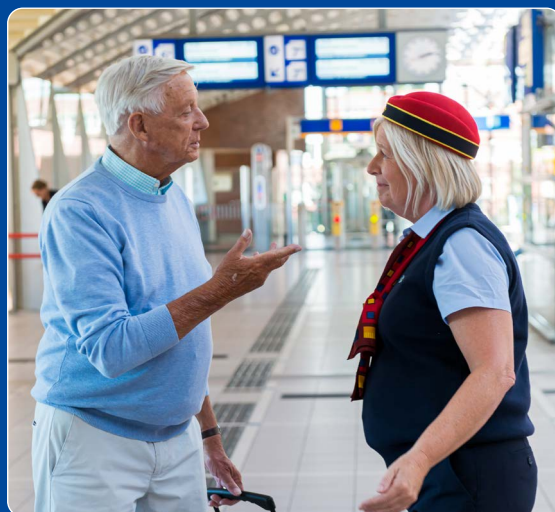


Dementia in Europe Yearbook 2021

Dementia-inclusive Communities and Initiatives across Europe



Contents

1. Preface.....	4
2. Introduction	6
2.1 Background to this report	6
2.2 Terminology	7
2.3 Methodology	7
2.4 Caveats to this report	8
3. Current policy context of dementia-inclusive communities and initiatives	9
3.1 Joint Action on Dementia 2016–2019	9
3.2 World Health Organization activities	13
3.3 World Dementia Council reports	16
4. Dementia-inclusive communities/initiatives – concepts and models	20
4.1 Responsibility for development	20
4.2 Provision of funding	21
4.3 Toolkit or guidance available	22
4.4 Review process	24
4.5 Common symbols	25
4.6 Related concepts and other work	25
5. Governmental policies – embedding dementia inclusiveness	28
5.1 Dementia Strategies	28
5.2 National/Regional policies and guidance	29
5.3 WHO Global Action Plan	30
5.4 Second EU Joint Action on Dementia	30
5.5 Dementia inclusiveness in other policy areas	31
6. Awareness raising campaigns – development and implementation	33
6.1 Outline of campaigns' themes and targeted audience	34
6.2 Involvement of people with dementia	35
6.3 Funding	35
6.4 Mediums used	36
6.5 Coordinators and other involved stakeholders	36
6.6 Timeframes	37



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7. Dementia Friends and other training programmes.....	39
7.1 Global Dementia Friends Network (GDFN).....	40
7.2 Coordination and funding of programmes.....	41
7.3 Target of programmes.....	41
7.4 Evaluations.....	41
7.5 Involvement of Dementia Friends in other areas of work.....	42
7.6 Other courses and training programmes.....	42
8. Involvement of people with dementia and working groups	44
8.1 Working groups.....	44
8.2 Involvement in Alzheimer's associations.....	45
8.3 Involvement by government and decision-makers.....	45
8.4 Other examples of involvement.....	46
8.5 Resources	47
9. COVID-19.....	48
9.1 Delays and disruption to services, projects and programmes.....	48
9.2 Advocacy and campaigning.....	49
10. Good practice examples.....	51
10.1 Belgium (Flanders).....	51
10.2 Belgium (Wallonia).....	52
10.3 Bulgaria	53
10.4 France	53
10.5 Ireland	54
10.6 Italy.....	55
10.7 Netherlands	57
10.8 Slovenia.....	58
10.9 United Kingdom (England, Northern Ireland and Wales)	60
11. Conclusions and recommendations	61
12. Acknowledgements	64

1. Preface



It gives me great pleasure to introduce the 2021 Alzheimer Europe Yearbook, which this year examines the subject of dementia inclusive communities and initiatives.

Dementia-inclusiveness is a concept which encapsulates a broad range of programmes and projects, with the intention of reducing the stigma associated with the condition, as well as raising awareness and knowledge about dementia amongst the general public. Such programmes and projects can include public-focused awareness raising campaigns, high-level training for the public and non-clinical staff and dementia-focused supports and groups. Such activities are crucial, helping to ensure that people with dementia and their carers continue living as well as possible in their communities, reducing the stigma and isolation that are often associated with the condition.

Alzheimer Europe last examined this subject in our 2015 Yearbook, at a time when the policy context looked very different. Whilst dementia-inclusive initiatives and projects have long been a feature of work undertaken to support people at a local and regional levels, policy at a national, European and global level has not always recognised or included this vital work.

It is therefore welcome that when developing the 2021 Yearbook, we have seen a great deal of progress in this field, with policy initiatives and projects such as the World Health Organization's Global Action plan on the Public Health Response to Dementia, the Alzheimer's Society's Global Dementia Friends Network, the second EU Joint Action on Dementia and World Dementia Council reports all having identified the importance of dementia-inclusive communities and initiatives.

