

The background of the cover is a solid blue field with several large, white, five-pointed stars scattered across it, mimicking the design of the European Union flag.

# Dementia in Europe Yearbook 2015

“Is Europe becoming  
more dementia friendly?”





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# 1. Foreword



It gives me great pleasure to present this comparative report on dementia-friendly communities (DFCs). This report is about communities and initiatives that are working towards becoming more friendly and inclusive of people with dementia.

dwellings, transportation, businesses and services that are part of the day-to-day living of most citizens, museums, cinemas, theatres and any other sector of the community, that are better adapted to the needs of people with dementia and where they can feel respected and valued. Key aspects of this work towards becoming dementia friendly include tackling the stigma of dementia and promoting a greater involvement of people with dementia in society.

The concept of DFCs has been recently introduced in dementia research and practice and has rapidly attracted attention from local and national governments, Alzheimer’s organisations and academics in Europe. This report shows evidence of several countries that are using different approaches in their work but that share the same common goal of ensuring that people with dementia can live meaningful lives and that they feel respected, treated with dignity, safe and included as much as they wish in their communities.

The report is based on information provided and reviewed by Alzheimer Europe’s member associations, to whom we are immensely grateful. Some external experts, from countries where Alzheimer Europe has no member, also helped compile the information. For the first time, the European Working Group of People with Dementia has also been involved in the development of the report. Their testimonies provide a powerful insight into how people with dementia would like to see communities, villages, cities and countries become more inclusive and dementia-friendly. The names of all those who made it possible to produce the report are acknowledged at the back of the publication. However, I would like to single out the outstanding contribution of Ana Diaz, Project Officer of Alzheimer Europe, who coordinated the data collection and developed this comparative report.

The report shows the work of several countries in Europe where the concept of DFCs is in the process of becoming part of the everyday lives of people with dementia. The concept of whole communities becoming dementia friendly has not yet been developed everywhere in Europe. This absence should, however, not be interpreted as if these countries are not undertaking major efforts to provide appropriate support and care, to improve the quality of life, and to involve people with dementia as much as possible in the community.

We hope that the report will help readers to better understand the potential of this new concept as well as the work that still needs to be done to make sure that people with dementia are an integral part of our lives and societies. We hope that it can provide the basis for further discussion and development of dementia-friendly communities throughout Europe.

Building on the framework developed by the World Health Organisation to create age-friendly cities, the report also looks at other ways in which European countries in Europe are working to be more inclusive and to promote the participation of people with dementia in the wider community.

**Jean Georges**  
*Executive Director*  
Alzheimer Europe

The report provides information about national policies and practices that aim to create physical environments, home





## 2. Introduction

### 2.1 Background to the report

This comparative report on dementia-friendly communities has been produced as part of the 2015 Work Plan of Alzheimer Europe, which has received funding from the European Union in the framework of the Health Programme.

Decisions about the broad areas to be addressed were informed by a literature review on the topic. Agreement on the specific sections to be included for each area was reached at a meeting with 15 Alzheimer Europe (AE) member associations at the beginning of 2015. Based on this, a questionnaire was drafted and later reviewed by four members of the group. The questionnaire was also presented to the Executive of the European Working Group of People with Dementia (EWGPWD)<sup>1</sup> and their comments and suggestions were incorporated into the questionnaire. The questionnaire was sent out to all AE members. In addition, in countries where AE has no member (i.e. Estonia, Hungary, Latvia and Lithuania), relevant informants were identified and invited to participate.

33 organisations representing 31 countries returned the questionnaires<sup>2</sup> (see Table 1). Questionnaires were completed by the national organisation and, whenever necessary, with the aid of relevant national experts in the field of social policy, law and social support<sup>3</sup>. Organisations were contacted again when necessary to clarify certain issues and information was transferred into a database and analysed. The final report was sent to all participating organisations for final approval prior to publication.

In addition to this, members of the EWGPWD were invited to share their experiences with and views on each of the topics addressed in the report by providing a short written testimonial (“personal accounts”). These personal accounts provide a powerful insight into how people with dementia would like to see communities, villages, cities and countries become more dementia inclusive and dementia friendly. Personal experiences provided by members of the EWGPWD are presented at the end of each section.

Table 1: Participating countries

EU Member States			Non-EU Member States
Austria	Germany	Poland	Jersey
Belgium (Flanders & Wallonia-Brussels)	Greece	Portugal	Monaco
Bulgaria	Ireland	Romania	Norway
Croatia	Italy	Slovenia	Switzerland
Cyprus	Latvia	Slovakia	Turkey
Czech Republic	Lithuania	Spain	
Denmark	Luxembourg	Sweden	
Finland	Malta	UK (England, Northern Ireland, Scotland, Wales)	
France	Netherlands		

<sup>1</sup> In 2012, Alzheimer Europe set up the European Working Group of People with Dementia (EWGPWD), comprised of people with different forms of dementia and of different ages and nationalities, to advise the board of Alzheimer Europe and to participate in all activities and projects organised by Europe Alzheimer. The executive is composed of the chair and three vice-chairs.

<sup>2</sup> In the case of the UK, separate questionnaires were received for Scotland (Alzheimer Scotland) and the rest of the UK (Alzheimer's Society). In some cases, different answers were provided for England, Wales and Northern Ireland (NI). The reader is informed when the information applies to the whole of the UK or only to certain parts of the UK (i.e. England, NI, Scotland, Wales). In the case of Belgium, the questionnaire was sent to the AE member “Ligue Alzheimer asbl”. Two different questionnaires were received, one with reference to Wallonia and Brussels and another for Flanders. The reader is informed when the information applies to the whole of Belgium or only to certain parts (i.e. Flanders or Wallonia and Brussels).

<sup>3</sup> Please see the acknowledgements section of this report for further details of participants.

## 2.2 Relevance of the topic and layout of the report

This comparative report looks at the development of dementia-friendly environments for people with dementia. The concept “dementia-friendly communities” (DFCs) has developed rapidly in some parts of Europe, and there are now examples of towns, cities, counties and organisations that are working towards becoming dementia friendly. As the concept is relatively new, there is currently no authoritative definition of what DFCs are (Prior, 2012). A definition put forward by the Alzheimer Society of Ireland suggests that “the initiative is about transforming our villages, towns, cities and counties into better places to live for people with dementia. The overall vision is to reconfigure the communities that we all live in and mainstream dementia into the everyday life of the community”.

The first part of this report addresses key aspects of the conceptual development of the term DFC in Europe. It provides

an overview of how DFCs are implemented and monitored and offers examples of DFCs in different countries.

The concept of whole communities becoming dementia friendly has not yet been introduced everywhere in Europe. The second part of the report builds on the framework developed by the World Health Organisation (WHO, 2007). The framework identifies eight interconnected core elements of an age-friendly city that influence the health and quality of life for older adults, namely outdoor spaces and buildings, transportation, housing, social participation, respect and social inclusion, civic participation and employment, communication and information, and community support and health services. Drawing on this framework, and adapting it where necessary for people with dementia, the second part of the report provides information on national policies and notable practices in Europe addressing the core principles that underpin the framework.





# 3. Dementia-friendly communities in Europe

## 3.1. Background to the term

The term dementia-friendly communities (DFCs) has emerged in recent years. According to Mitchell, it reflects “a growing movement to remind society that people with dementia have the same right as everyone else to be treated with dignity and respect, to lead independent, autonomous lives and to continue to be active citizens in society whose opinions are heard and acted upon” (2012:1). The work towards building dementia-friendly communities also builds on the “Age-Friendly Cities” movement, that has been largely developed by the World Health Organisation (WHO) and which aims at creating environments that are accessible and inclusive of the needs of people of all ages.

Defining the concept as it applies to dementia may be problematic due to the lack of literature on the topic and the outwardly diverse ways in which the idea has been used (Prior, 2012). Whilst recent work has brought some light into this, these reports have mostly been written and based on the experiences of developing DFCs in the UK.

The report “Dementia Capable Communities: the views of people with dementia and their supporters”, provides evidence supporting the concept of DFCs. In this piece of work, carried out by Innovations in Dementia in 2011, people with dementia were involved in the conceptualisation of the term. The report highlighted five aspects of community life that people with dementia identified as important to them (the physical environment, local facilities, support services, social networks and local groups), and suggested four main actions needed to become dementia friendly, namely: improve awareness of dementia, support local groups for people with dementia and carers, provide accessible information about local services and facilities, and think about how local mainstream services and facilities can be made more accessible for people with dementia.

Some other key reports that have been produced in recent years include “Knowing the Foundations of Dementia-Friendly Communities for the North East” (Prior, 2012) and “Creating a Dementia-Friendly York” (Crampton et al., 2012). These reports underline that DFCs should aim at reducing stigma, increasing understanding and awareness about dementia, and supporting people with dementia to remain active, included and independent. In its report, the Joseph Rowntree Foundation proposed a model for realising a dementia-friendly community: “The Four Cornerstone

Model”. This model emphasises that the voices of people with dementia should be at the heart of dementia-friendly communities, and sets out four main structural supports or “cornerstones” that underpin a dementia-friendly community, namely:

1. **Place** (e.g. housing, transport and outdoors),
2. **People** (e.g. what do people in the community know, think and feel about dementia? Do they have a positive and supportive attitude towards people with dementia?),
3. **Resources** (e.g. what are the city’s resources and how dementia friendly are they? This means thinking beyond health, social care and other public sector services to the shops, businesses, facilities and assets that the whole city offers),
4. **Networks** (e.g. this relates to the way people work together to support people with dementia).

The report “Building dementia-friendly communities: A priority for everyone” (Alzheimer’s Society, 2013) is another example of the body of literature that has developed in recent years addressing this topic. Overall, the report aims to provide guidance to geographical areas that are planning to become dementia friendly or that are already committed to becoming dementia friendly. The report showcased examples of projects that were making a difference for people with dementia in the UK. In the report, key areas in which communities working to become dementia friendly should focus are identified. These areas include: involvement of people with dementia; challenge stigma and build understanding; accessible community activities, acknowledge potential; ensure an early diagnosis; practical support to enable engagement in community life; community-based solutions; consistent and reliable travel options; easy-to-navigate environments, respectful and responsive businesses and services.

Most recently, the British Standards Institution (UK’s National Standards Body) published the “Code of practice for the recognition of dementia-friendly communities in England” (2015). The guidance has been developed in conjunction with Alzheimer’s Society and the Department of Health. It provides recommendations for who should be involved in developing a dementia-friendly community, what areas of a community to consider and what changes to expect as a result. DFCs are defined as:

*“geographic areas where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia-friendly community people are aware of and understand dementia, and people with dementia feel included and involved, and have choice and control over their day-to-day lives. A dementia-friendly community is made up of individuals, businesses, organisations, services, and faith communities that support the needs of people with dementia” (2015:10).*

Finally, Alzheimer Disease International (ADI) produced in 2015 a booklet entitled “Dementia-Friendly Communities: New domains and global examples”, this booklet provides some examples of good practices worldwide. In the booklet, two new emerging domains were identified: “support for carers and the empowerment and equipping of faith-based communities to carry out the important work of nurturing the spiritual health of persons with dementia” (2015:10).

In a nutshell, this new concept that has emerged in the dementia landscape seems to reflect a shift from understanding dementia as a medical condition to a broader conceptualisation of the term. It can be regarded as a manifestation of the social model of understanding dementia in practice (Mental Health Foundation, 2015). This way of understanding dementia goes beyond the responsibility of health and social care services and professionals, and incorporates the whole community (Joseph Rowntree Foundation, 2012). DFCs are not about getting people with dementia to “fit in”, but about the coming together of communities and adapting and developing the environments where people with dementia live, to be more responsive and inclusive (Mental Health Foundation, 2015). It aims to challenge the stigma, inequalities and isolation often associated with living with dementia, so that people with dementia are no longer considered special or unengaged, but as having an active role in their communities and being included in mainstream everyday life.

### 3.2 National policies addressing the development of DFCs

At a European level, work towards becoming dementia friendly can be seen as building on several policies and legislation such as the EU Directives on non-discrimination and equality, the Charter of Fundamental Rights of the European Union, and other international texts such as the United Nations Convention on the Rights of Persons with Disabilities. At a national level, similar policies and legislation are available in many European countries, as for example the Equality Acts, or countries that have signed and ratified the UN Convention on the Rights of Persons with Disabilities.

The development of DFCs is addressed in some national dementia strategies in Europe. In the UK (England), the Prime Minister’s Challenge on Dementia (2012) committed to make communities in England more dementia friendly. The initial ambition was to have 20 cities, towns and villages in England, signed up to become dementia friendly by 2015. Now a key aspiration is to see by 2020 “over half of people living in areas that have been recognised as dementia-friendly communities, according to the guidance developed by Alzheimer’s Society working with the British Standards Institute. Each area should be working towards the highest level of achievement under these standards, with a clear national recognition process to reward their progress when they achieve this” (Prime Minister’s Challenge on Dementia 2020).

The Irish national dementia strategy acknowledges the work towards becoming more age and dementia friendly that has been developed in the country, and emphasises

the need for a “whole community response” to dementia, with health and social care services as only one part of the whole package of support that people with dementia need. Communities are key to ensuring that staying at home with dementia is a feasible option.

The Scottish Government, has noted as a key outcome for their current national dementia strategy (2013–2016) the importance of dementia-enabled and dementia-friendly local communities that contribute to greater awareness of dementia and reduce stigma. Supporting dementia-friendly local communities is central for creating and sustaining a society where people with dementia feel included and at the heart of the community.

One of the objectives of the Maltese national dementia strategy is to develop continuing information and educational campaigns targeting different groups in the community. It is stated that the ultimate aim of these campaigns will be to create dementia-friendly communities.

Finally, the Luxembourg Dementia Plan highlights the stigma associated with dementia and the social exclusion that some people with dementia may experience. One of the measures proposed is to promote the social participation and inclusion of people with dementia and their families in the community. To achieve this, public awareness and educational campaigns, and specific actions that could promote a more active participation of people with dementia, are planned.

### 3.3 The DFC movement in Europe

Organisations from seven countries (Austria, Belgium, Germany, Ireland, Netherlands, Norway, UK) described examples of DFCs in their countries, and according to them this concept is largely used in their country.

Some countries (Denmark, Jersey, Finland, Switzerland) are currently working towards introducing and developing this concept in the country. In Denmark, the Dementia Alliance, is a partnership between the Danish Alzheimer association, the national organisation for older people, two trade unions and the pension foundation. This Alliance is leading the work to develop and implement the concept in the country. Six municipalities in Denmark are currently working towards becoming dementia friendly. In Jersey, the Alzheimer association is leading the work and is compiling information on best practices around the world. In Finland, some examples of DFCs exist, nevertheless this work has not been developed in a coordinated way throughout the country. The province of North-Karelia, supported by the Alzheimer Society of Finland and in collaboration with local authorities and local educational institutions, is working towards becoming a dementia-friendly province. Some similar work has been carried out in Switzerland, where there are some single initiatives of cities and towns that are working towards becoming dementia friendly. This work has been mostly led by the Swiss Alzheimer’s Association and draws on the principles developed by Peter Prior in the UK. The association has published a

brochure entitled “People with dementia: our fellow citizens” and a factsheet on dementia-friendly communities. These publications have been distributed among the 2,324 Swiss communities (local authorities) in Switzerland.

In Malta and Luxembourg, the development of DFCs in the country is encouraged in their national dementia strategies, but the work has not yet fully started.

The initiative “Ayuntamientos Solidarios” (solidarity with people with dementia) is a similar idea that has been developed in Spain. To date, some 398 local authorities have supported this initiative, which was started by CEFA in 2012 (the Spanish federation of associations of families of people with Alzheimer’s disease and other dementias) and is calling for a coordinated national dementia strategy. Local authorities supporting this initiative are invited to support the call for a national strategy, raise awareness about dementia, provide information and training to carers and support the work of the local Alzheimer associations.

More than half of the participating organisations reported that the concept of DFCs is not used in their country or that it has been introduced very recently (Bulgaria, Cyprus, Croatia, Czech Republic, France, Greece, Italy, Latvia, Lithuania, Monaco, Poland, Portugal, Romania, Slovakia, Slovenia, Sweden, Turkey).

### 3.4 Definitions

Countries where DFCs have been developed, were asked to provide a definition of the term as it applies to their country.

Based on the definitions provided, table 2 provides a summary of the main components of DFCs.

**Table 2: Main components of DFCs**

The whole community is involved and is committed to working together. Local networks.	Belgium, Ireland, UK (Scotland, Wales)
Raising awareness of dementia. Tackling stigma. Learning about dementia.	Belgium, Germany, Ireland, Malta, Norway, UK (England, Scotland)
Empowering people with dementia	Belgium, Ireland, UK (England, Scotland)
Active participation in the community, inclusion, contribution.	Belgium, Germany, Ireland, Malta, Norway, UK (England and Scotland)
Appropriate support and care	Belgium, Germany, Ireland, Norway
Respect	Belgium, UK (England, Scotland)
Quality of life, living life to the fullest, best life possible.	Belgium, Netherlands, UK (England, Scotland)

In keeping with existing literature, two main aspects were mentioned in almost all the definitions: the need to increase awareness of dementia that could help to change attitudes about dementia and tackle stigma; and the need to promote the active participation and inclusion of people with dementia in the wider community, so people with dementia can participate in the activities that are meaningful to them and stay as active members of the community. This highlights two different levels:

- the daily lives of people with dementia: so that they can live their lives to the fullest, enjoy a good quality of life, and remain as active and independent as possible

- the societal level: which involves the commitment of the whole society to tackle stigma and any other barriers that would hinder people with dementia to remain citizens in society, and active members of the community.

Other relevant aspects mentioned in the definitions include that priorities and activities should come from the community themselves, and the existence of partnerships between local authorities and community groups.

### 3.5 Who is leading the DFCs work?

In all countries, the Alzheimer organisations are leading the work or have had a wide influence in its development. In some countries, no single organisation is leading this work, and DFCs are the result of a collaborative effort between a number of organisations. For example, in Belgium (Flanders), the work has been led by the Association of Flemish Cities and Municipalities (Vereniging van Vlaamse Steden en Gemeenten), the King Baudouin Foundation (Koning Boudewijnstichting), Flemish Dementia Expertise Centre (Expertisecentrum Dementie Vlaanderen) and the Flemish Alzheimer’s Association (Alzheimer Liga Vlaanderen). In the Netherlands, the concept is being developed by the local chapters of Alzheimer Netherlands, the local municipalities and provincial government organisations. In the UK (Scotland), Alzheimer Scotland, the Dementia Services Development Centre at the University of Stirling, and the Life Changes Trust have all had a strong influence in its development.

According to the UK Alzheimer’s Society’s five year strategy “Delivering on Dementia” a major strategic priority for the organisation will be working to create dementia-friendly communities across England, Wales and Northern Ireland. The Society’s role in leading this work was announced on 2012 as part of the Prime Minister’s Challenge on Dementia. The Society is now working in partnership with the Dementia Action Alliance<sup>4</sup> to meet this ambition. In Northern Ireland, the Dementia-Friendly Communities programme is working in partnership with Health and Social Care Trusts and local councils on Dementia-Friendly Community Steering Groups. In England, the development of DFCs is a collaborative effort of Alzheimer’s Society and the Local Dementia Action Alliance<sup>5</sup>.

In Malta, the development and implementation of dementia-friendly communities is a collaborative effort between the government, the Malta Dementia Society and the National Focal Point on Dementia.

<sup>4</sup> The Dementia Action Alliance brings together organisations across England committed to transforming the lives of people with dementia and their carers. To become a member, organisations sign up to the National Dementia Declaration for England and submit an Action Plan setting out how they are delivering the outcomes described in the Declaration (DAA website).

<sup>5</sup> Local Dementia Action Alliances (DAA) bring together regional and local members to improve the lives of people with dementia in their area. They can be established at any level (e.g. village, city, county, region) and can overlap geographically (DAA website).



