, with Brecon Town Council and Alzheimer’s Society, held a public meeting which explored the idea of making Brecon a ‘dementia-friendly community’. A community-led steering group, made up of carers, committed individuals, health and social care professionals and a range of other community and voluntary organisations, was constituted as a not-for-profit organisation by April 2014, enabling them to enrol members and raise funds. At the same time they established a local Brecon Dementia Action Alliance bringing together regional and local members to improve the lives of people with dementia. This currently (November 2015) includes Brecon Medical Practice, Powys Health Board, Brecon Library Service, Dyfed-Powys Police, Brecon Mountain Rescue, Brecon Beacons National Park Authority, the local Fire Service, Barclays Bank, Lloyds Bank, a local mental health NGO (Mind) and Brecon Theatre.

**Nature of activity:** The mission of this partnership is to create a social movement that mobilizes all sections of the community. They want to challenge the myths and stigma around dementia, increase awareness and understanding, support and promote social inclusion, and most importantly give a voice to people with dementia and their carers so their needs can be fully recognized and the appropriate support offered.

**Website:** [http://www.dementiafriendlybrecon.org.uk/](http://www.dementiafriendlybrecon.org.uk/)
47. A more dementia-friendly society, Norway

Where: Oslo and other cities, Norway

Who is involved: The National Association for Public Health.

Nature of activity: The Norwegian National Association for Public Health is spearheading a campaign to make Norway a more dementia-friendly society. They already have several municipalities signed up to participate in the campaign and several more that are considering becoming part of the campaign.

In the municipality of Moss, Berit runs a jewellery store and cares after her mother who has dementia. Berit appreciates the importance of dementia-awareness training. She occasionally has old customers, now living with dementia walking into her store and asking for her – most often it is about “showing them the way to the groceries”. Above all, this initiative campaigns to fight ignorance.

Website: http://nasjonalforeningen.no/tilbud/demensvennlig-samfunn/
48. ‘How can I help you?’ Creating a dementia-friendly community through support and empowerment in Mallow, Ireland

**Where:** Mallow, Ireland

**Who is involved:** The Crystal Project is led by the Health Service Executive North Cork Occupational Therapy Service. It involves collaboration between the Health Service Executive, The Alzheimer Society of Ireland, The Carers Association, families affected by dementia, University College Cork, local community groups and General Practitioners. The Project won an EFID award in 2014.

**Nature of activity:** The aim of this project is to create a ‘dementia-friendly community’ in Mallow by providing support for staff of local businesses, schools, and healthcare professionals etc., to be aware of the needs of those affected by dementia. Through awareness campaigns, dementia champions support programmes, and open access to the Memory Resource Room, the public will be better placed to understand the needs of those affected by dementia.

The project has created a Memory Resource Room, decorated with homely furniture and providing a calm environment for people concerned about their memory to discuss sensitive issues.

**Website:** [http://www.crystalproject.ie/](http://www.crystalproject.ie/)
49. Age Friendly Dublin City University (DCU) / Dementia Elevator, Republic of Ireland

Where: Dublin, Republic of Ireland

Who is involved: Dublin City University (DCU) and the Health and Safety Executive (HSE). The initiative has the backing of Alzheimer’s Society Ireland and is supported by Atlantic Philanthropies.

Nature of activity: ‘Dementia Elevator’ is an education and empowerment programme developed by DCU and the HSE to help individuals, communities and health systems engage appropriately with people with dementia. Elevator focuses on ability (rather than disability) and takes a person-centred approach to dementia care. The main aims of the programme are to improve quality of life and achieve ageing in place for people with dementia, by providing the right supports and skills within local communities.

‘Dementia Elevator’ is taking place in the context of an age-friendly university. In 2012 Dublin City University became the first third-level institution to adopt the concept and principles of an Age-Friendly University. Dublin City University has scrutinised its campus to make the environment more dementia-friendly and commenced a communication strategy to see how staff and the student body are affected by dementia and what can be done to make life easier. It runs a public facing clinic called ‘memory works’ designed to help people make sense of their memory problems and cope better with the impact of these on their lives. In the autumn of 2015 the University hosted the first international age-friendly universities conference in collaboration with their international partners, Arizona State University and Strathclyde University.

A ‘DCU Elevator Award for Innovation in Dementia’ was established by the Dementia Elevator programme at DCU to highlight initiatives from around the country that contribute in a meaningful and significant way to the everyday lives of people with by dementia. The first winner of this award was a community choir set up in Naas for people with dementia and their carers. The winning proposal was developed by Kildare Liaison and Social Service (KLASS) in response to feedback from carers about the growing demands placed upon them and the associated physical and mental health impact. The KLASS community choir aims to provide social support for carers, not just amongst their peers, but also from a team of interested, volunteering professionals. It offers an enjoyable, creative and fun activity for both carers and the individuals with dementia they care for, while simultaneously offering support activities specifically aimed at carers. An award of €1000 will now allow KLASS to develop their idea.

The Elevator project works closely with dementia-friendly counties to develop and disseminate training to where it is most required. “Fear and stigma are the biggest barriers.”

Website: Dementia Elevator [http://dementiaelevator.ie/](http://dementiaelevator.ie/)
Useful resources

- Alzheimer’s Disease International website: [www.alz.co.uk](http://www.alz.co.uk)
- Alzheimer’s Society website: [www.alzheimers.org.uk](http://www.alzheimers.org.uk)
- Alzheimer’s Research UK website: [www.alzheimersresearchuk.org](http://www.alzheimersresearchuk.org)
- Alzheimer’s Europe website: [www.alzheimer-europe.org](http://www.alzheimer-europe.org)
- European Foundations’ Initiative on Dementia (EFID) – [www.efid.info](http://www.efid.info)