Our national member organisations have led the way in this work, particularly at the local level, with community-level initiatives being developed and implemented by our members in response to local needs. From the responses and contributions of our members, it is evident that they continue to play a lead role in the funding, development and implementation of these campaigns and initiatives, driving forward the push for dementia-inclusive communities through their innovation and dedication.

It is evident that governments at a national, municipal and local level are beginning to play a greater role, ranging from provision of funding to participation in dementia-inclusive municipality schemes, often in collaboration with our national member organisations. This is an incredibly welcome development and a trend which we hope will continue in the years ahead. In addition, the involvement of businesses and other organisations in schemes such as Dementia Friends is encouraging and demonstrates a willingness to engage to help improve the quality of life of people with dementia.

However, there remain a number of challenges where progress continues to be slow. There is still inconsistency and significant variation across Europe in the level of engagement and support from the State. In addition, whilst an increasing number of countries report having some form of working group for people with dementia or their carers, a significantly smaller number report that these groups are involved by governments and decision-makers in the policy-making process.

Alzheimer Europe hopes that this policy report will serve two main objectives. The first is to provide a snapshot of the current situation in Europe, recognising how much progress has been made in recent years, whilst identifying future areas of focus to consolidate and build on this work. The second is to provide some examples of the excellent work taking place across Europe, in the hope that it will provide information which will encourage decision-makers and others to provide greater support for dementia-friendly initiatives in their countries and localities.

I would like to thank all of our members for their contributions and informing our report, without which, this report would not be possible.

Finally, I would also like to acknowledge the work of Owen Miller, our Policy Officer, for compiling and writing this report.

Jean Georges

Executive Director
Alzheimer Europe

2. Introduction

2.1 Background to this report

Alzheimer Europe last visited the subject of dementia-inclusive communities in its Dementia in Europe Yearbook 2015 “Is Europe becoming more dementia friendly?”

The policy context in which much of this work takes place has changed considerably since the publication of the 2015 Yearbook, with the EU’s second Joint Action on Dementia dedicating a work package to the subject and the World Health Organization’s adoption of its Global Action Plan on Dementia and publishing “Towards a dementia-inclusive society: WHO toolkit for dementia-friendly initiatives”. In addition, the World Dementia Council provided additional policy context in 2020 on the outcomes of dementia-inclusive communities and initiatives.

As such, the 2021 Yearbook will re-examine the topic in light of these developments, specifically with regard to how countries have worked to implement measures at a national level.

Our focus will be on dementia-inclusive communities and initiatives in the context of the day to day lives of individuals. Therefore the report does not include initiatives aimed at health or care professionals, or services delivered by clinicians and care professionals.

To ensure the report covers a significant breadth of the policies and activities taking place across Europe, the report is split into the following sections:

- Current policy context of dementia-inclusive communities and initiatives
- Dementia-inclusive communities/initiatives – concepts and models
- Governmental policies – embedding dementia inclusiveness
- Awareness raising campaigns – development and implementation
- Dementia Friends and other training programmes
- Involvement of people with dementia and working groups
- COVID-19
- Good practice examples
- Conclusion and recommendations
- Acknowledgements.

Throughout the report, we have included contributions from members and supporters of the European Working Group of People with Dementia (EWGPWD) about what dementia inclusiveness means to them and the aspects they feel are most important in such work. These contributions provide a helpful insight into the views of people with lived experience of dementia.

2.2 Terminology

Alzheimer Europe is aware of an evolution in the terminology associated in this field of work, with the term “Dementia-Friendly Communities” becoming increasingly outdated, as it is perceived by some people with dementia and their carers to be patronising and unsuitable. This point has been raised a number of times by members of the European Working Group of People with Dementia (EWGPWD).

Alternatives such as “dementia-inclusive” are becoming more commonly used, however, this brings its own challenges, as the term is sometimes used to denote an initiative or scheme which is not dementia specific in nature, rather, one which is more generally accommodating or suitable for people with dementia (e.g. a scheme which may be age friendly or for people with other conditions which affect mobility or cognition)

A universally-agreed term, used across different settings, across languages and across the world does not, at present, exist. The debate and the evolution of terminology will be a continuous process that must be driven by people with dementia, their families and carers, to determine the most appropriate language to use.

As such, in this report, Alzheimer Europe has opted to use “dementia inclusive” to refer to the communities and initiatives featured – we use this in its broader sense, however, the majority of work identified in the report will refer to schemes and projects which are dementia-specific in nature. We have included the phrase “dementia friendly” only in cases where the term is directly translated or quotes from pre-existing areas of work. The “Dementia Friends” programme is a specific stand-alone programme which, in the majority of countries, uses this term or a direct translation therefore we have not amended these references.