### 3.6 How many communities are working towards becoming dementia friendly?

Table 3: Dementia-friendly communities by country

<b>Austria</b>	Counties/regions: 1 Cities/towns: 2 and 1 district in Vienna
<b>Belgium</b>	<b>Wallonia and Brussels:</b> Cities/towns: 24 <b>Flanders:</b> 73 projects in 50 municipalities
<b>Germany</b>	Information is not available
<b>Ireland</b>	Counties/regions (11): The Alzheimer Society of Ireland funded projects are in Donegal; Galway; Ballina & Killaloe /Cavan / Wicklow / Mallow – North Cork. Genio <sup>6</sup> funded projects are in Mayo / Kinsale / South Dublin / & South Tipperary
<b>Netherlands</b>	Counties/regions: 70 Cities/towns: 25 in Noord Brabant, 10 in Gooi en Vechtstreek and five in Midden Kennemerland Villages: 30
<b>Norway</b>	Counties/regions: 17
<b>UK</b>	<b>England:</b> 105 currently registered for the Alzheimer’s Society recognition process, over 150 Local Dementia Action Alliances established <b>Northern Ireland:</b> (Towns/cities): Coleraine; Ballymoney; Derry/Londonderry; Strabane; Newry; Belfast (Shankill area) <b>Wales:</b> 9 communities have received Alzheimer’s Society Working to Become Dementia-Friendly recognition – Brecon, Swansea, Newport, Tredegar, Usk, Raglan, Caerphilly, Rhymney, and Pontypool. <b>Scotland:</b> Counties/regions: 9 – East Lothian; Inverclyde; East Dunbartonshire; East Sutherland (part of Highland Council area); Orkney; Shetland; Dumfries & Galloway; Western Isles; West Dunbartonshire Cities/towns: 13 – Dundee, Edinburgh, Stirling, Motherwell, Bathgate, Bishopbriggs, Dunbar, Musselburgh, Haddington, Tranent, North Berwick, Helensburgh, Inverness Villages: 2 – Leslie (Fife); Kirriemuir (Angus) Neighbourhoods: 3 – Portobello, Cramond, Pentlands (Juniper Green, Currie and Balerno) all in Edinburgh

<sup>6</sup> Genio Limited is an Irish registered company. Genio works to bring Government and philanthropic funders together to develop better ways to support disadvantaged people to live full lives in their communities.

### 3.7 Steps to building a dementia-friendly community

Most of the participating organisations provided information regarding the process for building a dementia-friendly community in their country. The process often begins by signing a commitment or agreement and identifying a person (or champion) or network that will lead the work. This is for example the case in Belgium (Wallonia and Brussels) and Norway. Likewise, in England, to become part of the dementia-friendly communities’ recognition process, a representative from a community will need to fill out an online application form.

By signing the agreement or registering for the process, the community commits to a number of conditions. In Belgium (Wallonia and Brussels), the signatories commit to appoint an “agent Proxidem” (agent proximité Démence, similar to a local dementia officer) within the first year of becoming dementia friendly, and to organise at least one of the activities that are suggested by the Ligue Alzheimer (e.g. Alzheimer cafes, day care or respite care, participation in the cycle of conferences organised by the association, etc.). The “agent Proxidem” is a person working for the municipality and receives a three-day course training on dementia provided by the Ligue Alzheimer. The “agent” meets and supports people with dementia and their carers living in the municipality.

In the UK (England, NI), by registering for the process, the community commits to the following conditions: meeting the foundation criteria for a dementia-friendly community that have been developed (see Box 1 for further information on the foundation criteria), providing a brief six-monthly update, completing an annual self-assessment of progress towards the criteria, providing information on progress

and complying with the terms and conditions for use of the “working to become dementia friendly” symbol. If the application is successful, the community is provided with information on how to work towards becoming dementia friendly and how to monitor progress.

In Belgium (Flanders), communities wishing to work towards becoming dementia friendly are provided with guidelines and an inventory of 21 possible actions or themes for local dementia policies. This is called a “dementia monitor”<sup>7</sup>. It is expected that this information about how other communities have worked towards becoming more dementia friendly may “inspire” and guide their work.

In Ireland, the Alzheimer Society of Ireland (ASI) is playing a significant role in providing leadership on the DFCs initiative in terms of educating the internal and external stakeholders. The ASI works as a leader and a conduit for bringing together the players, laying the groundwork and providing the personnel and the resources to implement the project. A key aspect is the existence of a lead agency or organisation working in collaboration locally so that a number of partners come together to plan and develop a DFC so as to ensure sustainability after initial funding ceases.

In Scotland, no specific criteria exist, but common to this activity is the need to involve people with dementia. The work in the Netherlands is based on community development principles. They try to reach out to and involve as many local and community organisations as possible (social, cultural, sports). An important criterion is that all activities should aim at improving the quality of life of people with dementia.

<sup>7</sup> This was developed by the Association of Flemish Cities and Municipalities (Vereniging van Vlaamse Steden en Gemeenten), the King Baudouin Foundation (Koning Boudewijnstichting), Flemish Dementia Expertise Centre (Expertisecentrum Dementie Vlaanderen) and the Flemish Alzheimer’s Association (Alzheimer Liga Vlaanderen).

## Box 1: Examples of the process towards becoming dementia friendly

### Norway – Main steps to building a DFC:

1. Sign a collaboration agreement with the Norwegian Health Association and approve that they, as a community, want to work towards becoming more inclusive of people with dementia.
2. Establish a working group. The group develops a plan for the process of becoming dementia friendly. The group should include people with dementia and carers.
3. The Norwegian Health Association delivers educational workshops to equip people working in retail, or other businesses, with the skills needed to understand and support customers with dementia.
4. The Norwegian Health Association collaborates with the different communities and helps them to increase the media attention and to highlight positive initiatives or outcomes.

### UK Alzheimer’s Society

A community that registers for the recognition process is committing to taking each of the foundation criteria and interpret them from a local perspective to fit the size, type, stage of progression and resource, and describe how they are working towards and the actions they intend to take. These criteria are: (1) Make sure that there is a local structure in place to maintain a sustainable dementia-friendly community; (2) Identify a person or people to take responsibility for driving forward the work to support the community to become dementia friendly and ensure that individuals, organisations and businesses are meeting their stated commitments; (3) Have a plan to raise awareness about dementia in key organisations and businesses within the community that support people with dementia; (4) Develop a strong voice for people with dementia living in the community; (5) Raise the profile of the work to increase reach and awareness to different groups in the community, (6) Focus on a number of key areas that have been identified locally and (7) Have in place a plan or system to update the progress of the community after six months and one year. Once a community has demonstrated how they meet the criteria, they are issued with a symbol which they can give to organisations and businesses in their community that wish to be part of the dementia-friendly communities’ initiative (British Standards Institution, 2015: 7)

## Toolkits and guidance documents

Several countries (Belgium, Ireland, Netherlands, Norway, UK (England, Scotland)) have developed guidelines, toolkits, checklists or other educational material (e.g. leaflets, videos, etc.) that are available to communities working towards becoming dementia friendly.

## Box 2: Example of toolkit

In Scotland, a working group in Motherwell devised a tool-kit which takes the staff from shops and businesses through measured development stages towards “dementia-friendly community” status. The toolkit includes:

- a “Commitment” letter,
- a basic dementia awareness presentation,
- hints and tips for shops and businesses fold out leaflet,
- carrying out an environmental audit,
- an action plan,
- a certificate of achievement,
- a dementia-friendly award window or door sticker,
- promotional advertising, business advantage recognition

### 3.8 Dementia-friendly symbols

Dementia-friendly symbols are intended to give more visibility to the communities, services, business or initiatives that are working to become dementia friendly. Box 3 provides information on existing dementia-friendly symbols<sup>8</sup>.

#### Box 3: Dementia-friendly symbols

**Belgium (Wallonia-Brussels):** a logo exists that was developed by the Ligue Alzheimer and is provided to the cities or towns that join the ViaDem (“Villes amies de la demence”) programme.

**Norway:** The symbol is unique for DF. The logo is used along with the logo of the county. It is provided to businesses, initiatives or other services which have undergone training in how to respond better to the needs of their clients with dementia. The symbol is provided as a sticker.

**UK (England, Wales, NI):** The symbol is trademarked by Alzheimer’s Society and to use it, the community and organisations must comply with the terms of use. Alzheimer’s Society retains the right to withdraw that permission if it is felt that the conditions of use have been breached.

**Belgium (Flanders):** There is no general symbol for dementia-friendly initiatives or communities. In Bruges, there is a symbol that is used and which was chosen by people with dementia themselves.

**Ireland:** No single symbol or logo in use. The Alzheimer Society of Ireland has developed a logo for the DFCs that it is supporting to use with the material they are producing and the organisations that are working towards becoming dementia friendly.

**UK (Scotland):** No single symbol or logo in use. Alzheimer Scotland has developed a logo and a partnership logo for organisations and groups working towards becoming dementia friendly. This is made available to organisations with whom Alzheimer Scotland is working directly. However, other symbols and logos are in use in various localities



Belgium (Bruges)



Ireland



Norway



Netherlands



Belgium (Wallonia and Brussels)



UK (Scotland)



UK (England, Wales, NI)

<sup>8</sup> Austria and Germany have not yet developed a symbol.

### 3.9 Measuring and monitoring progress

In some countries (Austria, Belgium, Germany), the progress and impact of the DFCs is not being measured or monitored. In Belgium (Wallonia and Brussels), the Ligue Alzheimer meets regularly with the “agent Proxidem”. These meetings provide opportunities for exchanging information and talking about the work the city is making to become more dementia friendly.

In Ireland, and in some parts of the UK (England, Wales, NI), communities working towards becoming more dementia friendly that are registered or supported by the Society have to complete a monitoring tool on regular basis. In Ireland, DFCs supported by the Society complete a monitoring tool every six months. The project coordinator visits and supports the projects in a variety of ways and the projects come together three times per year to participate in a Learning Forum to share the learning among all projects including Genio and those receiving small awards.

In the UK (England, Wales, NI), tangible progress is considered as an important aspect of taking part in the recognition process. Communities registering for the recognition process are required to report back on a six monthly and annual

basis in two different formats to detail the progress they have made since joining the recognition process (i.e. six-month progress update and annual self-assessment). Local Dementia Action Alliance members similarly have to submit an action plan which they update when they make progress on their objectives.

In Norway, a long-term evaluation is planned. This evaluation will involve two different surveys, one that will be completed by the general public and another one which will be completed by people with dementia. Similar surveys were carried out before the DFC programme was launched and this initial data (baseline data) will serve as a basis for comparison with the subsequently acquired data. There is also a continuous and ongoing evaluation of the outcomes.

In Scotland, there is no agreed methodology for measuring progress. In Motherwell (Scotland), the project team used “mystery shoppers” in the 9–12 month period after the launch of the project. This involved face-to-face scenarios and telephone contact. Organisations signing up to the Motherwell project produced an action plan which can also be monitored for progress.

### 3.10 Examples of dementia-friendly communities

#### Belgium (Flanders):

Since 2010 Bruges has been a dementia-friendly city. The King Baudouin Foundation and the local government have financially supported this work in the city of Bruges. Bruges strives to improve the quality of life of people with dementia

and their environment by bringing about a mental shift of all citizens, organisations, companies, institutions and authorities to arrive at a more respectful and equal communication and interaction.

#### Ireland:

The “Wicklow Dementia-Friendly” (WDF) project aims to remove the barriers people face around lack of knowledge within communities through targeted education awareness raising activities. People with the power to bring about change are given the knowledge needed to ground their practice and interaction in a dementia-friendly way. WDF aims to increase awareness of dementia and reduce stigma, and look at ways in which communities, neighbours, friends and everyday service providers (such as retailers, banks, Gardaí – police – , health services) can support people with dementia to carry on, as normally as they can, for as long as possible. Like everyone else, people with dementia want to go out, do their shopping, pursue hobbies and interests and make use of local facilities like leisure centres, golf clubs and libraries. The project aims to build awareness

and understanding of dementia at every level of society. The project will be informed about the barriers to living well with dementia by people living with a diagnosis themselves. Workshops are delivered throughout the county. Those participating include: general practitioners, pharmacists, dentists, retailers, leisure, sports and social clubs.

People with dementia are involved in the planning of activities, they work with WDF to guide and inform the projects. The project is developing the idea of Dementia Friends to support people going about their daily activities. The project has developed good linkages throughout the county. Numerous organisations at a local level are committed and are involved in the project.

### Netherlands:

Since April 2015, the town of Doorn has been working towards becoming dementia friendly. There are a number of local organisations involved and this work has been financially

supported by the local municipality. So far, they have provided training on dementia to a well-known chain of supermarkets in the area (Albert Heijn) and to the police force.

### Norway:

In Norway, the municipality of Moss has been working towards becoming dementia friendly since 2014. They have worked to increase awareness of dementia among staff

working in retail and taxi drivers. It is planned to expand this work to staff working in banks, staff working in public transport and to the general public.

### Scotland:

The work towards becoming dementia friendly in East Lothian started in 2014. This work being carried out by Dementia Friendly East Lothian (DFEL) is a collaborative initiative of local residents, carers, volunteers, paid health and local authority staff from a range of departments, local businesses and social enterprises, all of whom have some experience of dementia. There are now six communities in East Lothian actively engaged in becoming dementia friendly, with local people and organisations taking the lead. DFEL aims to support people and communities to raise awareness and understanding of dementia and its impact on people and their families and carers; to provide a forum and impetus for community-led discussions about how they collectively support people with dementia and what more they can do, and to develop a community response to dementia, where people living with dementia and those that support them inform local decisions that impact on people with dementia and the services they receive.

The group leading this work spent six months opening conversations in the community, talking to people and encouraging others to join in. They received great support from the local press. In April 2014, the organising group designed and ran two community events and suggested good places to go if you have dementia and what people would like to see changed. In November 2014, a learning event gave an opportunity for a wide range of people from across East Lothian to share stories and experiences and identify priorities to take forward in the action planning for 2015 and beyond. The group continues to support people in developing their own dementia-friendly activities and produce regular information briefings on what's happening around East Lothian. The group's main foci going forward are:

- Awareness raising and producing and disseminating information materials in accessible formats or widening access to existing information about dementia.
- They have drafted a training strategy and are pressing for greater investment in dementia training for health and social care staff and also for people working and living in the community such as shop assistants and staff in local businesses.
- Care service providers and planners need to understand and consider the role that community resources and organisations can play in providing effective care at all stages of dementia, supporting people with dementia to live meaningful independent lives in the community for as long as they wish to do so. DFEL plans to develop case studies to illustrate this and to use every opportunity to raise the profile of dementia and increase opportunities for people with dementia to have more say and influence on the decisions that matter to them.
- Talking about dementia is key to addressing stigma and breaking down barriers. There is a need to forge links between professionals and the community, as professionals need to talk with communities, not just amongst themselves. The other important aspect is about people involved in service provision talking to each other and sharing ideas and information about what they do e.g. between care homes and day centres. One suggestion is to consider “twinning” dementia-friendly communities to share experiences. Communities need to be given opportunities to meet and talk and DFEL will explore various options for doing so (annual event, regular forums/meetings, online chat, etc.) but also provide a forum for people with dementia to influence decisions.

### 3.11 Personal account



"I was diagnosed with vascular dementia in 2010. Since then it has been important for me to stay active, both physically and intellectually, and keep everyday life as normal as possible, take part in activities I would normally join in and not isolate myself.

From early on it has been important for me to make other people aware of my situation.

Whether I have lived in a large or small community my experience is that being open about my situation has made everyday life easier. People around me are accommodating and I feel included. Although my contributions may be somewhat limited at times, I experience that I still have a role to play and something to give, practically or in discussions and meetings."

*Alv Orheim, EWGPWD, Norway*

### 3.12 Conclusion

This section has shown the relevance and potential of the work that has started in Europe in recent years. It has provided evidence of countries in Europe where this work has been soundly developed (Austria, Belgium, Germany, Ireland, Netherlands, Norway, UK) and of countries that are currently working to further develop and implement DFCs (Denmark, Finland, Jersey, Malta, Switzerland).

This work recognises that the voices of people with dementia and their carers should be the starting point of the work towards becoming dementia friendly. These are communities that are more inclusive of people with dementia and that enable them to live well. Raising awareness about dementia, tackling stigma and providing adequate care and support all seem relevant for this endeavour. Some of the examples also suggest that whilst appropriate health and care support are of utmost importance, dementia requires "a community response", and thus that the support that people with dementia may need to live well in the community is beyond the health and social care systems. People with dementia want to feel part of the communities, and to remain involved and included.

The work included in this section shows that efforts towards becoming dementia friendly are often based on a grass-roots approach (bottom up). This means involving people

with dementia, carers and the whole community in the identification of needs, and using this to inform the future development of policies and practices. Nevertheless, works towards becoming dementia friendly may also require a top-down strategy at strategic and locality level (e.g. governments, local councils, local authorities, etc.).

The examples of DFCs described in this section illustrate different ways and approaches of working towards the development of DFCs, and suggest that, what is developed and works in one country may not be appropriate for another. Guiding principles can inform the general development of DFCs through Europe, but local solutions are needed.

The concept of whole communities becoming dementia friendly has not yet been developed everywhere in Europe. This absence should, however, not be interpreted as if other countries are not undertaking major efforts to provide appropriate support and care, to improve the quality of life, and to involve people with dementia as much as possible in the community. In the next section of this report, the work that many European countries are doing to develop national policies, practices and initiatives that may contribute towards making Europe a better place to live for people living with dementia is presented.





## 4. Journeys towards becoming dementia friendly in Europe

This section of the report draws on the framework developed by the World Health Organisation (WHO) on Age-Friendly Cities. According to the WHO definition, age-friendly environments “encourage active ageing by optimizing opportunities for health participation and security in order to enhance quality of life as people age” (2007:72). To achieve so, it should adapt its structures and services to be accessible to and inclusive of older people with varying needs and capacities. The WHO report identifies eight core age-friendly features: outdoor spaces and buildings, housing, transportation, social participation, respect and social inclusion, civic participation and employment, communication and information, community support and health services. These features overlap and interact.

Building on this framework, and adapting it where necessary for people with dementia, this section of the report provides information on national policies and notable practices in Europe addressing the following core principles<sup>9</sup>:

1. Outdoor spaces and safety
2. Housing: Adaptation schemes and use of technology
3. Transportation: driving and transport
4. Social participation
5. Social inclusion and stigma
6. Civic participation: voting and employment

### 4.1 Outdoor spaces and safety

“Outdoor spaces” is one of the core features that are included in the WHO framework for age-friendly cities. This section provides information on national policies (4.1.1) and notable practices (4.1.2) ensuring that the physical environment is adapted to the needs of people with dementia. It also provides information about initiatives that enable safer walking for people with dementia (4.1.3). The section concludes with a personal account from a person with dementia (4.1.4).

A positive environment may help to promote cognitive stimulation and functioning, independence, social participation in the community and physical activity (Innovations in dementia, 2011, Burton et al., 2004). Good design and attention to orientation can make a significant difference to a person with dementia’s ability to navigate their surroundings (Innovations in dementia, 2011).

#### 4.1.1 National policies addressing the adaptation of outdoor spaces to the needs of people with dementia

Being outside is essential for physical, mental wellbeing and quality of life (Duggen et al., 2008). Recent research has shown that people with dementia go out significantly less than the general population of older adults (Alzheimer’s Society, 2013). Environments should be accessible, safe and respond to the physical needs of the individuals, but in the case of people with dementia, environments should also address the sensory and cognitive changes that are part of dementia. Six principles seem to be particularly relevant to people with dementia: familiarity, legibility, distinctiveness, accessibility, comfort and safety (Mitchell, 2012).

Participating organisations were asked about national policies, laws or other legal provisions in their country addressing the need to design or adapt the outdoor environment to the various needs of people with dementia. Several countries (Croatia, Czech Republic, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Lithuania, Malta, Norway, Poland, Portugal, Sweden, Switzerland, Turkey, UK (England, NI, Scotland)) identified one or more of such national documents. Overall, these documents aim at tackling discrimination and/or supporting equality, and in most cases, there is a great emphasis on the needs of people with physical disabilities<sup>10</sup> (i.e. issues that affect mobility and motor skills). Typically, the responses provided refer to the accessibility of public buildings, public services and community resources (i.e. “barrier-free”). For example, according to the Finnish Act, buildings should “be suitable for people whose capacity to move or function is limited”. Similarly, in Portugal, the law makes reference

<sup>9</sup> Whilst health and social support is one of the core features identified in the WHO framework, this is not addressed in this Yearbook. This decision was made as the care and support available to people with dementia has been described in previous Yearbooks (see for example 2012, 2013 and 2014 AE Yearbooks).

<sup>10</sup> It may be interesting to bear in mind whilst reading this section that some countries include people with dementia in their definition of people with disabilities, whilst others do not do so explicitly.

to accessibility for people who may have temporary or permanent mobility issues. Some of these policies (Finland, Sweden, Turkey) also refer to the usability, maintenance, renovation and aesthetics of public spaces.

In some countries (Ireland, Lithuania, Norway, Switzerland, UK), disabilities acts, equality legislation, and/or anti-discrimination acts promote fairer and more equal treatment and opportunities for all members of the society. These often require public bodies to ensure that their public buildings are “as far as practicable” accessible to persons with disabilities. Among other rights, the right of people with a disability to access transportation, goods and services, and nature are often mentioned. According to their Constitution, in Denmark, all citizens have the constitutional right to be treated equally regardless of their disabilities and of the cause(s) of the disability. Public buildings and transportation should be accessible for people with disabilities. According to the law, in Denmark, new public buildings have to be easy to access and suitable for people with any type of disability.

Some of the national policies specifically refer to the needs of people with “cognitive disabilities” (France, Malta, Sweden). The National Strategic Policy for Active Ageing: Malta 2014–2020, states that the physical environment in the community and public spaces should be sensitive to individuals with cognitive decline. Among other changes, appropriate signage, lighting and colour coding are specifically mentioned. Such changes “should be incorporated in the planning and design of public spaces frequented by older individuals and services including banks, shops and local councils” (p.73).

People with dementia can also benefit from the recommendations and measures included in national policies for Active Ageing (Malta, Finland, Lithuania). In Finland, there is an emphasis on promoting physical activity and mobility among older adults, and thus a commitment to promote safe and accessible walking and cycling routes.

A more general approach is provided in the Norwegian Act (2013) which promotes the embracement of the principles of Universal Design in public “buildings, facilities and outdoor areas intended for the general public”. Examples of promoting Universal Design also exist in Ireland and Lithuania. In Lithuania drawing on the idea of “design for all” and on best practices from Estonia, they have developed an online resource where advice and guidance for the planning and design of outdoor and built spaces that are suitable for all citizens are provided to architects, engineers, planners, project developers, designers, contractors and builders. In Ireland, a series of best practices issued by an independent State body provides comprehensive guidance on how to design, build and manage building and spaces so that

they can be readily accessed and used by everyone, regardless of their age, size, ability or disability.

There are fewer policies or documents addressing the requirements for outdoor environments to be dementia friendly or adapted to the needs of people with dementia. Nevertheless, some examples exist, such as the guidelines and checklist produced by the Oxford Institute for Sustainable Development in the context of the initiative “Neighborhoods for life”, which provide a set of principles and accompanying design recommendations that should be considered by planners and designers in developing dementia-friendly urban areas. Also, in Belgium (Wallonia and Brussels) some local authorities have signed “Alzheimer contracts”. These contracts constitute a political declaration of their willingness to take the necessary steps to make the public infrastructures more dementia friendly.

#### 4.1.2 Notable practices

Seven countries (Finland, Malta, Ireland, Poland, Sweden, Switzerland, UK (Scotland)) identified notable practices in their countries to adapt the outdoor and built environment to the needs of people with dementia or make it more accessible to them. Some of the examples provided include:

- **Malta:** in Summer of 2015, in a pilot project, a number of talks were organised with several local councils across the Maltese Islands. The aim of these information sessions was not only to enhance knowledge on dementia but to pass on tips that can be used to make the locality more dementia friendly including the use of signage and colour coding. Depending on the feedback gathered, it is planned to extend this to the whole of the Maltese Islands with the objective of having a dementia-friendly nation by the next decade.
- **Ireland:** in Skerries (North Dublin area) in 2014–2015 a new board walk was installed at the wildlife pond in a local park. This area was targeted so that there could be more interaction with seniors and people with dementia in the safe environment of the park, with benches and a new wildlife viewing area incorporating a feast for the senses through sight, sound and touch. Appropriate seating and interpretive signage were installed. As part of the project, leaders engaged with people with dementia in the area to determine what was important when planning the areas in the local park. This initiative was organised by Interagency Voluntary & Statutory Informal Community Group – Skerries Community Liaison Committee.
- According to the Polish association, in **Poland**, some of the improvements aiming at helping people with disabilities in general have also been relevant to people with dementia. Some of the benefits

highlighted include the renovation of pavements and clearer signposting in cities and towns (maps, signposts, etc.) and the availability of clearly signed public toilets and of more places to sit down and rest.

- **UK (Scotland):** in Callander Wood, Falkirk, a pilot woodland activity programme for people with early stage dementia was delivered by Forestry Commission Scotland Rangers in association with a PhD student at Dundee University. Activities included woodland walks, bird box building, photography, willow weaving, bird and tree identification, fire lighting and woodland cooking.
- **Switzerland:** there are a number of dementia sensory gardens on private grounds. Often these gardens are in nursing homes. A good example is Sonnweid in Wetzikon, Zurich.

#### 4.1.3 Feeling safe whilst out and about

Many people with dementia are able and want to go out and about independently. Some have expressed their concerns of “getting lost”, “being distressed” or “becoming disoriented or confused” when out alone. Nevertheless, some people want to be allowed to take risks. Risk enablement is based on the idea that measuring risk involves “balancing the positive benefits from taking risks against the negative effects of attempting to avoid risk altogether”. Positive risk-taking involves using the existing resources and support to achieve the desired outcomes, and to minimise the potential harmful outcomes (Morgan, 2007).

Some countries reported the use of Global Positioning Systems (GPS) to enable safer walking (France, Germany, Netherlands, Norway, Sweden, Turkey<sup>11</sup>, UK (Scotland)). The German Alzheimer Society is funding ongoing research to validate and improve the benefits of using GPS technologies for people with dementia. In Scotland, several examples exist of small-scale pilot schemes (i.e. GPS and Safer Walking schemes). In North Lanarkshire (Scotland), by logging onto the system, an authorised carer or relative can find the current location of the person with dementia online or look up his/her past movements. Carers can either collect the individual themselves or can call statutory agencies, such as the police or social services if there is an emergency. Similar technologies are used in other parts of Scotland (Fife Council safer walking for people with dementia pilot; Safe walking scheme in Edinburgh). The use of GPS technology is also common in Sweden, where people with dementia and their relatives can apply to get one of these devices at their municipality. In Sweden, the device can only be activated if it is authorised by the police. Sweden also reported the use of personal digital assistants (PDA) by people with

dementia when they are out and about. This device can prompt the person on which direction to take, and can help the person to find their way home or to any other destination. The device has a “crisis button” that can be used in an emergency situation.

GPS solutions can enable people with dementia to remain independent whilst out and about and give them a sense of control over life. Nevertheless, some people with dementia may not feel comfortable with the use of technology or see such devices as intrusive (Robinson et al., 2007), so they should not be used without discussion or consideration of the ethical issues (Alzheimer Europe, 2010; Department of Health, 2010).

Several organisations described different notable practices that involved the police, most notably regarding the development of protocols for missing people that could improve the search of a missing person who has dementia, or for raising awareness or providing training about dementia to the police force (Belgium, Denmark<sup>12</sup>, Slovenia, Ireland, UK (NI)).

In 2013, in Belgium (Wallonia and Brussels) the unit of missing persons of the Federal Police developed a protocol for older people reported missing. The goal is to create, in every nursing home, a file containing relevant information about each resident. This allows the police to start searching for the missing person straight away, rather than at this critical point, starting to gather the information. This project was developed by the Federal Police in partnership with the local police services and institutions for older people (who can join the protocol free of charge); the public prosecutor as moral guarantee and the Ligue Alzheimer. The role of the Ligue Alzheimer is to provide information about dementia and missing people in the context of dementia. The Ligue Alzheimer is working with six home care providers to implement this initiative for people with dementia living at home.

In Belgium (Flanders), protocols for missing people with dementia living at home and/or in care facilities have been developed. This initiative started in 2008 in Antwerp (HEKLA), and has been recognised by the Federal Police. Whilst it initially had only a local scope, it has now been implemented in other parts of Flanders and Wallonia.

In Ireland, in 2015, Wicklow Dementia Friendly (WDF) made contact with first-responders (e.g. ambulance drivers) in their county and recently provided dementia awareness training to Gardaí (police force) in the county with a particular focus on missing persons. A more informed police force creates a more dementia-friendly area, with improved and appropriate responses to people with dementia living in the area.

<sup>11</sup> In Turkey, some tracking systems (devices specifically designed for this service or applications to be used on mobile phones) are offered by Turkish GSM operators or private companies, people with dementia or their carers can buy these equipment/ services privately.

<sup>12</sup> Some examples exist at local level, this is not a national initiative.

In Turkey, the Alzheimer association called for an amendment to the legislation on missing persons. As a result of this work, whilst there is a waiting period of 24 hours for any person who goes missing, if the person has been diagnosed with dementia the search can be started immediately.

For some countries, initiatives that enable safer walking are particularly relevant due to their geographical particularities. For example, according to the Jersey Alzheimer’s Association, people with dementia can be exposed to serious risk

to health and safety if they become lost given the size and nature of the island with its extensive coastline and dangerous tides. Also, Finland and Poland referred to some level of concern regarding the number of people that are declared missing every year.

A few organisations (Finland, Poland, Netherlands) referred to rescue services (not dementia-specific) for missing people, these services whilst not specifically for people with dementia, could be relevant to them.

#### 4.1.4 Personal account



“There are certain things in the community that make me feel safe when I am out and about. For example, if there is good signage that helps me to find my way. It is important that it is printed in a size that is big enough and that is easily recognizable from the background. Images and pictograms are very helpful. Another thing that makes me feel safe is when there is a telephone number that I could use in case of an emergency, for example if I am using a lift. I don’t feel safe, when there is nobody whom I could ask, if I needed to. It is particularly useful when it is clear that the person understands about dementia, and then I feel confident and comfortable when asking.”

*Helga Rohra, EWGPWD, Germany*

## 4.2 Housing

Housing is another one of the core features suggested in the WHO framework for age-friendly cities. Older people, and people with dementia of any age, value having the appropriate housing and support that allow them to age comfortably and safely within the community to which they belong (WHO, 2007).

This section looks at national policies and practices relating to the design and adaptation of the home environment to the needs of people with dementia (4.2.1), and in particular, to the existence of adaptation schemes (4.2.2) and the use of assistive technology (4.2.3). The section also provides information about the involvement of people with dementia in design and planning (4.2.4 and 4.2.5). It concludes with a personal account from a person with dementia (4.2.6).

### 4.2.1 National policies relating to the adaptation of the home environment to the needs of people with dementia

Some national dementia strategies (Belgium, Luxembourg, Malta, Sweden<sup>13</sup>, UK(Scotland)) recognise the relevance of the home environment to people with dementia. In addition, some countries have developed recommendations (Denmark, Germany, Netherlands), guidelines (Czech Republic, Finland, Ireland, UK – England and Scotland), and the

Expertisecentrum Dementia in Belgium (Flanders) published a book in 2012 entitled “*Architectonica. A home for people with dementia*”.

The national dementia strategies in Luxembourg, Malta and Sweden, emphasise that physical environments in nursing homes should respond and be adapted to the needs of people with dementia. Others, such as Germany, Ireland and Scotland, have focused on the home dwellings of people with dementia living in the community. These documents stress that good home design may help people with dementia to continue to live in their own homes and in familiar surroundings, adapted to ensure maximum use of retained abilities and to promote more independent living. The Scottish National Dementia Strategy, for instance, highlights the relevance of the familiar home environment to people with dementia (Commitment 5). Nevertheless, it is acknowledged that whilst a good number of people with dementia live in their own homes in the community, their homes may not have been built to today’s standards of accessibility. It is then stated that “well-designed housing is particularly important to people with dementia and can extend the amount of time that they are able to remain living at home, by reducing accidents and delaying the need for residential care”. The key actions of this commitment were to increase the awareness about dementia among staff working at housing organisations and to develop a guide

<sup>13</sup> In the case of Sweden “National Dementia Care Guidelines”.

that could provide guidance on improving the design of housing for people with dementia (“Improving the Design of Housing to assist People with Dementia”).

In Ireland, in 2015, the Centre for Excellence in Universal Design (which is part of the National Disability Authority) produced and published guidelines to inform policy and practice in relation to the design of dementia-friendly dwellings (“Universal design guidelines: dementia-friendly

dwellings for people with dementia, their families and carers”). These guidelines embrace the principles of universal design and are intended to be “used for the design of new build and the retrofit of existing dwellings to ensure that people living with dementia have the choice to live as long as possible in their own homes and in their own communities by creating dementia-friendly dwellings that support the individual with dementia and also his or her family and carers” (Pierce et al., 2015:4).

#### 4.2.2 Adaptation schemes

Most participating organisations reported the existence of adaptation schemes in their country. Table 4 provides some examples of these schemes.

Table 4: Types of schemes and professionals involved by country

<b>Austria</b>	Public support through the “Fonds soziales Wien”, the social and counselling centres in the provinces (federal states), the public health insurance and Ministry of Social Affairs. Provided by ergotherapists. People with dementia can access this scheme on request.
<b>Finland</b>	People with dementia can be reimbursed for reasonable costs resulting from the adaptation of their home. In addition, all citizens are entitled to a tax reduction of maximum EUR 2400 per year if they employ someone to adapt/renovate their house. In 2007, as part of the project “Listening home”, the Ministry of Environment in collaboration with a private company (Sosiaalikehitys Oy) published a guide with examples of good practices in house adaptation schemes.
<b>Germany</b>	The Long-Term Care Insurance (§ 40) grants subsidies for the adaptation of buildings and apartments up to EUR 4000 a year.
<b>Monaco</b>	People over 60 can apply for financial help for house adaptation. The adaptation(s) should be recommended by a geriatrician, in addition the person will be referred to an occupational therapist for assessment.
<b>UK</b>	<p><b>Scotland</b></p> <p>House adaptation schemes are generally provided by social landlords (local authorities and housing associations) for their tenants, and by care and repair services for people living in private sector housing. The Help to Adapt scheme (2015–2017) is a Pilot project in 12 (out of 32) local authority areas. The Scottish Government is the lender; the Link Group is delivering the scheme. The project is designed to make it easier and safer for older people to use the equity in their homes to pay for adaptations such as ramps, door widening, door-entry phones, relocated switches or plugs, stair lifts, through-floor lifts, handrails, and adapted kitchens, showers, toilets and/or bathrooms. Homeowners aged 60 or over will be able to apply for a loan of up to £30,000 to pay for adaptations, with no monthly interest charges or compound interest. The loan is repaid when the homeowner sells the house or the homeowner dies, with the amount repaid being linked to the value of the house.</p> <p><b>Northern Ireland</b></p> <p>In Northern Ireland a person with a disability may apply for Disabled Facilities Grant to modify their home to meet their needs.</p> <p>Referral usually comes through an Occupational Therapist and the scheme is administered by the Northern Ireland Housing Executive (NIHE) where a Grants Office can help with the application process.</p>

### 4.2.3 Use of technology

The use of technology enables some people with dementia to live more independently and may support and reassure their carers (Cahill et al., 2007; Hagen et al., 2005). However, limitations of using technology in dementia also exist. Some people may experience difficulties whilst using technology, or may not feel comfortable using it. Other shortcomings include that the outcomes of using these technologies (i.e. their effectiveness at helping the person to live independently at home) have not been sufficiently investigated, and also that the cost of the technologies and the training required to use it, are often not reported (Morris et al., 2013). A discussion of the different kinds of ethical issues which could be relevant to the use of assistive technology in dementia can be found in the report “The ethical issues linked to the use of assistive technology in dementia care” (Alzheimer Europe, 2010).

Some of the participating countries identified one or more relevant policy documents addressing the use of assistive technology in their country. In Ireland, one of the 14 priority actions outlined in the National Dementia Strategy (2014) is for the Health Service Executive (HSE) to evaluate the potential of assistive technology to support carers and people with dementia. In the UK, the Prime Minister’s Challenge on Dementia makes a call for further research on “assistive technologies and assisted living, including research on how information and communication technologies can best help people with dementia and carers” (Prime Minister’s Challenge on Dementia 2020, 2015). In Malta, among the aims of the national dementia strategy is the provision of assistive/information technologies. Recommendation 6.3.4 (m) encourages the state to provide financial assistance to purchase/rent new assistive/information technology with the aim of increasing autonomy and quality of life. In France, there is a provision in the draft bill for “Adapting the society to ageing” (projet de loi d’adaptation de la société au vieillissement) to promote the use of smart and assistive technology for older people who are dependent to enable them to live at home.

The Scottish Government has a National Telehealth and Telecare Delivery Plan and a funding scheme to promote initiatives designed to help people manage and monitor their own health, enable people to live safely at home and improve access to services and support. These initiatives are collectively known as Technology Enabled Care. Also, in Norway, there is a National Governmental Programme for Assistive Technology. Austria and Germany reported the existence of ongoing research and development in the field of Ambient Assisted Living (AAL) in their countries. In

Germany, this R&D has been financially supported by the Government (Ministry of Research and Technology).

Several participating countries (Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Jersey, Latvia, Lithuania, Luxembourg, Malta, Norway, Poland, Portugal, Sweden, Switzerland, UK (England, NI, Scotland)), identified initiatives in their countries that facilitate and encourage the use of smart or assistive technologies for people with dementia living at home. In several countries (Denmark, Finland, Ireland, Norway, Portugal<sup>14</sup>, Sweden, UK (Northern Ireland and Scotland)) government grants are available for people with dementia for purchasing assistive technology or people can access these products free of charge<sup>15</sup>. Most often, this is for community alarm or telecare services, specifically for monitored personal alarms. The personal alarms are targeted at older people living independently at home, and respond to calls for assistance through a central control room and, where necessary, send assistance and support or contact a relative or named keyholder such as a neighbour. In the UK (Scotland), local authorities provide a range of telecare equipment, based on individual assessment which can include environmental monitoring equipment to detect falls, smoke, gas, flood, extreme temperatures, and external doors opening. The equipment can also detect changes in people’s movements from their usual habits which can indicate someone is unwell or has fallen but been unable to summon help through the alarm pendant issued by the council. Similarly, in Denmark, Sweden and Finland, people with dementia have access to a range of technological aids. In these countries, an assessment by a health professional (e.g. by an occupational therapist) is required. In several countries (Ireland, Greece, Latvia, Lithuania, Luxembourg, Netherlands, Poland, Portugal), these personal alarms and other devices to promote safety at home (e.g. wandering alerts, flood detectors, monitored fall detectors, heat extreme sensors, GPS devices, etc.) are also available through private providers.

Some organisations reported the existence of “exhibition centres” or “demonstration projects”<sup>16</sup> where people with dementia and their families are provided with information on and/or can try out existing products (Belgium (Flanders), Finland, Germany, Ireland, Jersey, Norway, Spain). These initiatives promote awareness of existing technological products, offer information on their benefits and limitations and enable people to try the products before they purchase them. In some cases, the person can be assisted by a member of staff to try the product on an individual basis or have a short-term loan of the product to test it out at home. In Ireland, for example, the Memory Technology Library is part of the Genio 5 Steps to Living Well with

<sup>14</sup> In Portugal, these grants are only for older people on a low income.

<sup>15</sup> This is not dementia specific, but people with dementia can benefit from this.

<sup>16</sup> In the case of Germany and Norway this is a “model apartment”.

Dementia Programme in South Tipperary. The library is for people with memory difficulties and dementia, and their family and friends. It offers a space where these products can be seen and tried out with a member of staff on an individual basis. In Spain, the National Centre of Reference for Personal Autonomy and Technical Aids (CEAPAT) offers online information of existing products and solutions. The Spanish Alzheimer Foundation (FAE), in the context of the DomAlz project, has set up a working group to develop research on home automation (domotics) and smart home applications for people with dementia and their carers. The main aim of the project is to develop intelligent systems and applications that can be easily installed at home to help people with dementia with activities of daily living and to allow their carers to monitor their activity and “tele-control” the house in case any intervention is needed.

In Norway, North Germany and in the UK (Scotland), model apartments for people with dementia exist. The apartments in Germany are part of a project entitled “Safe living with dementia. A model apartment for people with dementia”. The apartment can be visited by professionals, volunteers and the general public. Volunteers can also attend training on advising people with dementia and carers at home. Topics that are addressed include safety, orientation, design and use of light and colour.

#### 4.2.4 Involvement of people with dementia in design and planning

Six participating countries (Jersey, Malta, Netherlands, Ireland, Sweden, UK (NI)) provided examples of consultations or of involvement of people with dementia in design and planning. Jersey and Malta reported that such consultations have been most often conducted via the Alzheimer’s association.

- **UK (Northern Ireland):** Hemsworth Court, a supported housing scheme for people with dementia in Belfast, was designed to dementia-appropriate specifications. Tenants are encouraged to give feedback on adjustments needed to meet their needs and are included in regular reviews.
- In the Netherlands, a peer support group of people with dementia visited and provided feedback on the dementia model home in Woerden, but people with dementia were not involved in the development of the home.
- In Ireland, as part of the development of the “Universal Design Guidelines: Dementia-friendly dwellings for people with dementia, their families and carers” a large consultation process was undertaken. This included consulting with people with dementia. The guidelines encourage the use of participatory design approaches “where people with dementia, their family and carers can take part in the design process”.

#### 4.2.5 Notable practices

Eleven of the participating organisations provided examples of other notable practices in their countries, some examples of these practices are provided below:

- **Belgium (Flanders):** in Flanders, the Dementia Expertise Centre provides information and advice about adaptations and design to care home facilities (e.g. small-scale living facilities for people with dementia).
- **Monaco:** in 2014, the Monegasque government made a real estate donation to the social sector. These apartments are for people who have specific needs in terms of accessibility and adapted housing. People with dementia, who have a cognitive or physical impairment can benefit from one of these apartments, which are better adapted to their specific needs.
- **UK (Scotland):** Dementia Circle is a project funded by Alzheimer Scotland. The team works with people with dementia and their carers to identify and develop products that will help people with dementia stay independent for longer in their own homes. Products and equipment for daily living activities are tested and recommended by people with dementia and include equipment to remind people to take medication, to help with eating and drinking, easy to use telephones and TV remote controls and products to support personal hygiene. Dementia Circle has also developed Pocket Pal, a mobile application that helps people to remember how to use equipment around the home – like the washing machine, the cooker, or the kettle.
- **UK (England):** the dementia-friendly technology charter (2014) was produced as part of the dementia-friendly communities’ strand of the Prime Minister’s Challenge on Dementia. The charter, developed by a diverse working group led by Tunstall Healthcare, gives people with dementia and their carers information on how to access technology. It also provides guidance to health, housing and social care professionals on how to make technology work for people based on their individual needs.
- **Transnational examples:** Remodem, is a transnational project which involves partners in Scotland (Western Isles and Shetland), Sweden, Norway, Faroe Islands and Greenland. All these countries have remote areas where people frequently have more difficulties accessing specialist health and care services than those living in towns and cities. In the Western Isles, “Giraff” robots have been tested which are just under five feet tall, with wheels and a TV screen instead of a head. The screen allows for two-way conversations in a video-call system and uses a Skype-like interface. The Giraff is kept in the home of the person with dementia, and the controls

for the robot are with the person’s relative or carer. The relative can call up the robot from a computer to effectively wake it up, and the person with dementia will not have to do anything at all. The caller’s face will appear on the screen, and the caller can then navigate the robot through the home of the person with dementia to check that all is well, or just to provide reassurance or have a chat. The machines will allow relatives and carers to check on them, potentially from hundreds of miles away.

- **In Finland and in the UK (Scotland)**, staff working at housing organisations have received training on dementia. In the UK (Scotland), the Chartered Institute of Housing has organised a range of seminars and a national conference on housing and dementia to increase knowledge of dementia and design among housing staff and their organisations. In Finland, staff providing housing advice in the Central Union for Welfare of the older people, are provided with short information sessions about dementia.

#### 4.2.6 Personal accounts



“I have a wireless device at home that has my voice recorded saying “lock the door” this helps ensure my home is locked and secure. I have used my door prompt for 4 years now. Since I started using it, my family and neighbours feel reassured knowing that I am being prompted to lock my door. I also feel reassured and safe. Once it is set up you just forget about it. I was wasting time and energy repeatedly going back home to check the door.

Another technology that I have at home is a button alarm I wear around my neck while I am at home which, if I fall or need assistance, I can press and a voice will ask me if I need help. I started using the alarm 4 years ago after having falls and not been able to get to the telephone. This device helps me feel secure and safe in my own home. If I am having a difficulty I just press and they respond by speaking to me and assessing my wishes and needs. If I cannot respond they will send help. This is 24-hour reassurance in my own home.”

*Agnes Houston, EWGPWD, UK – Scotland*

### 4.3 Transportation

Safe mobility and transport are essential to continued engagement in social and community life. Lack of appropriate transport can prevent people with dementia from participating in their local community and from being able to attend activities (Alzheimer’s Society, 2013; Bartlett and O’Connor, 2010). Lack of confidence, concerns about getting lost or mobility issues may all have an impact on the use of transport. The concerns and challenges that people with dementia experience may also depend on where the person lives, for example those living in remote areas or in more disadvantaged countries may experience structural problems (lack of transport, expensive, not reliable, etc.), whereas others may be more concerned about dealing with the complexities of the transport system in place.

Transportation is another core feature of an age-friendly city identified in the WHO framework (2007). This section looks at aspects related to driving and dementia from a legal point of view (4.3.1) and also to notable practices that enhance safe driving among people with dementia (4.3.2). It also provides information on notable practices and challenges relating to transportation that people with dementia may face (4.3.4). The section concludes with a personal account from a person with dementia (4.3.5).

#### 4.3.1 Driving

For many older adults transportation mobility is synonymous with being able to drive (Dickerson et al., 2007). Driving is a complex activity and it is difficult to achieve a balance between the rights of the driver and the imperative to maximise road safety (Ray and Eggar, 2013: 3). Annex 3 of the Directive 2006/126/EC of the European Parliament and of the Council of 20 December 2006 on driving licences sets the minimum standards of physical and mental fitness European drivers must meet to obtain or renew a driving licence. In Annexe 3 it is stated:

*“Driving licences shall not be issued to, or renewed for, applicants or drivers suffering from a serious neurological disease, unless the application is supported by authorised medical opinion. Neurological disturbances associated with diseases or surgical intervention affecting the central or peripheral nervous system, which lead to sensory or motor deficiencies and affect balance and coordination, must accordingly be taken into account in relation to their functional effects and the risks of progression. In such cases, the issue or renewal of the licence may be subject to periodic assessment in the event of risk of deterioration.”*



Determining whether a person with dementia can continue to drive safely and for how long is not an easy task (Mitchell, 2013). There is some agreement that most people with moderate and severe dementia are not fit to drive. Nevertheless, there is no consensus on the neuropsychological tests that should be used to determine fitness to drive in mild dementia. Some research suggests that some people with mild dementia may be able to drive safely for around three years after diagnosis, depending on individual circumstances (Breen et al., 2007). With diagnosis happening now at earlier stages, this may be for even longer periods of time.

The information reported by the participating countries evidenced differences regarding the process and practices around driving and dementia. More specifically, in regards to the doctor’s role in reporting unfit drivers:

- In around one third of the countries doctors are obliged to report unfit drivers (Czech Republic, Denmark, Finland, Greece, Italy, Jersey, Lithuania, Norway, Portugal, Sweden).
- Some countries referred to the duty of confidentiality and that systematic reporting would be deemed unethical, but that doctors are allowed to break the doctor-patient confidentiality under certain circumstances. These circumstances mainly refer to drivers who continue driving despite doctor’s recommendations to stop driving. In such cases doctors are recommended to inform the licensing agency, however this is often on a voluntary basis (Croatia, Cyprus, France, Germany, Ireland, Netherlands, UK).
- Six countries reported that whilst doctors are not legally obliged to report a diagnosis of dementia, this is not an uncommon practice in their country (Austria, Finland, Luxembourg, Monaco, Romania, Poland, Switzerland).
- Eight countries reported that doctors do not generally inform the licensing agency about the diagnosis of dementia (Belgium, Bulgaria, Slovakia, Slovenia, Spain, Turkey, Latvia, Malta).

In Belgium, Ireland, Latvia, Slovenia and the UK, drivers are required to inform the licensing agency of any illnesses or health related condition that can have an impact on fitness to drive, including dementia. In Finland and in the Netherlands, it is not obligatory but it is strongly recommended. Several countries reported that some people with dementia may inform the licensing agency or the police, but that this is on a voluntary basis (Cyprus, Denmark, France, Germany, Italy, Jersey, Luxembourg, Malta, Monaco, Netherlands, Switzerland). In 13 countries, this is not a common practice (Austria, Bulgaria, Croatia, Czech Republic, Greece, Norway, Poland, Portugal, Romania, Slovakia, Spain, Sweden, Turkey).

#### 4.3.1.1 Transitions to non-driving status

Some countries (Germany, Greece, Luxembourg, Malta, Monaco, Norway, Poland, Turkey) reported that there are no procedures in place to support the transition to non-driving status (i.e. driving cessation). In these countries, the responsibility to deal with this matter seems to fall on families. Some countries highlighted the difficulties that many families face to convince their relative with dementia to stop driving. In some cases, family members do resort to other approaches such as convincing the individual that the vehicle does not function any more or offer themselves to drive the person around (Germany, Greece, Malta, Poland, Turkey). In Monaco and Norway, decisions are made mainly by doctors on a case by case basis.

Several countries reported that individuals at a mild stage of dementia, when sufficient skills are retained, may be able to continue driving (Belgium, Croatia, Cyprus, Denmark, Finland, France, Ireland, Italy, Jersey, Netherlands, Slovakia, Slovenia, Sweden, Switzerland, UK). For this, the person with dementia will need to pass a driving assessment to evaluate whether their dementia has affected their safe driving ability. There are some commonalities but also differences in regards to this evaluation process. In most countries the evaluation involves:

- Physical testing (e.g. hearing, vision, etc.).
- Neuropsychological evaluation. In Finland, the Mini-Mental State Evaluation (MMSE) test is used. People with dementia planning to continue driving should have an MMSE score 20 or higher. In the Netherlands, the CDR rating is used and this may be supplemented by a neuropsychological examination. In several countries the clock drawing test is used.
- In Finland, in addition to the testing, information from relatives and friends that the person is driving safely and that the person has no traffic offences due to dementia is highly valued in the assessment (but not compulsory).
- In some countries (for example in Belgium, Ireland, the Netherlands, Switzerland, UK) this information can be sometimes complemented with a driving test (e.g. on road test) – this is not like the learner’s driving test. Normally an assessor will accompany the person as they drive around familiar routes and assess the ability of the person to drive competently and safely.

On the basis of the outcomes of the assessment, the licensing authority will decide whether the person should be allowed to continue driving. This decision will be reviewed yearly in some countries and in others at shorter periods (e.g. 6 months). In some countries (Ireland, Netherlands, UK) individuals retain a duty to inform the licensing agency of any change in their condition. This could prompt an earlier

review. In some cases, doctors may allow the person with dementia to continue driving but may recommend some retraining sessions (Ireland), or may limit the driving (e.g. to drive on well-known routes, to avoid busy roads or not to drive at night – France, UK).

In the UK, if someone with a diagnosis of dementia is unsure of their ability to continue driving, they can take a driving assessment. A driving assessment is an overall assessment of the impact that the dementia is having on a person’s driving performance and safety, and it makes some allowances for the bad habits that many drivers get into. It includes an interview with an occupational therapist and tests of reaction time and vision. A key part of the assessment is an on-road session with an advanced driving instructor in a dual-braking car (where there is a brake on the passenger’s side as well as on the driver’s side). Where appropriate, mobility centre staff will suggest strategies and adaptations to help the person to continue driving with greater safety and confidence.

#### 4.3.1.2 Support in the transition to non-driving status

In around one-third of the participating countries, doctors routinely inform people with dementia of the risks of continuing driving whilst living with dementia (Cyprus, Czech Republic, Greece, Ireland, Jersey, Latvia, Malta, Monaco, Netherlands, Spain, Switzerland, UK). This is mostly done at the time of diagnosis, at the follow-up visits, or sometimes, once there is evidence that the person may no longer be able to drive safely. In three countries (Finland, France and Slovakia) doctors are legally obliged to discuss driving issues with their patients. In France, the doctor is legally bound to inform and warn the person of the risk that a treatment or a cognitive impairment may affect his/her ability to drive, e.g. frequent or serious risks that are normally foreseeable. At every medical consultation or when modifying treatment, the doctor must renew the information. The doctor may be liable under civil or criminal law if it is proved that s/he failed to inform the person of the normally foreseeable risks. In Finland, doctors are legally obliged to report to the police any patient with a medical condition which makes him or her unfit to drive. Thus, the matter of driving must be discussed with patients.

The majority of the participating countries reported that there is no counselling or support services in the country to support people with dementia at the time they need to stop driving or to help them plan for the cessation of driving in the future. Several organisations referred to the general counselling services that are provided by the Alzheimer’s associations and believed driving may be discussed in such context. Others pointed out that doctors, occupational

therapists and specialist doctors in memory clinics can provide advice about driving.

#### 4.3.2 Notable practices

Six countries (Germany, Greece, Netherlands, Norway, Slovakia, Sweden) identified examples of notable practices in relation to driving and dementia in their country. Some of the examples are:

- **The Netherlands:** The University of Groningen (2013–2014) carried out a national research project aiming at developing a reliable and valid methodology that could help to determine fitness to drive in people with cognitive problems and dementia. It included the development of a fitness-to-drive test battery for people with dementia and also advising people with dementia about their fitness to drive and about existing options for support in driving (e.g. compensation techniques, car adaptations, etc.). It was envisaged that such an approach could enable people with mild dementia to drive safely for a longer period of time. This project was commissioned by the Department of Infrastructure and Environment.
- **Germany:** Deutsche Alzheimer Gesellschaft is funding a scientific study that is being carried out by the University of Düsseldorf. The study aims at developing recommendations for German general practitioners (GPs) on managing fitness to drive in dementia. The first results of this study were published in 2015. Research is ongoing.
- **Greece:** in Greece, a questionnaire has been developed to help doctors to assess fitness to drive in people with dementia.
- **Slovakia:** in 2014 a memory centre in the country developed a brochure about driving and dementia for people with dementia and their carers. This brochure has been used widely in the country.

Whilst some good practices were identified, several organisations felt there are still several challenges in terms of driving and dementia in their country. The most relevant challenges refer to the lack of control over what the person with dementia does (i.e. a person with dementia may continue driving even though not being supposed to) (Austria, Belgium, Croatia, Czech Republic, Denmark, Finland, France, Greece, Italy, Jersey, Latvia, Luxembourg, Malta, Netherlands, Norway, Poland, Portugal, Romania, Slovakia, Spain, Switzerland, Turkey, UK (Scotland)) and the lack of alternatives for people with dementia once the person has to stop driving (Austria, Belgium, Croatia, Cyprus, Finland, France, Germany, Ireland, Jersey, Luxembourg, Romania, Slovakia, Spain, Switzerland, UK (Scotland)). Another important challenge referred to the lack of clear guidance and procedures about driving whilst living with dementia in the country

(Austria, Belgium (Wallonia and Brussels), Croatia, Czech Republic, Denmark, France, Germany, Greece, Jersey, Latvia, Luxembourg, Malta, Monaco, Norway, Poland, Portugal, Romania, Slovakia, Slovenia, Spain, Switzerland, Turkey). For some countries (Croatia, France, Latvia, Norway, Poland, Romania, Spain, Switzerland) the lack of tools to measure fitness to drive is an important challenge. Two participating countries (Belgium (Flanders), Poland) referred to the need to provide training to and increase awareness among the police force or health professionals. Two referred to the need of support services, i.e. services to aid transition following driving cessation (Ireland), and support to families (Luxembourg).

### 4.3.3 Transportation infrastructure

Transportation services and infrastructures are a crucial determinant of whether people with dementia can get out and about (Innovations in dementia, 2011). They are linked to opportunities for social, civic and economic participation, as well as to access to essential health services (WHO, 2007). Transportation services should be available, affordable, accessible and reliable.

### 4.3.4 Notable practices

Four participating countries (Jersey, Cyprus, Croatia, UK (England, NI, Scotland)) reported notable practices aiming at enabling people with dementia to use transportation. Some of the examples provided include:

- Initiatives raising awareness of dementia and/or providing training (Jersey, UK (England, NI))
  - In Jersey, awareness training will be provided shortly to bus company staff. An educator from the Jersey Alzheimer’s Association will be teaching about dementia in a variety of settings. Even though Jersey is a small Island, people living with dementia can be very isolated given present poor transport links. In addition, a new community-run minibus service has started in a number of the local parishes in Jersey, staffed by volunteers and linking with the existing bus service.
  - In the UK (England), following consultation with local people with dementia and their carers, Liverpool Dementia Action Alliance transport working group brought the transport sector together to explore how the experience of passengers with dementia could be improved. Personalised training is being provided to Virgin Trains to improve the understanding of staff about dementia so that they can respond more
- In Northern Ireland, the Alzheimer’s Society has committed to work with Shopmobility<sup>18</sup> to extend the Department of Regional Development’s scheme that provides mobility scooters to train people with dementia and assistants to use them. This will enhance the benefit of being active and involved in community life for people with dementia on a par with people living with other disabilities.
- The Scottish Dementia Working Group has a Transport Group which has produced a short guide called “Travelling with dementia”.
- Croatia and Cyprus referred to the existence of transportation to bring people with dementia to day care. In the case of Cyprus, this is a private company that provides free transportation to and from a day care centre in a rural area. Whilst this may be part of the standard care in some countries, these two countries emphasised that this is a way to make possible access to care for these people who otherwise would not be able to attend.

appropriately to passengers with dementia who may be lost or confused. Other providers are now taking up the offer of training. Joint work with British Transport Police and the local authority is exploring the idea of a place of safety as a more appropriate response for people who are lost than conveyance to A&E<sup>17</sup> or a police station. Merseytravel, the local passenger transport executive, is considering how to capture emergency contact details for holders of concessionary travel passes and how it might amend its concessionary scheme for people who are eligible for a travel pass but cannot use it without assistance on the journey, to include a travelling companion such as a family carer or friend.

- First Bus (one of the UK largest bus operators) has explored how to make services more accessible to people with dementia. In partnership with the Alzheimer’s Society, a 2.5 hour training module was produced for their 13,500 drivers that forms part of the annual Driver Certificate of Professional Competence. The objective is to raise awareness of dementia, so that drivers are equipped to help someone experiencing difficulties while travelling.
- Translink, Northern Ireland’s regional transport provider has committed to use Alzheimer’s Society delivered dementia awareness training as part of staff induction and intends to review at 3 yearly intervals.

<sup>17</sup> Accident & emergency department.

<sup>18</sup> Shopmobility is a service that helps all people who consider themselves to have mobility problems to continue to get around city and town centres independently, with freedom, confidence and dignity. Examples of Shopmobility equipment include: manual and electric wheelchairs, scooters, rollators (walking aids with seats) and portable hearing loops.

Some countries reported notable practices for transportation in their countries (Croatia, Cyprus, Finland, Ireland Jersey, Sweden, Switzerland, UK (England, NI and Scotland)) that are not specifically for people with dementia, but, that according to them, people with dementia often benefit from:

- In several countries, older people and often people with disabilities can use public transport free of charge or at a reduced rate. In Switzerland, some local authorities have subsidised taxi services (taxi voucher) for old-age pensioners.
- **Assisted travel on trains:** in Scotland, all train operators use a common booking system that allows people to book assistance for their travel to anywhere on the National Rail network. Assistance can include helping people off and on trains, assistance to find reserved seating, making onward connections and helping with luggage. It does not include any personal care or constant attendance during the journey.
- **Alternative routes:** in Finland “service routes” are designed to serve, in particular, older people and people with reduced mobility. The routes have been tailored to accommodate the needs of these people. The routes are operated with low-floor minibuses. On these routes, there is no hurry and when needed the driver can help passengers to get on and off the bus. The service routes provide easy access to the local services such as shops, health centres, libraries, swimming pools, etc. The routes have designated bus stops but if needed the person can get on or off the bus elsewhere. Small deviations from the route are possible within the limits of the timetables. The service routes operate on weekdays and usually each route operates only on certain weekdays as stated in the timetables.
- **Companion entitlements:** in Switzerland and in some parts of the UK (Scotland), if a person with dementia needs a companion to help him/her to use public transport, the companion can be entitled to travel free of charge. According to Alzheimer Scotland, travelling with a companion can make things much easier for someone with dementia. A companion travel logo can be added to the entitlement card, allowing a companion to travel free on the same journey. The companion and journey can vary, but the companion can only travel for free when they are with the person who holds the entitlement card. The person is not obliged to travel with a companion, but the entitlement is there if required.
- **Communication aids:** the “Thistle Card” is a scheme that was developed by the South East of Scotland Transport Partnership (UK, Scotland). The scheme was launched in 2011 and is available across 12 (out of 32) local authority areas. The Thistle Card enables holders to communicate to public transport staff (drivers) any difficulties they may have which may not be immediately visible, such as mobility, speech, hearing or sight problems. Card holders can attach a number of stickers including a short message such as “please wait for me to be seated before moving”; “please talk slowly and clearly”; and “let me know when we arrive at ...”. Bus drivers are trained to recognise the at-a-glance symbols on the cards and will be made aware of any assistance the passenger might need quickly and easily. Although there is no sticker or symbol on the card relating specifically to people with dementia, the messages around speaking slowly and clearly and telling passengers when they have reached their stop are very relevant. It may be possible to combine use of the Thistle card with Alzheimer Scotland’s Dementia Helpcard which people with dementia can carry and show to transport staff. This explains that the card holder has dementia and would appreciate some help and understanding as well as specifying specific issues that the person may have. A similar initiative (Safe Journey Card) exists in England. This is a flexible, low tech solution for people with dementia to privately let drivers know if they need extra assistance

These examples of notable practice are mostly for older people or for people with disabilities. Often, people with dementia will qualify by virtue of their age, younger people (under 60) may have to qualify on grounds of disability, or because they are no longer able to drive, on medical grounds. According to the participating organisations, these schemes may provide an alternative means of travel for people who can no longer drive and may enable people with dementia to continue to get out and about and maintain community and social connections, and help with reducing social isolation. In some cases (e.g. Switzerland), the procedures for getting access to these schemes may be cumbersome.

Whilst a good number of notable practices in transport exist, in almost all participating countries, the information about public transport is not provided in a dementia-friendly manner (see table 5). Some other reported barriers include: lack of awareness of dementia among people working in transportation schemes, lack of alternative flexible schemes for people who do not or can no longer drive and practical problems whilst getting in and out of the public transport (see table 5).

**Table 5: Main reported barriers**

Insufficient availability of public transport	Croatia, Cyprus, Denmark, Finland*, Germany, Greece, Ireland*, Jersey, Luxembourg, Slovakia, Switzerland, UK (Scotland)*.
Quality of the available public transport (e.g. unreliable, not flexible, etc.)	Belgium, Croatia, Finland*, Greece, Ireland*, Italy, Jersey, Luxembourg, Romania, Slovakia, UK (Scotland).
Price of the transportation	Bulgaria, Finland*, Jersey, Latvia, Lithuania, Romania, Slovenia.
Problems to get on or off public transport	Austria, Belgium, Bulgaria, Cyprus, Croatia, Denmark, Finland*, France, Germany, Greece, Ireland, Jersey, Lithuania, Luxembourg, Malta, Netherlands, Romania, Slovakia, Spain, Switzerland, UK (Scotland).
Problems getting the ticket	Austria, Belgium, Bulgaria, Czech Republic, Croatia, Denmark, Finland*, France, Germany, Greece, Italy, Jersey, Latvia, Lithuania, Norway, Romania, Slovenia, Spain, Switzerland, UK (Scotland).
Information about public transport is not provided in a dementia-friendly manner	Austria, Belgium, Bulgaria, Cyprus, Czech Republic, Croatia, Finland*, France, Germany, Greece, Ireland, Italy, Jersey, Latvia, Lithuania, Malta, Monaco, Netherlands, Norway, Poland, Portugal, Romania, Slovakia, Slovenia, Spain, Sweden, Switzerland, Turkey, UK (Scotland).
People working in transportation schemes lack awareness or understanding of dementia	Austria, Belgium, Croatia, Cyprus, Denmark, Finland*, France, Germany, Greece, Italy, Latvia, Lithuania, Luxembourg, Malta, Monaco, Netherlands, Norway, Poland, Portugal, Slovakia, Slovenia, Spain, Sweden, Switzerland, Turkey, UK (Scotland).
Lack of interventions that may facilitate the use of existing transportation schemes by people with dementia	Austria, Belgium (Flanders), Cyprus, Czech Republic, Croatia, Denmark, Finland*, Germany, Ireland, Italy, Jersey, Latvia, Lithuania, Malta, Netherlands, Poland, Portugal, Slovakia, Slovenia, Sweden, Switzerland, Turkey, UK (Scotland).

(\*) Situation may vary in different parts of the country

Some organisations (Finland, Ireland, UK (Scotland)) stated that public transport services may vary across the country, for example, large urban areas tend to have good transport links, whilst smaller towns and remote/rural areas are not as well-serviced.

Alzheimer Scotland also pointed out that the connecting journey from home to the bus stop or train station may inhibit use of public transport both because of the distance required to travel, and lack of safe road crossings and potentially the state of the pavements and roadways. Changes to familiar routes and timetables, particularly for buses, can cause people with dementia to become confused by the changes (temporary or permanent) and may result in people deciding not to undertake journeys. In Scotland,

despite people with dementia being covered by the Equalities Act, public transport providers tend to focus their adjustments and support to people with physical disability and sensory impairment whose condition may be more apparent. There appears to be less recognition of the impact cognitive impairment can have on travellers with dementia.

The Netherlands presented an example of how some changes in the transport system may affect people with dementia. Since 2014, people have to use a payment card to travel in public transport. This means that travellers need to swipe in at the start of their journey and to swipe out at the gates when leaving the station. If a person with dementia does not swipe in, s/he may be issued with a penalty fare, if s/he doesn't swipe out, s/he will pay more than needed.

### 4.3.5 Personal accounts



“I was diagnosed with an early Alzheimer’s disease at the age of 59. Two years after the diagnosis I had to return my driving license based on neuropsychological tests. I had been driving since I was 18 and it felt like I was deprived of my human rights. I was so angry that I changed my doctor but I couldn’t get my license back. For the next two years I took the bus and train to visit my mother twice a week with my dog until an unpleasant accident happened on the train. I was getting out of the train when a ticket inspector asked me to show my ticket. It was hard for me to find the ticket because I was carrying my dog. The ticket inspector didn’t let me out because he suspected I was traveling without a ticket. The train moved on and I was told to get out on the next stop. I got lost in the dark. I was confused. I didn’t know which way to go. I called home but I couldn’t know where I was. My wife suggested that I asked someone for help. A friendly bypasser took me to the right stop. The experience was scary for me and my family. Nowadays I take a taxi to visit my mother”.

*Raoul Grönqvist, EWGPWD, Finland*

## 4.4 Social participation

The WHO (2007) recognises social participation as a key element for good health and well-being throughout life, and thus, it is identified as another core feature in its framework for age-friendly cities. This section provides information on national policies addressing the social participation of people with dementia (4.4.1) and on notable practices promoting the participation of people with dementia in mainstream everyday life activities and in the social, cultural and spiritual life of the community (4.4.2 and 4.4.3). The section concludes with a personal account from a person with dementia (4.4.4).

### 4.4.1 Participation of people with dementia in society: national policies

Many people with dementia wish to continue doing the activities that they used to do prior to their diagnosis (Branson et al., 2011). These activities and day-to-day tasks can contribute to people’s sense of independence, self-esteem and purpose. People living with dementia may experience exclusion from social participation and from social engagement in diverse ways. After diagnosis, long-established social networks can break down and people with dementia may need to negotiate a new set of relationships (Innovations in dementia, 2011). People with dementia may also experience limited opportunities for meaningful occupation, for engaging in leisure activities or for enjoyment of the arts. It may be more difficult for them to maintain contact with a faith community and then have more limited opportunities for spiritual expression (Cantley and Bowes, 2012).

The social participation of people with dementia has been addressed in some of the existing national dementia

strategies (Belgium (Flanders), Finland, Ireland, Luxembourg, Malta, Switzerland, UK (Scotland)). In Malta, one of the main objectives of the national dementia strategy is that of engaging people with dementia in the workings of society in general. This is particularly important during the implementation phase (Chapter 9) which specifically states that individuals living with dementia and their caregivers and family members should be directly involved during the various stages of the implementation process. In Finland, the national memory programme (2012–2020) states that “the third sector is responsible for cooperating with local authorities and joint authorities to provide people with dementia and their families with opportunities to engage in social activities, access to peer support and information to help them cope with daily routines and enjoy a richer life”. The Dementia Plan in Belgium (Flanders), Luxembourg and Switzerland similarly promote the social participation of people with dementia, mainly through the development of dementia-friendly communities in the country. In Norway, this topic may be addressed in the new National Dementia Strategy which is currently under development.

One of the key outcomes of Scotland’s National Dementia Strategy (2013–2016) is to promote “dementia-enabled and dementia-friendly local communities that contribute to greater awareness of dementia and reduce stigma. They should also be, as much as possible, visible, connected and active participants in their local communities – including in social events, the arts, and religious and community groups. Nurturing and supporting dementia-aware and dementia-friendly local communities is important in creating and sustaining a society where people with dementia and their families and carers feel included and at the heart of the community”<sup>19</sup>.

<sup>19</sup> The Life Changes Trust (an independent Scottish charity) is of significant importance in funding dementia-friendly community activity over the course of the current strategy and beyond.

Other relevant national policies addressing the social participation of people with dementia in Scotland are the Charter of Rights for People with Dementia and their Carers in Scotland, 2009 (developed by the Scottish Parliament Cross-Party Group on Alzheimer’s and Alzheimer Scotland) and the Standards of Care for Dementia in Scotland: Action to support the change programme, Scotland’s National Dementia Strategy, 2011 (Scottish Government). The standards of care are underpinned by the Charter of Rights. These standards have been developed to help people with dementia and their carers understand their rights, and how these rights can help make sure that they receive the support they need to stay well, safe and listened to, wherever they live and in whatever setting they receive support and services from health and social care staff. Relevant standards are:

- People with dementia and their carers have the right to live as independently as possible with access to recreational, leisure and cultural life in their community.
- People with dementia have the right to help to attain and maintain maximum independence, physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.
- People with dementia and their carers have the right to access opportunities for community education and lifelong learning.

When these standards are met, it is expected that people with dementia will feel safe, secure and live as independently as possible; preserve the relationships important to them; and feel involved and included in their community wherever they live.

Under the Equality Act (2010), businesses in some parts of the UK (England, Wales, Scotland) are required to make “reasonable adjustments” to ensure their services are accessible to people with disabilities. This includes removing any physical barriers that prevent people with disabilities from accessing their services, where reasonable, and also not treating a person with disabilities less favourably (Alzheimer’s Society factsheet). According to the Equality Act, a person has a disability “if he/she has a physical or mental impairment, and the impairment has a substantial and long-term adverse effect on his/her ability to carry out

normal day-to-day activities” (Chapter 1: 6). In addition, in the Prime Minister’s Challenge on Dementia 2020 (2015), all businesses in England are encouraged and supported to become dementia friendly, with all industry sectors developing dementia-friendly charters. It is stated that the national and local government will be taking a leadership role with all government departments and public sector organisations becoming dementia friendly.

In Germany, the Alliance for People with Dementia (Allianz für Menschen mit Demenz) is an initiative of the German Federal Government and is part of the demographic strategy<sup>20</sup>. At the inaugural meeting, (2012) the partners adopted a joint declaration, on which basis an agenda was elaborated with specific resolutions and measures. The agenda is shaped by the principle of inclusion. Inclusion is also the declared objective of the UN Convention on the Rights of Persons with Disabilities, which was ratified by Germany and thus is binding. In Germany, people with disabilities, including those with dementia, have a right to non-discrimination, equal opportunity and equal participation in society. Establishing and developing the necessary framework conditions is a task for society as a whole. It also includes raising awareness of dementia and bringing about a change in how we interact with people living with dementia.

#### 4.4.2 Participation in everyday life activities

National organisations were asked about initiatives that enable people with dementia to participate in everyday life activities in their community. Around one-third of the participating countries (Austria, Belgium, Finland, Germany, Ireland, Jersey, Latvia, Netherlands, Norway, Spain, Sweden, Switzerland, UK (England, NI and Scotland)) identified one or more dementia-friendly initiatives in this area, i.e. facilities, businesses and services that are working to better respond to the needs of customers with dementia. The most commonly reported businesses that have made efforts to better respond to the needs of customers with dementia are banks and chemists’ (see Table 6). There were also several examples of these types of initiatives in small local businesses, including hairdressers and local groceries.

<sup>20</sup> The Alliance brings together public agencies and civil society organisations, including peer support groups, which work to support people with dementia on a federal, state and municipal level, and pools the forces of all responsible stakeholders. The German Alzheimer’s Association (Deutsche Alzheimer Gesellschaft), as the representative of people with dementia and their families, is an important partner of the Alliance. In addition, people with dementia who are involved in peer-support groups have formulated their own visions and expectations of the Alliance.

Table 6: Dementia-friendly facilities, businesses and services.

<b>Banks</b>	Belgium, Germany, Ireland, Jersey, Netherlands, Norway, Switzerland, UK (England, NI, Scotland).
<b>Supermarkets and shopping centres</b>	Germany, Ireland, Netherlands, Norway, UK (England, NI, Scotland).
<b>Small/local shops</b>	Belgium, Ireland, Latvia, Netherlands, Norway, UK (England, NI, Scotland).
<b>Hairdressers</b>	Germany, Ireland, Latvia, Norway, Sweden, Switzerland, UK (England, NI, Scotland).
<b>Chemists'/pharmacies</b>	Austria, Belgium, Ireland, Norway, Spain, Switzerland, UK (England, NI, Scotland).
<b>Restaurants and coffee shops</b>	Belgium (Flanders), Ireland, Netherlands, UK (England, NI, Scotland).
<b>Post offices</b>	Ireland, Norway, Sweden, UK (England, NI).
<b>Others</b>	Finland, Norway, Switzerland.

These initiatives vary in scope and in their focus. In terms of their focus, initiatives usually involve increasing staff awareness and knowledge about dementia, and learning more about the impact of dementia on their customers with dementia. A main goal is that staff are informed and confident to signpost customers who need dementia support. It may also involve making a commitment and action plan to support people with dementia who use their services. In some cases, it may involve improving the physical environment, for example making adjustments to their premises such as better signage or lighting. In the opinion of the participating organisations, this is relevant as an improved experience for people with dementia and greater understanding and patience shown by staff in these businesses, can help people retain independence and carry on doing the things they want or need to do in their communities. Bad experiences or bad reactions from staff and other customers can put people with dementia off trying to maintain these activities.

In terms of their scope, some of the described practices refer to small independent local businesses which are working towards becoming dementia friendly. For example, Germany and Latvia described the existence of a few hairdressers that are working to become dementia friendly. In Bruges (Belgium), several shop-owners have received training about dementia. Shops classified as “dementia-friendly”, can display a logo of a knotted red handkerchief. Also, the UK (England, Scotland) referred to the work done at a local level where small or local businesses are working to become dementia friendly. This can be part of the work of the DFC efforts, or more naturally occurring initiatives.

On the other hand, some of these initiatives have a larger scope. In some countries, a number of national work streams have been introduced to drive this forward:

- UK (England, NI): In the same way that dementia affects everybody differently, it affects all industries differently. The Alzheimer’s Society has worked with a number of key stakeholders to produce industry-specific guidance around dementia-friendly approaches, including:
  - Working with Lloyds Banking Group and other financial institutions to create the dementia-friendly financial services charter. The charter has been designed to enable the sector to work towards becoming dementia friendly. Signing up to the dementia-friendly charter is a commitment to understand the barriers within the finance industry that are faced by people who have dementia and their carers, and take action to remove those barriers where it is possible and appropriate to do so.
- UK (Scotland):
  - Alzheimer Scotland has worked with one national bank to develop support materials (hints and tips and a poster on supporting customers with dementia) and a training session which was delivered by local branch staff to their colleagues on the same date as part of staff training. Staff were then asked to consider how they could improve their working practices and personal level of customer service for people with dementia. Each branch now has a dementia-friendly banking symbol on display in their premises.
  - A large supermarket chain received dementia training for all its charity champions who are expected to cascade their learning to other staff. A poster and “table toppers” (with information about dementia, how to support customers with dementia and where to go for more help) have been developed for all staff canteens.



- Finally, some branches of a large pharmacy chain have made consultation rooms and display space available to Alzheimer Scotland’s Dementia Advisors for drop-in surgeries on set dates and times where customers and staff can ask about dementia and be signposted to local sources of support.
- In Belgium (Wallonia and Brussels):
  - The Ligue Alzheimer has participated in discussions about how to make banks more age and dementia friendly, this involved work with the headquarters of the bank BNP Paribas in Brussels.

Initiatives to support chemists’ and pharmacies to become dementia friendly were reported by Austria and Belgium (Wallonia and Brussels). This initiative started in 2013 and was a joint effort of the Institute for Palliative Care and Organisational Ethics, Alpen-Adria University Klagenfurt-Wien-Graz, Alzheimer Austria, and the Austrian Chamber of Pharmacists. To date, 18 chemists in two regions (Vienna and Lower Austria) have joined this initiative. The project is entitled “*Dementia-friendly community pharmacies. Community-based health promotion for people with dementia and their caregivers*”, and is based on palliative care and health promotion principles. It aims at making community pharmacies more dementia friendly by supporting dignity and improving the quality of life of people with dementia and of their caregivers. This necessitates the involvement of all relevant partners, i.e. people with dementia and their caregivers, community pharmacists and health care and community partners. In the first phase of the project, workshops for community pharmacists were created covering the topics of “pharmaceutical care”; “networking in the community” and “communication”. In the second phase, the chemists’ conducted pilot-projects based on a needs-assessment with caregivers of people with dementia. These projects range from issues related to the core-business of pharmacies – to improve the pharmaceutical care for people with dementia and networking with local medical doctors – to community projects. A toolbox encompassing project-related documents has been developed to ensure sustainability. Some chemists’ and pharmacies in Belgium (Wallonia and Brussels) are also working to become dementia friendly. These pharmacies and chemists’ distribute information about dementia, support and relevant activities. The Jersey Alzheimer’s Association is working with the local Pharmacists’ forum.

Some organisations (Finland, Ireland, UK (NI, England)) have produced customer-facing guides or training. For example, in Ireland, the Dementia Elevator<sup>21</sup>, has provided retailer training online and along with the Alzheimer Society of Ireland have supported a number of dementia-friendly community projects to hold training for businesses in their areas in order that retailers are more aware of their customers with dementia. The areas which have undergone training include Wicklow Dementia-Friendly Project, Dementia Aware Donegal, The Crystal Project, Mallow, County Cork. This training and support started in 2014 and will run until 2016.

The Alzheimer’s association in Germany, in collaboration with other partners, has developed the handbook “Living alone with dementia. Challenges for municipalities”. This handbook includes educational programmes for employees of banks and supermarkets and the neighbourhood.

Since 2010, the Swiss Alzheimer’s Association has created a number of information sheets for different type of businesses about “people with dementia as a client”. The first of these information sheets was for hairdressers.

In summary, the initiatives described in this section may help retailers and businesses to be aware and better understand the obstacles people with dementia may encounter and support them to change their local environments to be more accessible and their staff to be more aware and supportive of people with dementia.

#### 4.4.3 Involvement in social, cultural and spiritual life in the community

Table 7 displays information on the countries that reported initiatives which promote the participation of people with dementia in social, cultural and spiritual life. The information provided by the participating organisations referred mostly to the participation of people with dementia in mainstream activities, but also sometimes referred to activities organised by the Alzheimer’s associations specifically for people with dementia and their carers. The majority of initiatives described in this section refer to the former examples (i.e. activities to promote the participation of people with dementia in mainstream activities).

<sup>21</sup> Dementia Elevator is an education and empowerment programme developed by Dublin City University and the Health Service Executive (with the support of Atlantic Philanthropies) to help individuals, communities and health systems engage appropriately with people with dementia.

Table 7: Participation of people with dementia in social, cultural and spiritual life.

<b>Leisure and exercise</b>	Belgium (Wallonia and Brussels), Denmark, Finland, Germany, Greece, Ireland, Jersey, Luxembourg, Monaco, Netherlands, Norway, Spain, Sweden, UK.
<b>Excursions, holidays, hotels</b>	Belgium (Wallonia and Brussels), Denmark, France, Finland, Germany, Ireland, Jersey, Luxembourg, Netherlands, Portugal, Spain, Sweden, Switzerland, UK.
<b>Cultural activities</b>	Belgium, Denmark, France, Finland, Germany, Greece, Ireland, Jersey, Luxembourg, Monaco, Netherlands, Norway, Portugal, Romania, Spain, Sweden, Switzerland, UK.
<b>Educational activities</b>	Denmark, Ireland, Jersey, Luxembourg, Netherlands, Slovenia, Sweden, UK.
<b>Socialisation and dementia cafes</b>	Austria, Belgium, Croatia, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Jersey, Luxembourg, Malta, Netherlands, Norway, Portugal, Romania, Slovenia, Spain, Sweden, Switzerland, UK.
<b>Spiritual and religious activities</b>	Finland, Germany, Greece, Ireland, Jersey, Luxembourg, Monaco, Netherlands, Sweden, UK.

#### 4.4.3.1 Leisure and exercise

Many people with dementia remain (or wish to be) physically active despite their illness but may lack the confidence to take part in organised physical activities, or sometimes, existing facilities may lack accessible options or may not be suited to their needs. Encouraging people with dementia to keep active in a variety of ways is likely to keep them more physically healthy and may also help with maintaining social skills and preventing isolation. It promotes a sense of community connection and enables socialisation with peers. Several of the participating organisations reported initiatives aimed at promoting the participation of people with dementia in recreational and leisure activities in their community. In Finland, some of the Alzheimer’s associations organise sporting activities for people with dementia in local gyms and football clubs. These initiatives provide possibilities for people with dementia to stay physically active and to participate in mainstream activities in their local community. “Splashchat” is a swimming activity for people with young onset dementia organised by the Jersey Alzheimer’s Association in partnership with occupational therapists. The activity is run in an indoor swimming pool and is followed by coffee in a bar/restaurant. In Belgium (Wallonia and Brussels), some sport organisations, such as ADEPS, welcome people with dementia to participate in their walking activities.

In 2014, Glasgow Life and Alzheimer Scotland encouraged leisure centre activities to be more dementia friendly and increase opportunities for people with dementia, their families and carers to participate in sport or healthy activities. This local initiative built on an existing Active Ageing programme. A project coordinator provided training and a written guide for leisure centre staff on making their activity

classes and their premises (including cafes) more dementia friendly and initiated referral pathways from health and social care staff to leisure centres for people with dementia who wanted to be physically active. The activities included swimming, bowling, walking and easy exercise. This project showed that it is possible for people with dementia to continue to be physically active and demonstrated how simple adjustments (such as shorter length sessions and better signage) and staff training can facilitate this. In Scotland, another Dementia-Friendly Walking Community project is about to start, run by a charity called Paths for All and funded by the Life Changes Trust. This funding will help ensure that everyone affected by dementia also has the opportunity to take part, enjoy the benefits of walking, improve their health and well-being and be part of a larger community.

#### 4.4.3.2 Holidays

In Finland, a national organisation called “Rural health and holiday foundation – MTLH” organises supported holidays for persons who would not be able to go on holiday otherwise. The holidays are organised for groups and have a preplanned, tailored programme. People with dementia and their family members are eligible to apply for these holidays. In the UK (Scotland), the hotel staff of a privately run hotel (Alona Hotel) in Motherwell, North Lanarkshire has undergone Dementia Friends sessions. Also, hotel management have improved signage within the hotel. This initiative provides a supportive environment and welcoming and understanding staff for people with dementia using the hotel.

Some Alzheimer’s associations, such as the Swiss and the French associations, organise holidays for people with dementia and their caregivers.

#### 4.4.3.3 Arts and cultural life

Several organisations provided examples of initiatives that aim to provide opportunities for people with dementia to continue to participate in mainstream social and cultural life. Inspired by the Museum of Modern Art (MoMA)<sup>22</sup> in New York, a number of countries have implemented initiatives to make museums more accessible for people with dementia. The “Meet Me at MoMA” project was developed to involve people with dementia and their families in responding to the works exhibited at the museum. It provides a welcoming space for people with dementia to participate in facilitated discussions about exhibited artworks. This initiative has been adapted and implemented by a range of other cultural bodies throughout the world. The Museum of Modern Art, in Antwerp (Belgium), (Meet me @MHKA) organises group visits for people at an early stage of dementia and their carers. The M – Museum Leuven, (“Forgot to come out?”) in Leuven, Belgium, has developed an audio-route for people with dementia and their carers. In addition, staff working at the museum have received training to better support people with dementia during museum visits. Since 2013, in Amsterdam, the Stedelijk Museum (Onvergetelijk Stedelijk “Unforgettable Stedelijk”) makes art accessible for people with dementia and their caregivers. The initiative consists of interactive tours in the museum. The aim is to offer people with dementia an opportunity to express themselves and to engage in a dialogue with their environment. The museum offers a safe, positive and inspiring environment to get in touch with others.

In Ireland, the Azure project aimed to explore how people with dementia and their carers could have a deeper involvement in cultural institutions and participate in cultural activities. In 2012, the Azure pilot project culminated in an international round table hosted at IMMA (Irish Museum of Modern Art) that generated significant interest among a range of professionals from the arts community and those working with people with dementia. Since the pilot project in 2012, the Butler Gallery in Kilkenny has continued to curate events for people living with dementia and their carers. The pilot project was evaluated and clearly shows the value and impact of engaging with the arts both for the person living with dementia and their families. This initiative requires specialised training, which has been developed by the MoMA in New York City. The Azure steering group has established an ongoing partnership with MoMA and seeks to bring their expertise to Ireland to train arts facilitators to develop the practical skills required to deliver this innovative programme. Creating a pool of trained facilitators in Ireland will, in effect, create a sustainable resource for the future. The training will focus on building capacity amongst

staff of approximately 10–12 existing organisations, totaling 12–16 staff to facilitate sessions on an ongoing basis.

There are several examples of similar initiatives across the UK, including the National Museum Liverpool’s House of Memories, Dulwich Picture Gallery’s Visual to Vocal programme and Tyne and Wear Archive and Museum’s Platinum Extra Care Programme.

In Joensuu, Finland, a museum has organised a mobile exhibition of high-quality photos of art targeted to people with dementia and their families. In Sweden, the programme “Meeting with the Memories” assists museums in Sweden to develop applications with interactive displays that are suitable for people with dementia and their families.

In the UK (Scotland), National Galleries Scotland has organised a series of free relaxed tours of art galleries for anyone affected by dementia as well as the general public. In 2014, the Edinburgh Festival Theatre held a performance of a play in the Studio at the Festival Theatre which was followed by an informal cream tea reception that provided an opportunity for the audience to meet the performers and the musicians in the show. This was the start of a programme of work to make the Festival and King’s Theatres in Edinburgh dementia friendly. This programme of work includes: more “relaxed” performances, Dementia Friends sessions being delivered to theatre staff and volunteers, and the application of dementia design principles to the redevelopment of the King’s Theatre. Dementia-Friendly Days are also held by the Macrobert Arts Centre at the University of Stirling. Activities include art, dance, drama and film.

In Newcastle (UK), the Dementia-Friendly Cinema project was initiated by the Elders Council of Newcastle who also provided seed funding to start the project. It has been developed and informed by a steering group which includes the Elders Council, Tyneside Cinema, Alzheimer’s Society, Newcastle Carers, Dementia Care, Newcastle Quality of Life Partnership and Newcastle University’s Institute for Ageing. During the summer some of the world’s most beloved musicals for older people were screened. These events were open to everyone and enhanced to suit the needs of people with dementia. A public consultation contributed to the choice of films and of measures to make the cinema more safe and comfortable for the audience. For example, the volume was slightly lowered and the lights left on low. Similarly, the Plymouth Arts Centre started screening dementia-friendly matinee films in 2015. Although the screenings are not exclusively for people with dementia, the general public attending are made aware that there may be people talking during the film, moving around and leaving

<sup>22</sup> The MoMA has a number of projects for people with dementia. Meet Me at MoMA, is a monthly interactive gallery-discussion programme for individuals with dementia and their family or professional care partners. Specially trained museum educators facilitate all programme offerings.

the cinema. The cinema house lights are left on low so that people can see to move around if necessary.

In Jersey, the central library, second library and mobile library are offering “books on dementia by prescription” (a UK initiative) and the Jersey Alzheimer’s Association has delivered dementia awareness teaching to library staff. In the UK (Scotland), “Living well with Dementia” is an initiative in Glasgow libraries providing a reading list of 25 recommended books for people with dementia and their families and adding a readily identifiable sticker to indicate which books are on the list. Dundee Central Library is the first public library in Scotland to provide a Dementia Information Service. Leisure and Culture Dundee, which manages Dundee libraries, received funding from the Scottish Library and Information Council to provide an area that houses an extensive range of resources to help those living with the condition as well as families, carers and professionals learn more about dementia. The Dundee service was launched in May 2015. This initiative provides a source of information for people with dementia and their families to help them better understand their condition and to realise that they are not alone. It also raises awareness of dementia to the wider public.

#### 4.4.3.4 Dementia cafes

Several countries run dementia café schemes. Originally pioneered by Dr Miesen in the Netherlands in 1997, the dementia café model is a setting in which people with dementia, their families and professional carers can come together in a friendly and comfortable place to socialise and get information and support. It is held on a set date at a set time, and is based on a set format. It usually follows a programme of themes, which for the most part is repeated each year. Dementia cafés are currently organised in Austria<sup>23</sup>, Belgium<sup>24</sup>, Croatia, Denmark, Finland<sup>25</sup>, Greece, Ireland, Italy, Jersey, Luxembourg, Malta, the Netherlands, Portugal, Slovenia, Sweden, Switzerland and the UK.

The “bistrot memoire” is a similar initiative developed in France where people with dementia and their carers can meet weekly in a social public space that is not stigmatised and that is part of the city, as for example restaurants or coffee shops. Typically, the sessions are organised during week days in the afternoon, last around 3 hours and there are around 20 participants. Participants can arrive and leave at any time.

#### 4.4.4 Personal account<sup>26</sup>



“I go to yoga. I’ve always admired people that do yoga but I was too busy being a mum and a daughter and when I got a diagnosis of dementia I was reading all this stuff that says it is good for you. And I thought wow, I could do yoga. That would tick a few boxes. So I found a gym that offered yoga and I put myself forward and explained to them that I had dementia, that I had issues. I’d never done yoga before but I think it would be good for me. And that was about eight years ago and I went and what happened was that I learnt yoga, it has enabled and helped me in preventing falls, because yoga helps your core. So I’ve integrated into something that is not dementia and then they learnt about dementia. They learnt that there were certain ways they could put their mats that would cause me distress. And I had to have the tenacity and the courage to put my hand up and say, “I want to continue to do this. Could you tweak what you are doing?” And we discussed it and they changed it. They never ever in this class, they never ever used the word dementia, but when new members come, if they put their mat the wrong way or if the music is too loud or inappropriate, they would say, “In this session, this is how we organise it”. So they don’t make me special. They just enabled you to be part of something and we’ve managed to grow”.

*Agnes Houston, EWGPWD, UK (Scotland)*

<sup>23</sup> In Austria and Belgium (Wallonia and Brussels) these are called “Alzheimer cafes”.

<sup>24</sup> In Austria and Belgium (Wallonia and Brussels) these are called “Alzheimer cafes”.

<sup>25</sup> In Finland these are called “memory cafes”.

<sup>26</sup> This text is part of a consultation that was carried out by AE in a joint project with INTERDEM in Brussels on May 2015.

## 4.5 Social inclusion and attitudes

“Respect and social inclusion” is another of the core features highlighted in the WHO framework for age-friendly cities (WHO, 2007). This section provides information on national policies and notable practices aimed at tackling stigma and changing attitudes to dementia (4.5.1 and 4.5.2). It provides information of existing working groups of people with dementia (4.5.3). The section concludes with a personal account from a person with dementia (4.5.4).

and the reactions of people close to them (Alzheimer’s Society, 2008). People with dementia are often portrayed as incapable or frail, and thus they are not consulted, and their voices are not heard and attended to, on all matters concerning them. A multitude of interventions are advocated to address stigma (Vernooij-Dassen et al., as cited by Nolan et al., 2006). Examples include public awareness raising, education, increasing direct contact, and also legislative, advocacy and human rights approaches.

### 4.5.1 Tackling stigma and changing attitudes: national policies

Stigma is a complex and multidimensional concept. It involves attitudes, feelings and behaviours (Nolan et al., 2006). Research has shown that the stigma of dementia is very pervasive. It involves the representation of dementia,

From a policy perspective, several national dementia strategies (Belgium (Flanders), Cyprus, Finland, France, Ireland, Italy, Luxembourg, Malta, Norway, Sweden, UK (England, NI, Scotland)) commit to reducing the stigma associated to dementia in their country<sup>27</sup>. The organisations in Germany, Lithuania and Monaco, also identified a national policy aiming at reducing stigma in their country<sup>28</sup>.

**Table 8: References to awareness, stigma, and changing attitudes to dementia in national policies**

<b>Raising awareness of dementia</b>	Belgium (Flanders), Cyprus, Finland, Germany, Ireland, Italy, Lithuania, Luxembourg, Malta, Monaco, Norway, Sweden, UK (England, NI, Scotland).
<b>Reducing stigma associated with dementia</b>	Belgium (Flanders), Cyprus, Finland, France, Germany, Ireland, Italy, Lithuania, Luxembourg, Malta, Monaco, Norway, Sweden, UK (England, NI, Scotland).
<b>Changing attitudes to dementia</b>	Belgium (Flanders), Cyprus, Finland, Germany, Ireland, Italy, Lithuania, Luxembourg, Malta, Monaco, Norway, Sweden, UK (Scotland).
<b>Changing perceptions of dementia</b>	Belgium (Flanders), Cyprus, Finland, Germany, Ireland, Italy, Lithuania, Luxembourg, Malta, Monaco, Norway, Sweden, UK (England, NI, Scotland).

### 4.5.2 Notable practices

Participating organisations were asked about initiatives aiming at raising awareness of, and changing perceptions of and attitudes to dementia among children and young people, local authorities, councils and policy makers in their country. Different types of interventions to raise awareness of dementia among children and young people were reported by the participating organisations. Some countries (Belgium, Finland, France, Sweden) have produced books for children explaining the various aspects of dementia. Another approach reported by some of the participating organisations is to create links between the Alzheimer’s associations (or other relevant care or health organisations) and schools (Cyprus, Greece, Ireland, Jersey, Luxembourg, Monaco, Netherlands, Slovakia, Slovenia, UK (Scotland)).

Alzheimer Scotland staff work with older children, giving awareness sessions and speaking at school assemblies, and in some areas, the Dementia Friends programme is being delivered to children. In Portugal, the project “Memo e Kelembra nas Escolas” is a creative way of introducing the topic of dementia in a more positive way to children at school. The facilitator of the session presents the book “O pequeno elefante Memo” to the children. There is also time for feedback and questions. The sessions are ended with the “elephant dance”. This activity has been implemented in 19 schools (3,429 pupils) in Portugal. In Ireland, the Dementia Services Information and Development Centre (DSIDC) produced a pilot programme which is aimed at secondary level schools (14–16 years old). This programme

<sup>27</sup> Austria is currently in the process of developing a National Dementia Strategy, and according to Alzheimer Austria, this strategy will address the social participation of people with dementia in society and will aim at tackling the taboo surrounding dementia.

<sup>28</sup> The policies reported by these countries are: “Alliance for people with dementia: fields of action” (Germany); The Law on Equal Rights”, issued by the Parliament of the Republic of Lithuania”, 18th November, 2003, No IX-1826 (Lithuania).

is called “Will Grandad Remember Me? A Dementia Awareness Project for Schools” which was piloted over the past year in two schools in Dublin. One programme was over a period of five weeks (800mins) in a boys’ secondary school and the other (120mins) in a girls’ school. This programme has focused on awareness of dementia and brain health and factors which are important in terms of healthy living and encouraging young people to think about keeping their bodies and brains healthy. In Germany, the programme “Music and contact” (Alzheimer Association Soest), brings together children from kindergarten and people living in residential care. The initiative “Visit in another country”, provides information to children at school (aged nine years and older) about dementia and organises visits to nursing homes in Stuttgart and the surrounding area. Conferences on the topic of dementia have been organised for secondary level schools (Salzufflen, Berlin). Recently, the German Alzheimer’s Association announced a creativity contest for children and young adults aged 12 to 21. In the contest, they will be invited to provide ideas which could make the lives of people with dementia better.

Finally, some countries have developed material that forms part of the educational curricula for students (Malta, UK (England, NI, Scotland)). Malta, has a booklet that forms part of the educational curriculum for students aged 10–11. In 2007, Alzheimer Scotland produced a resource pack for schools aimed at children aged 10–12 which enabled teachers to deliver a timed lesson, raising awareness of dementia and asking children to consider how they could provide support and understanding. The original pack will be redeveloped to fit with the new curriculum and will be distributed to all primary schools in Autumn 2016. A school pack has also been developed by East Dunbartonshire Council for use in their local primary schools.

Examples of efforts to raise awareness of dementia among local authorities, councils, policy makers and politicians were also provided by some of the participating organisations (Austria, Belgium (Wallonia and Brussels), Croatia, Cyprus, Czech Republic, Finland, Germany, Greece, Ireland, Lithuania, Luxembourg, Monaco, Netherlands, Norway, Slovenia, Spain, Turkey, UK (England, NI, Scotland)). At a European level, in 2007 Alzheimer Europe set up the European Alzheimer’s Alliance which is a non-exclusive, multinational and cross-party group that brings together Members of the European Parliament committed to supporting Alzheimer Europe and its members in making dementia a public health priority in Europe. The European Alzheimer’s Alliance currently has 110 Members from 27 Member States of the European Union and from 6 of the 7 political groups in the European Parliament.

In Finland, the Alzheimer Society ran a campaign during the Parliamentary Election season in 2015 (Muistii5 – Memory15) to raise awareness of the needs of people with dementia

and their carers among parliamentary candidates. In Ireland, at the time of the last general election the ASI asked those running in the election to become a political friend of dementia. 46 elected TDs (Members of Parliament) and senators make up this cross-party political support.

In some countries (Austria, Belgium (Wallonia and Brussels), UK (Northern Ireland)) raising awareness among local authorities, politicians and policy makers is part of the DFC work. DFCs in Northern Ireland have engaged directly with Members of the Legislative Assembly, raising awareness of dementia in their constituencies through briefings. The Society has also produced an MLA (Members of the Legislative Assembly) briefing entitled “Dementia in your constituency”. The Society has also provided workshops to Belfast City Council and Helm Housing.

Other countries (Croatia, Poland, Slovenia), are approaching and working closely with politicians, policy makers and civil servants in order to raise awareness of dementia and develop a national dementia strategy in the country. For example in Croatia, the recently formed Croatian Alzheimer Alliance works in the development of a national strategy and informs policy makers about different issues such as diagnosis, treatment, care, etc. In Poland, the Ombudsman supports the work of the Alzheimer associations and is encouraging policy and decision makers to consider implementing a national dementia strategy.

Finally, several Alzheimer’s associations organise (or are involved in) campaigns that aim at changing the perceptions of dementia in society. An example is the initiative “Forget dementia. Remember man” (Belgium, Flanders). This initiative is part of the implementation of the Dementia Plan Flanders 2010–2014: Towards a dementia-friendly Flanders. It includes a campaign and a website that promote a more positive image of people living with dementia. As part of the campaign, individuals and organisations can sign a “declaration of engagement”. By endorsing the declaration of engagement, individuals and organisations support the principles of the campaign and are encouraged to make small changes in their communities that could make the communities more dementia friendly. The website, is managed by the Dementia Expertise Centre (Expertisecentrum Dementie Vlaanderen) and the Flemish Agency for Care and Health (Vlaams Agentschap Zorg en Gezondheid), in collaboration with the Flemish Alzheimer’s Association (Alzheimer Liga Vlaanderen), the Association of Flemish Cities and Municipalities (Vereniging van Vlaamse Steden en Gemeenten), the Association of Flemish provinces (Vereniging van Vlaamse provincies), Flemish Elders Council (Vlaamse Ouderenraad) and the King Baudouin Foundation (Koning Boudewijnstichting).

In Ireland, the Alzheimer Society of Ireland launched a public awareness campaign in June 2015 (“Forget the stigma of

dementia”). The national campaign sought to rally the public to sign up to a simple, three-step challenge to fight the stigma of dementia. It included a poster campaign at bus stops, in buses and darts, on buses, at train and bus stations throughout Ireland’s three major cities. It also included a social media campaign and a “Learn, Listen, Link” challenge which asked people to agree to learn the facts of dementia, thereby debunking the myths, listen to and empathise with people with dementia and link up with them, not isolate them. The campaign featured two people living with dementia and a carer. More than 4,050 people signed up making it the largest social movement for dementia in Ireland to date.

Early in 2015, Alzheimer Scotland launched an awareness raising campaign aimed at changing the perceptions of dementia in Scotland. The campaign is being rolled out in phases. The first phase of the campaign “Let’s talk about dementia” was aimed at supporting people who are worried about themselves, a family member or friend to encourage families and friends to talk more openly about dementia. The campaign aimed to break down some of the barriers such as the fear of dementia, stigma, and the worry that nothing can be done to help; encourage people to seek help and raise better awareness and understanding of dementia.

The Dementia Friends programme is another initiative to change people’s perceptions of dementia. The initiative has been developed by the Alzheimer’s Society (UK) and has received funding from Public Health England. The programme aims to transform the way the nation thinks, acts and talks about the condition. Dementia Friends are people who have taken part in a 45-minute information session on dementia meaning they are more aware of the condition and have taken an action to commit to being more understanding of people with dementia. A Dementia Friends Champion is a volunteer who encourages others to make a positive difference to people living with dementia in their community. They do this by giving them information about the personal impact of dementia, and what they can do to help. Dementia Friends Champions deliver the Dementia Friends sessions. They have received specific training to do this. According to the Society, there are over one million Dementia Friends across England and Wales. This initiative has been transferred to other countries (Netherlands, UK – Scotland, Turkey). In Turkey, the aim of the Dementia Friends programme is to raise awareness of dementia in the community (e.g. prevention, timely diagnosis, living well with dementia and existing support and care in the community) and to tackle stigma. Inspired by the work undertaken by the UK, the programme was started by the Turkish Alzheimer Society (Türkiye Alzheimer Derneği) in September 2015, and since then, they have organised seven public meetings and 250 people have become dementia friends in the country. They plan to provide the programme online

and are currently working with different groups in the community (local administrations, charity groups, other NGOs, hospitals, pharmaceutical companies, GSM companies, etc.).

Some countries organise awards for people who have excelled in their work, made an outstanding contribution in the community through their voluntary work or contributed in any other way. For example, since 2013, the Alzheimer Society of Finland recognises a “memory friend of the year” (a person who has actively volunteered as a memory friend for a person with dementia). In Jersey, there is an annual award made by the hospital for outstanding person-centred care. The Jersey Alzheimer’s Association makes an annual award which recognises the contribution of an individual or group in advancing the cause of people with dementia and care providers.

Other countries have developed the idea of “Dementia Ambassadors” (Belgium (Flanders), Cyprus, Finland, UK (England and Scotland)). There are similarities but also differences in the way this concept is used in different countries. In Scotland, dementia ambassadors are people in social service and educational roles who have volunteered to develop their skills of working with people with dementia as part of the national “Promoting Excellence learning framework”. There are over 700 dementia ambassadors across social service settings. There are also dementia ambassadors working in educational settings, such as colleges, local authority learning and development teams and independent and voluntary sector training providers. In Belgium (Flanders), the ambassadors are well-known and lesser-known Flemish people who want to draw attention to dementia and to demonstrate that a different way of understanding dementia is possible. In Finland, whilst there are no national champions some of the local associations (e.g. Pirkanmaa region) have set their own dementia ambassadors. These are typically nominated visible figures in the community who promote the cause in their work. A similar initiative in Cyprus, is the “dementia friends”, these are well-known artists who use their musical and art talent to raise awareness of dementia. In Italy (Luserna San Giovanni, Turin), the “Rifugio Re Carlo Alberto” has developed the initiative “Us with you, Ambassadors for Alzheimer’s”. The aim of the initiative is to raise awareness of dementia in the community. A main goal is to empower people with dementia by “celebrating what is possible” in their lives and to enable them to live more socially included lives.

In Malta, the National Dementia Strategy (3.4 c) stipulates the need to identify and appoint a number of “Dementia Activists” with the remit of promoting dementia awareness in schools and the community.

### 4.5.3 Involvement of people with dementia

An essential factor in the work towards becoming more dementia inclusive and friendly, is the engagement and involvement of people with dementia. Community groups need to be pro-active in encouraging people with dementia to participate. Two examples of meaningful involvement of people with dementia are public consultations and the establishment of working groups of people with dementia.

#### Public consultations

Almost two-thirds of the participating countries reported that people with dementia, their carers or the Alzheimer’s association on their behalf, had been involved in public consultations over the last five years in their country (Austria, Greece, Belgium (Wallonia and Brussels), Croatia, Czech Republic, Denmark, France, Finland, Germany, Ireland, Italy, Jersey, Luxembourg, Norway, Sweden, Switzerland, UK (England, NI, Scotland)). In several countries, the Alzheimer’s associations are involved in or consulted about the development of policies or legislation that are relevant to people with dementia. A typical example of this refers to the involvement of the national association in the development of or in discussions about the national dementia strategy.

Alzheimer Austria has been involved in the changes in the law on guardianship and participates in the advisory committee for mental health in the Ministry for Health. The German Alzheimer Association has been involved in the hearing of the long-term care insurance law and co-chairs the National Alliance for people with dementia.

Some Alzheimer’s associations are also involved in working or expert groups and steering committees or make submissions on national policy issues representing people with dementia and carers. In Ireland, for example, the ASI has made ten policy submissions. These submissions are underpinned by a mandate from people with dementia and their carers.

To ensure that the voices of people with dementia and their carers are duly represented, some of the national associations have involved people with dementia and/or carers directly in these consultations. A major consultation the Alzheimer’s Society was involved in was the Care Act 2014 (England only), led by the Department of Health. This is the biggest change to social law in over 60 years and the Alzheimer’s Society was involved in the parliamentary process from the start. The Alzheimer’s Society met with people with dementia in focus groups to gain their views on what

they would want from a new social care system, and took the views of people with dementia to the Department of Health and influenced the legislation to ensure it works better for people with dementia. Social care legislation has also changed in Wales with the Social Services and Well-being Act 2014 (Wales). Similarly, the Alzheimer’s Society has been involved in the consultations and direct influencing to ensure it works in practice for people with dementia. In 2012/13, Alzheimer Scotland organised a series of Dementia Dialogue events in several areas on behalf of the Scottish Government where people with dementia, carers and health and social care professionals came together to give their views on Alzheimer Scotland’s 8 Pillars Model of Community Support and help formulate the second national dementia strategy. In Ireland, to represent the views of people with dementia in the national strategy, the Alzheimer Society of Ireland facilitated a roundtable between the Government’s working group on the strategy and people with dementia (members of the Irish Dementia Working Group).

In some cases, this involvement mainly refers to carers. In Switzerland, the Alzheimer’s association carried out a survey to seek input from carers, this input informed the development of the national strategy. In Greece, a caregiver was included in the working group of the national strategy to ensure the views of carers of people with dementia were taken into account.

Another example is the involvement of people with dementia in the work of national organisations. For instance, Alzheimer Scotland has carried out a series of consultation events considering their advanced dementia care model to help refine the model before it is published in Autumn 2015. People with dementia have been included in these events.

In Scotland and Ireland, where working groups of people with dementia exist, these have been very much involved in the development of national policies. The Chair of the Irish Dementia Working Group is on the Government’s national monitoring group for the national dementia strategy. This is a national consultative process on the implementation of the first Irish national dementia strategy. Members of the Scottish Dementia Working Group have been involved in the development of both national dementia strategies in Scotland and continue to be involved in their monitoring. In addition, people with dementia have been consulted during the development of local dementia strategies, for example in Fife. Representatives of the Scottish Dementia Working Group and National Dementia Carers Action Network are part of Alzheimer Scotland’s Human Rights and Public Policy Committee. A key party of the committee’s role is informing Alzheimer Scotland’s response to public consultations.



## Working groups

For the purpose of this report, working groups are defined as groups composed of people with dementia that have an advocacy or lobbying role. Working groups allow people with dementia to have a voice, influence services and policies and ensure that nothing is done for them without them. They can have different aims such as to campaign to improve services for or attitudes towards people with dementia in the country or advising Alzheimer’s organisations in different ways. Often, members of these groups give speeches at conferences, or talks to different audiences, to raise awareness and change attitudes about dementia. Working groups are different from peer support groups, as the latter are more concerned about sharing experiences and knowledge among its members and providing emotional (or other types of) support.

According to the national organisations, five countries have one or more working groups of people with dementia in their country (Finland, Ireland, Netherlands, Norway and UK (Scotland)). The Scottish Dementia Working Group was a pioneer in this work. It was established in 2002 and has now around 140 members in the country. At a European level, the European Working Group of People With Dementia (EWGPWD) was established in 2012 by Alzheimer Europe, this group is composed of 10 people from different countries and with different types of dementia. Its aim is to ensure that the activities, projects and conferences of Alzheimer Europe duly reflect the priorities and views of people with dementia. It also aims to ensure that people with dementia in Europe are considered as equally valuable members of society and treated accordingly. The chair of the group sits on the Board of Alzheimer Europe. At a global level, the Dementia Alliance International (DAI) is an independent self-advocacy organisation of people with dementia from all around the world that seek to represent, support, and educate others living with the disease. Membership is open and exclusive to anyone with a diagnosis of any type of dementia.

Whilst there is no national working group in Germany, there are about 70 groups of people with dementia at local level. To support networking between the groups and discuss national themes, once a year there is a national meeting for all the groups organised by the German Alzheimer’s Association. There will be an initiative to make it formal through changing of the statutes in November 2015.

The Dementia Engagement and Empowerment Project (DEEP) was a one-year project aiming to highlight groups

and projects involving people with dementia in the UK. The project was managed by the Mental Health Foundation, Innovations in Dementia and the Alzheimer’s Society, and was funded by the Joseph Rowntree Foundation. The project currently brings together groups of people with dementia from across the UK. It supports these groups to try to change services and policies that affect the lives of people with dementia.

The Alzheimer’s Society in Northern Ireland has recently recruited a member of staff to facilitate service user engagement and the setting up of User Engagement Groups is a priority in this context.

Some countries, for example Austria, Belgium and Switzerland, have peer support groups for people with dementia. The main aims of these peer-support groups are to empower people with dementia and to facilitate exchange of experiences and information among its members.

In 2015, France Alzheimer has carried out an extensive research about priorities and needs as experienced by people with dementia.

20 countries reported that there are no examples of similar initiatives in their countries (Croatia, Cyprus, Denmark, Greece, Italy, Jersey, Latvia, Lithuania, Luxembourg, Malta, Monaco, Poland, Portugal, Romania, Slovakia, Slovenia, Spain, Sweden, Switzerland, Turkey). Some of these countries are currently working in different ways to develop similar initiatives in their countries in the coming years (Cyprus, Denmark, Jersey, Luxembourg, Malta, Spain).

The main barriers to establish working groups in these countries are related to:

- Stigma, attitudes or lack of awareness: Cyprus, Greece, Jersey, Luxembourg, Poland, Spain
- Diagnosis made at moderate or severe stages of dementia: Cyprus, Greece, Malta, Poland.
- Lack of support from the Government or from policy makers: Croatia, Turkey.
- Financial and/or time constraints: Croatia, Greece.
- Lack of recognition of people with dementia as active members of society: Italy.
- Size of country: Jersey, Luxembourg.
- Overprotection from families: Poland.
- Cultural aspects: Switzerland, Belgium (Flanders).

	Finland	Ireland	Netherlands
<b>Number of WGs in the country</b>	1	1	1
<b>Scope</b>	National	National	National
<b>When was the group established?</b>	2013	2013	2014
<b>How many people are involved?</b>	15 people, half of them are people with dementia and half are family carers	13 people with dementia	15 people with dementia
<b>Frequency of meetings</b>	Quarterly	4–6 per year	4 per year
<b>Description and aims</b>	<p>The national working group brings forward the expertise gained from first hand experiences with dementia.</p> <p>It supports the work of the Alzheimer Society of Finland and highlights important themes, ideas and views which could otherwise be overlooked.</p>	<p>Aims:</p> <ul style="list-style-type: none"> <li>• To be a voice of and for people with dementia nationally and locally</li> <li>• To actively engage with a wide variety of organisations</li> <li>• To ensure that organisations are dementia friendly</li> <li>• To influence public policies that impact on the lives and human rights of people with dementia</li> <li>• To support policy and research work in dementia</li> <li>• To develop and promote information, awareness and education, and training in the field of dementia</li> <li>• To reduce prejudice and the stigma attached to dementia.</li> </ul>	<p>The Dutch working group of people with dementia is called the 'Kerngroep Dementie'.</p> <p>The meetings of the group are organised by Alzheimer Nederland. Their main aim is advocacy.</p>

Norway	Scotland	Europe
1	1 national working group. Alzheimer Scotland is also supporting the development of local activist groups. There are some established local groups such as the Highland Dementia Working Group, the Positive Dementia Action Group in Aberdeen and a Pioneer Group in Dunbartonshire in the West of Scotland.	1
National	National and local	European
2014	2002	2012
5–6 people with dementia and their carers	SDWG has approximately 140 members across Scotland	10 people with dementia (Czech Republic, England, Finland, Germany, Ireland, Jersey, Norway, Slovenia, Scotland, Sweden)
3–4 per year	On average SDWG members meet once per month to six weeks. Members also frequently represent the groups on various working groups relating to the implementation of the commitments of the National Dementia Strategy and other key stakeholder groups.	3 per year
The aim of the group is to give advice to the association and set the agenda in the Norwegian Alzheimer organisation.	<p>The SDWG is funded and supported by Alzheimer Scotland and grant funding from the Scottish Government.</p> <p>In partnership with Alzheimer Scotland, the SDWG aims to</p> <ul style="list-style-type: none"> <li>• Provide a voice for people with dementia nationally and locally</li> <li>• Influence public policies that impact on the lives of people with dementia and their families</li> <li>• Promote improved provision of services in Scotland</li> <li>• Develop information, education, awareness and training in the field of dementia</li> <li>• Reduce the prejudice and stigma attached to dementia.</li> </ul>	<p>The aim of the WG is to ensure that the activities, projects and conferences of AE duly reflect the priorities and views of people with dementia.</p> <p>It also aims to ensure that people with dementia over Europe are considered as equally valuable members of society and treated accordingly.</p> <p>The chair of the group sits on the board of Alzheimer Europe.</p>

#### 4.5.4 Personal accounts



“(…) But Helen, you have been fighting hard for people with dementia to be afforded the dignity of living well in their own homes. As an advocate, you know you are making a difference, so I am writing to you to tell you to keep working, keep fighting, because all the time you are doing this Alzheimer’s is attacking you and all you have worked for. (…)

“Keep up your advocacy work for as long as you possibly can Helen, because nothing will change until we bring dementia out of the shadows. You have been a community activist for as long as you can remember, and now you fighting for your own rights, and for the rights of everybody with this horrendous illness. If you put your emotions to one side and continue to tell your story the rewards are huge. Not for you, but for all those people living with dementia. As an advocate you are helping to create a better quality of life that, some day, we will all benefit from. Never give up as long as you have breath in your body and don’t let these disease define who you are. You have done so much since those early days. Through the help and support of The Alzheimer Society of Ireland, you have made many new friends, travelled to tell the world that Alzheimer’s isn’t a death sentence.”

*Helen Rochford-Brennan, EWGPWD, Ireland<sup>29</sup>*



“(…) I attend German and European conferences. I tell them to forget what books say about cognitive impairment and to instead please realise the still existing abilities people with dementia have and promote them! I tell doctors, carers, authors to talk to us, to listen to us, to involve us in their decisions about new programmes for people with dementia. We know best what we need, what burden our family carries day by day. I speak up for us all: Involve us, believe in us.”

*Helga Rohra, EWGPWD, Germany<sup>30</sup>*

## 4.6 Civic participation

Civic participation is the last of the core features highlighted in the WHO framework that is addressed in this report. This relates to the opportunities for people with dementia to continue to contribute to their communities and to be engaged in the political process. This section addresses some aspects related to the political participation of people with dementia (i.e. voting) (4.6.1) and employment (4.6.3). It also provides examples of notable practices in both areas (4.6.2, 4.6.4). The section concludes with a personal account from a person with dementia (4.6.5).

### 4.6.1 Voting

Whilst the right to political participation of people with dementia is not explicitly spelt out in European or national legislation, the right of people with disabilities<sup>31</sup> is governed by several international treaties and recommendations in Europe. Examples include the United Nations Convention on the Rights of Persons with Disabilities (CRPD), the International Covenant on Civil and Political Rights (ICCPR), and Recommendation R (2006) 5 of the Council of Europe. These documents emphasize the right of people with disabilities to vote and participate in political and public activities.

<sup>29</sup> This text has been extracted from “A letter to remember from Helen”. A letter that Helen who was diagnosed with early onset dementia wrote to herself. Helen is the chair of the Irish Working Group of People with Dementia and vice-chair of the EWGPWD. The full text can be accessed at <http://www.alzheimer.ie/Alzheimer/media/SiteMedia/Fundraising/Camino/2014/A-Letter-to-Remember-from-Helen-Rochford-Brennan.pdf>.

<sup>30</sup> This text has been extracted from Alzheimer Europe website. Helga is the chair of the EWGPWD, for the full text please visit <http://www.alzheimer-europe.org/Living-with-dementia/Personal-experiences-of-living-with-dementia/Helga-Rohra-Germany>.

<sup>31</sup> As already mentioned in this report, it should be borne in mind that some countries include people with dementia in their definition of people with disabilities, whilst others do not do so explicitly.

Following these recommendations, in some countries, recent changes in legislation have allowed for more people with disabilities to retain their right to vote. The legislation in Austria, Croatia, Italy<sup>32</sup>, Latvia, the Netherlands<sup>33</sup>, Sweden and the UK<sup>34</sup> guarantee the right to vote for all citizens, including those without legal capacity<sup>35</sup>. In Ireland, constitutionally, every citizen has the right to vote and there is no removal of legal capacity once a person receives a diagnosis of dementia.

Some legislation in Europe allows for the right to vote of persons with disabilities to be restricted or limited if the person concerned has been deprived of his or her legal capacity. This exclusion (or limitation) is either set out in the country’s constitution or in electoral legislation. Nevertheless, in most of these European countries, people with dementia can exercise their right to vote if they have not been deprived of their legal capacity. Thus, unless a court has decided to incapacitate the individual, the person has the right to vote irrespective of whether s/he is cognitively able to do so.

Around one third of the participating countries (Bulgaria, Czech Republic, Cyprus, Jersey, Greece, Lithuania, Luxembourg, Malta, Poland, Slovakia, Switzerland, Turkey) reported that individuals who have been deprived of their legal capacity cannot exercise their right to vote.

In some countries, a person who lacks capacity and for whom a guardian<sup>36</sup> has been appointed to make decisions on his/her behalf for all matters is not allowed to vote, whilst individuals lacking capacity with a guardian only for certain matters (e.g. managing property and/or finances) retain their right to vote:

- In Belgium, people with dementia who have been declared interdicted<sup>37</sup> (onbekwaam verklaard) are not allowed to vote. Nevertheless, a person who is temporarily under deputyship (voorlopig bewind)<sup>38</sup> can vote. Based on medical grounds, some people

(e.g. people with dementia, people with disabilities or with mobility problems) with a temporary deputyship can be excused from voting (i.e. not obliged), or can appoint someone they trust to vote on their behalf.

- In France, adults under curatorship (curatelle) are allowed to vote.
- In Germany, the Bundeswahlgesetz (Federal Election Act, 1993) contains some restrictions which affect persons with disabilities. A person who is under guardianship retains the right to vote unless, as stated in the Federal Electoral Law of 1993, s/he is under complete guardianship in all matters (i.e. if a guardian has been appointed to permanently manage all his/her affairs). In this case, the person is automatically deprived of his/her voting rights.
- In Denmark, people lacking capacity who have a deputy for all matters are not allowed to vote. People who have a deputy for managing their finances or property can vote<sup>39</sup>.
- In Monaco, people under tutorship (the strongest form of legal protection in Monaco) are not allowed to vote. Administration (a less strong form) is used more often than tutorship in Monaco. People under administration are allowed to vote.
- In Portugal and Romania, a person who has been declared interdicted has no voting capacity but a person who has been declared incapacitated can vote. However, in Portugal, according to the Electoral Law (2015) people with severe dementia, even if not incapacitated, who have been admitted into a psychiatric institution or if they have been declared as such by a board of doctors, are not allowed to vote.

In some countries, people with dementia may retain their right to vote if this is supported by a judicial decision. For example, in France, for adults under tutorship (tutelle), if the judge considers that the person should not be allowed to vote, this must be specified in the legal decision that establishes or renews the measure. If there is no mention of it, the right to vote is maintained. In Slovenia some adults

<sup>32</sup> Provided that the person retains the capacity to form and express the will.

<sup>33</sup> Provided that the person is still able to express his/her will and sign.

<sup>34</sup> People retain their right to vote as long as they are able to clearly express their voting choice.

<sup>35</sup> Legal capacity or competence can be defined as “the ability of a person to make decisions that the law will uphold” (Position Paper 5. Legal Planning and Dementia, 2005). People who cannot do this are said to “lack capacity”. Lack of capacity may be due to different circumstances (illness, injury, a learning disability, mental health problems, etc.). When that happens, the legal system looks for alternative ways of managing a person’s financial affairs, property and sometimes to make decisions about the person’s health and welfare. A deputy is appointed by the court to make certain decisions on behalf of the person who lacks capacity (please note that “deputy” is the term currently in use in the UK, the terminology used across Europe for this figure varies considerably e.g. guardian, tutor, curator, trustee, etc.). The guardian or deputy can be a friend or relative of the person who lacks capacity, but could also be a professional. Across Europe a diversity of types and degrees of legal incapacity measures and corresponding safeguard exist (FRA, 2013). In most European countries, the deputy can be appointed by the court to make decisions for some (e.g. managing property or financial affairs) or for all matters.

<sup>36</sup> Please note that the terminology used across Europe for this figure varies considerably e.g.: deputy, tutor, curator, trustee, etc.

<sup>37</sup> Interdiction is the higher degree of deprivation of legal competence that covers both personal and property issues.

<sup>38</sup> When a court orders someone to administer the property of the person with dementia.

<sup>39</sup> The former (i.e. higher level of deprivation of legal capacity where the person is under deputyship in all matters) is not often used for people with dementia in Denmark.

with disabilities without legal capacity may retain the right to vote. People with disabilities will be allowed to vote if the judge considers them as capable of understanding the meaning, purpose and effect of elections (European Union Agency for Fundamental Rights, 2014). Similarly, in Spain, the judge should determine for each person who lacks capacity and for whom a tutor or curator is appointed, if the person retains or not his/her right to vote.

In Norway, the Election Act (1985) contains a paragraph on the procedure to follow should the returning committee have reason to assume that a person has a serious mental disorder or is in a reduced state of consciousness. In such cases, the voter's unopened ballot envelope is put to one side and his/her name, address and birth date written on it, along with the reason for excluding the vote and whether the decision to do so was unanimous. The envelope is then given to the election committee which decides whether or not the vote should be rejected.

#### 4.6.2 Notable practices

Countries reported a variety of arrangements in place to assist people with certain disabilities to exercise their voting rights. For example,

- In regard to the polling station, in Ireland, people with disabilities can vote at an alternative polling station if the local station is inaccessible. In the UK, the polling station should be accessible and clearly signed.
- Some countries reported that people with disabilities can be helped at the polling station in different ways. In Ireland, a person with disabilities can ask for help to vote at the polling station by a companion or the presiding officer.<sup>40</sup> Similarly, in the UK, the council officials staffing it can provide assistance about where to go and what to do. A voter can ask for help to mark their ballot paper, either from the polling station presiding officer or from a companion. In Malta, polling booths are manned by a number of assistant electoral commissioners who will assist any individuals who need assistance with voting. The assistant commissioner shall require a voter asking for assistance to confirm this by taking an oath using a particular form. Nevertheless, carers or relatives are not allowed in the polling booth during voting even if the individual asks for that.

Other mechanisms in place to enable people with disabilities or with mobility problems to vote include voting at the place where the person lives and voting by proxy.<sup>41</sup>

- In Croatia, Finland<sup>42</sup>, Latvia and Lithuania individuals who due to mobility problems cannot attend a polling station can vote at home. This is also possible, in Croatia, Ireland, Poland, Latvia and Lithuania, for people with mobility problems in long-term care or hospitals.
- In Belgium, Croatia, Poland and the UK, a person with dementia can appoint a proxy to vote on their behalf at a single election or for more than one election. The proxy must vote in accordance with the wishes of the person with dementia.

Alzheimer Scotland produced guidance about “Voting and dementia” on its website in the lead up to elections.

#### 4.6.3 Employment

Dementia is “young onset” when it affects people before the age of 65. There is conflicting information about the prevalence of young onset dementia. Estimations suggested that young onset may represent around 5% of people with dementia. People with young onset dementia may still be in full employment at the time of diagnosis. Some countries are planning (or have already) to raise the retirement age, thus in coming years more people may be in full employment at the time of diagnosis.

In most of the participating countries relevant legislation for employment does not specifically refer to dementia. Whilst there is no specific reference to dementia in the legislation, the rights of people with dementia can often be protected to some extent by legislation relating to disability or sickness.

Several organisations reported that often people with dementia are advised to opt for early retirement in their country (Austria, Cyprus, Croatia, Germany, Malta, Monaco, Spain, Turkey). In some countries an individual who is certified by a medical panel as being incapable for suitable employment due to disease or impairment will be entitled to an invalidity pension (Cyprus, France, Finland, Germany, Malta, Spain). In some cases (Greece for example) a minimum percentage of disability or age is required to be able to stop working and be entitled to a state pension. In such cases, in some countries, people with dementia are entitled to apply for a disability allowance, support allowance or sickness benefit (Ireland, Netherlands, Slovenia, Switzerland, UK). A number of organisation stated that people with dementia in their country who have to stop working due to dementia may experience a loss of income (Germany, Jersey, Ireland, Latvia, Malta, Netherlands, Switzerland, UK (Scotland)).

<sup>40</sup> In Ireland, the presiding officer may refuse a request for assistance during the last two hours of voting.

<sup>41</sup> Also, voting by post is a frequent practice in several countries in Europe. In some cases, for example in Northern Ireland, only people who meet certain criteria can vote by post, or appoint a proxy. Disability is a criterion to have a postal or a proxy.

<sup>42</sup> The Election Commission should be informed of this at least once week in advance.

Some of the organisations provided information regarding existing measures to support a person with dementia to stay at work in their country should the person so wish. In Finland, employers can apply for financial support from the Labour Administration in order to modify the working conditions and enable a person with dementia to continue working. This support may be used in different ways, for example to make adjustments to equipment or premises, but also to provide peer support from another employee to the person with dementia. In addition, people whose ability to work is limited by ill health or disability can benefit from rehabilitation services.

In Germany, if it becomes clear that a person has some form of personal incapacity, due to dementia or other causes, the person would be covered by the Social Law IX (Sozialgesetzbuch IX) which guarantees better job security.

The new National Plan for Neurodegenerative Diseases in France has provisions for people with a neurodegenerative disease to continue working if they so wish. The suggested solutions include modifying the working conditions or the role of the person at work, increase awareness among occupational health and safety professionals, etc. In practice, a person who, at the time of diagnosis of dementia, is in full employment is referred to an occupational health doctor (médecin du travail). The doctor will assess the fitness to work of the person (considering the role and working conditions) and will provide recommendations on the adjustments that should be made, for example to take on a different role at work or to take a reduction to a part-time position for a maximum period of time of two years. If there are safety concerns, the person may be advised to opt for early retirement.

In Ireland, the Employment Equality Acts 1998–2011 outlaw discrimination in a wide range of employment and employment-related areas. The legislation defines discrimination as treating one person in a less favourable way than another person based on different grounds such as age and disability. Under the Employment Equality Acts the employee is entitled to appropriate measures to help them carry out their work. This means that if it is difficult for the person to carry out their work because of their dementia, the employer must put in place support or special facilities to help them. These measures can include time off to attend medical appointments, mentoring and peer support, adjustment of work hours, change of work duties etc. There are limits to this as appropriate measures cannot place a disproportionate burden on an employer. A person cannot be dismissed because they have dementia.

In the UK, the Equality Act 2010 legally protects people from discrimination in the workplace and in wider society. The act covers direct or indirect discrimination against people with “protected characteristics” including dementia and covers

equality in employment. Equality law recognises that ensuring equality for people with a disability (including dementia) means that employers have to remove barriers and/or provide extra help for a disabled worker or job applicants.

Despite these measures to support people with dementia who want to stay at work, some of the organisations suggested that there are gaps between the intentions stated in the legislation and the experiences of people with dementia in the workplace. Often people with dementia who decide to continue working experience stigma (Czech Republic, Ireland, Jersey, Luxembourg, UK), lack of support (Croatia, Germany) and lack of awareness and understanding from their employers or peers (Belgium, Czech Republic, Denmark, Finland, France, Germany, Greece, Malta, Ireland, UK).

#### 4.6.4 Notable practices

- The organisations in Finland, the Netherlands and Switzerland reported that, whilst this is not yet a systematic practice in their countries, there are a number of “single exemplary companies” which have shown a greater understanding of dementia and have found alternatives for the person with dementia to stay at work or for more open discussions and greater involvement of the person in the decision making processes.
- The project “FrühLink” (“Early Link”) is a joint project of the Alzheimer association in Münster and the Alzheimer association in Rhineland-Westphalia (Germany). The project is funded by a health insurance company. They carry out research activities and offer counselling to people with young onset dementia. They are also in contact with employers.
- The Alzheimer Society of Ireland has published a booklet called “I Have Dementia, I Have Rights” which explains the rights of employees if they receive a diagnosis of dementia and the responsibilities of employers in terms of equality law.
- Two informative guides for employers have been produced recently in the UK (one by the Alzheimer’s Society and the other one by the Dementia Empowerment and Engagement Project – DEEP). The Alzheimer’s Society guide for employers was launched in February 2015. It includes detail of good practice already going on and gives guidance for employers on how they can best accommodate people living with dementia to remain in their role for as long as possible and the best ways to deal with people having to change their role or leave their job depending on circumstances. The guide also looks at where the person may not have openly revealed or received a diagnosis and gives scenario based approaches to what can be done. The guide provides employers with a go-to resource for their queries when faced with this situation. DEEP has produced a good practice

guide with tips for employers about supporting a person with dementia in employment. It provides guidance which can help a person with dementia

discuss with their employer how the employer can help to support them to continue working.

#### 4.6.5 Personal account



“I have heard far too many stories of people receiving a dementia diagnosis and then either quickly making the decision to leave work or having the decision made for them without giving themselves time to think through the options or even being given options. Your working life does not end on the day you receive the diagnosis, nothing has changed since yesterday other than you have an explanation for your difficulties. Do not make a quick decision, you will probably regret it. Leaving a job is a fairly final action as if you have a diagnosis finding another job is unlikely to be easy.

“I have been very fortunate. I have an understanding employer who values my knowledge of the business and what I can still contribute. He WANTS to help me to continue to work for as long as I want to and am able to. We had a sensible discussion about what I can do and what I struggle with, we agree to review the situation at regular intervals and he has agreed to amend my role to fit my abilities as I decline. What more could I ask for? We both know there will come a point when I can no longer work, but that point is not being imposed on me by my employer, it will be imposed on me by this disease.

“My employer and I have contributed to an Employer’s Toolkit produced by the Alzheimer’s Society in England. The toolkit provides employers with all kinds of information to help them get value from people with dementia and to continue to make us feel worthwhile and able to contribute. It also helps keep our brains active, potentially slowing the decline. My employer said ‘you focus on what you can do and let me worry about the rest’. We must change the attitude that dementia means you cannot work. There is a long period from the symptoms first appearing to no longer being able to work. Don’t jump off the bandwagon and do not allow yourself to be pushed. Take responsibility, take control and discuss your situation with your manager, you still have rights, use them and do not lose your self-esteem. Be realistic about what you can do and learn to accept what you have to let go – not easy – but it lets you retain control for so much longer.”

*Hilary Doxford, EWGPWD, UK – England*







## 5. Discussion and conclusion

This report highlights the huge relevance of the work towards creating a society that is more inclusive and respectful of every citizen, and in particular of those living with dementia. This means a society where people with dementia can live well, enjoy meaningful lives, and feel safe, empowered and enabled to take decisions about how they want to live their lives as members of the community.

Good examples of such societies are provided in the concept of dementia-friendly communities (DFCs), a relatively new concept that has rapidly developed throughout Europe. Examples of countries where this concept has been implemented so far, and also of countries where it is now being developed, have been provided in the report. This sound work is very promising, and has been well developed at national level. Nevertheless, this report also suggests that a framework that could be used at a European level is lacking. It is foreseen that the topic of DFCs will be addressed in one of the Work Packages of the Second EU Joint Action on Dementia (2015–2018) that will be led by the UK. This may be a good opportunity for developing a model that could be used and implemented at a European level. This model should help to unify and conceptualise the work that has already been developed at national level, but should be flexible and allow for local differences. Such work could help to clarify the differences and interconnections between the standard care and support that people with dementia should receive and the work that should be developed as part of DFCs. It should also address aspects related to the methodology that could be used to build DFCs and how to monitor progress and evaluate impact. A systematic development and implementation of DFCs throughout Europe, also necessitates of a top-down approach, which should be developed in National Dementia Strategies.

Examples beyond Europe, of similar work that could help to build this, also exist. Unlike Europe, the United States (U.S.) launched a National Alzheimer’s Plan in 2012. The U.S. is currently supporting the development of dementia-friendly communities through a public-private voluntary collaboration entitled Dementia-Friendly America (DFA). DFA is a multi-sector, national collaboration that includes over 50 members, including people living with dementia and their caregivers. Its mission is to foster communities across the U.S. that are equipped to support people with dementia and their family and friend caregivers. DFA supports communities by offering them online resources and a community toolkit that offers substantive practice, policy

and process guidance about how to work towards becoming dementia friendly<sup>43</sup>. DFA is modelled after an initiative in one U.S. state, Minnesota. Under that model, called ACT on Alzheimer’s<sup>44</sup>, the tools and resources and technical assistance led to rapid engagement of 36 communities working to become dementia friendly across the state over a two-year period. This initiative is being scaled throughout the United States via the Dementia Friendly America initiative.

Whilst the concept of DFCs is particularly suitable for creating communities that are more inclusive and where people living with dementia and their carers feel respected, supported, and included in everyday life, there are many other examples in Europe of countries that also pursue this endeavour through more focused initiatives. Building on the framework provided by the World Health Organisation (WHO, 2007) for age-friendly cities, this report has explored and presented examples of such relevant examples of policies and practices in Europe. This report suggests, that, in the case of dementia, most of the core features highlighted in the WHO framework are rarely addressed in national policies. In most cases, people with dementia can benefit from some of the policies, legislations and provisions that apply to people with disabilities. The UN Convention on the rights of people with disabilities and the different treaties and acts on anti-discrimination and equality can be seen as part of the policy framework for many of the core features that were suggested by the WHO.

Driving, employment and voting are fundamental parts of the lives of many adults, including people living with dementia, and have different implications for social and civic participation. The report has looked at how a diagnosis of dementia can affect driving, voting and employment throughout Europe. The findings highlight the lack of consistency across countries. Some people with dementia may feel that dementia imposes too many challenges to their work, driving or voting. Some may decide that they prefer to discontinue these activities. Others may feel that they are still able to do so, and that with the appropriate support they can still stay at work or continue driving. A more inclusive Europe would see governments put in place the adequate legislation, policies and practical support so that every person with dementia could confidently decide whether or not they want to withdraw or continue which such activities. More people are now receiving a timely diagnosis, often at earlier stages. Thus, these topics often neglected in dementia policy, research and practice may

<sup>43</sup> See [www.dfamerica.org](http://www.dfamerica.org).

<sup>44</sup> See [www.actonalz.org](http://www.actonalz.org).

become more relevant for future generations of people with dementia.

Some people with dementia and their carers feel isolated in their communities. This report has described multiple and varied examples of initiatives that are working towards making businesses, local shops, restaurants, government institutions, libraries, banks, theatres, grocery stores, museums, emergency service personnel, and any other sector of the community, more inclusive and respectful of people with dementia. A main core action relates to tackling the stigma of dementia in our communities. Another priority could be to provide adequate training and skills to people in the community who are not part of the health and social systems, but who are part of the day-to-day lives of people with dementia, and to provide them with support so they can make small changes that can help to adapt their businesses or services to the needs of people with dementia. Tackling the stigma associated with dementia, promoting

a more positive image, and changing societal attitudes to dementia are the stepping-stones for building a more inclusive and dementia-friendly Europe.

Last but not least, a major change is the involvement of people with dementia in the policies and practices that matter to them. Understanding what is relevant to people with dementia and how they want to live their lives is paramount. People with dementia should be kept at the heart of the work to become dementia friendly. In some countries, small or large scale consultations with people with dementia themselves have been carried out. In other countries, consultations take place, but often involve carers or the Alzheimer organisations as representatives of the rights and needs of people with dementia. Finally, an exceptional example of the involvement and participation of people with dementia is the development of working groups of people with dementia at local, national, European and International level.

## Conclusion

This report has identified different ways in which communities can be more inclusive of people with dementia. It highlights several efforts in Europe to ensure people with dementia can enjoy a good quality of life and live well with dementia. The dementia-friendly community concept is relatively new and there is still a lack of consensus on its definition and in regards to how to implement and evaluate

DFCs. Nevertheless, several examples of geographical areas that are working towards becoming dementia friendly have been presented in this and other reports. Core features of DFCs are to keep people with dementia at the centre, to increase awareness and to change attitudes to dementia in our society.

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The background of the page is a solid blue color with several large, white, five-pointed stars scattered across it, mimicking the design of the European Union flag. The stars are of varying sizes and are positioned at various angles.

This comparative report looks at the development of the concept “dementia-friendly communities” in Europe. In addition, building on the framework developed by the World Health Organisation to create age-friendly cities, it provides a comparative overview of national policies and notable practices in Europe that aim at creating physical and social environments that enable people with dementia to be part of their communities and to feel respected and valued. Relevant topics addressed in the report include: outdoors spaces and safety, housing, driving, transportation, participation in social and cultural life, employment, voting, stigma and involvement of people with dementia in the development of policies and practices that matter to them. 31 countries have participated in this report, including most Members States of the European Union as well as Jersey, Norway, Monaco, Switzerland and Turkey.