2.3 Methodology

In February 2021, at a public affairs meeting attended by Alzheimer Europe’s national member organisations, Alzheimer Europe provided an overview of the previous work undertaken in this area, including the 2015 Yearbook, before setting out the current policy context and developments over the past six years. As part of this, Alzheimer Europe proposed a new approach for the 2021 Yearbook and outlined a rough timeline, inviting comments and input from members.

Following this meeting, a small group of members were invited to help contribute to the development and revision of a questionnaire which would be sent to members, with this group helping to shape the approach and questions within the survey. This process was carried out throughout March 2021.

In April 2021, Alzheimer Europe distributed the survey to its member organisations, with deadline set for receipt by May 2021. In total, Alzheimer Europe received a total of 27 responses (including two for Belgium, two from Italy and two from the UK) from 24 countries. Table 1 shows the countries who responded to the survey.

Table 1 – Countries who responded to the survey

Austria	Luxembourg
Belgium (Flanders)	Malta
Belgium (Wallonia)	Netherlands
Bulgaria	Norway
Croatia	Poland
Czech Republic	Portugal
Finland	Slovenia
France	Spain
Germany	Sweden
Greece	Switzerland
Ireland	Turkey
Israel	United Kingdom (England, Northern Ireland and Wales)
Italy	United Kingdom (Scotland)

Alzheimer Europe analysed the findings from the completed surveys, identifying overarching trends and themes, as well as examples and resources which may be of interest to other organisations working in the field of dementia. Members were given an opportunity to review a draft text of the report late in 2021.

2.4 Caveats to this report

The pace of development and work around dementia-inclusive communities and initiatives has resulted in a multitude of examples of activities aimed at improving the lives and experiences of people with dementia and their carers. This ranges from high-level awareness raising campaigns by national government through to activities of individual groups or businesses at a local level. As such, it is not possible to provide a comprehensive account of all the activities taking place across Europe and it is not the intention of this report to do so. The examples included within this report are some of the numerous examples provided by our members, who wished to demonstrate successful initiatives that have been undertaken and how these have helped to create more dementia-inclusive and informed societies.

The findings in section four through ten reflect the information received through the survey responses, which were completed by our national member organisations. The process for the development and distribution of the survey is outlined in the previous subsection.

As with all of the policy reports of Alzheimer Europe, it is important to note that the existence of a policy in a country, for example within a dementia strategy or other policy document, does not necessarily mean that the specific measures are being implemented or universally applied across a country.

3. Current policy context of dementia-inclusive communities and initiatives

As briefly outlined in the introduction, the policy context surrounding dementia-inclusive communities and initiatives has developed rapidly in the past six years, with a drive towards raising public awareness and understanding of dementia, as well as the creation and dissemination of resources intended to encourage individuals, communities and businesses to play their part in allowing people with dementia to remain active and able to participate in society.

In this section, an overview of the key points from three high-level policy areas will be provided, examining:

- The European Union-funded second Joint Action on Dementia (2016–2019)
- The World Health Organization’s Global action plan on the public health response to dementia 2017–2025
- The World Dementia Council’s papers on “building a global evidence base for dementia friendly initiatives”.

One of the most high-profile and successful programmes developed in relation to dementia-inclusive communities was the Dementia Friends programme which is covered separately in section seven (page 39), therefore this section will not examine the programme.

3.1 Joint Action on Dementia 2016–2019

In March 2016, a second EU-funded Join Action focused on dementia commenced involving 15 countries across Europe.



Building on the success of the first Joint Action on Dementia ([the Alzheimer Cooperative Valuations in Europe – ALCOVE](#)), the successor programme, [Act on Dementia](#), was undertaken with the aim of promoting collaborative actions among Member States to improve the lives of people living with dementia and their carers. Specifically, it sought to provide practical guidance for policymakers developing and implementing their national dementia plans, policies and strategies, including how to implement some of the good practice for dementia diagnosis, care and support, which had been identified in ALCOVE.

Of particular relevance to this Yearbook was Work Package 7 (WP7) on Dementia-Friendly Communities, led by the UK Government’s Department of Health, which involved work in Bulgaria, Greece, Italy and the UK (England). Alzheimer Europe, the European Working Group of People with Dementia, Imogen Blood & Associates Ltd and the Alzheimer’s Society (England) were also involved in this work package.

WP7 collated and provided evidence-based information and recommendations on promoting, developing and sustaining dementia-inclusive communities, including defining what “good” looks like for a system-wide approach, understanding how good practice is sustained and promoting the various benefits, including economic benefits, for communities of being dementia inclusive.

In advance of the pilot sites in the aforementioned countries, [Imogen Blood & Associates produced an evidence review](#) covering the following areas:

- Identify best practice examples in relation to the development of Dementia-Friendly Communities (DFCs)
- Provide a definition of DFCs
- Identify the components of an effective DFC
- Develop a set of indicators to test the success of the forthcoming pilots within WP7.

This evidence report defined the components which were considered as being fundamental to the development and success of a dementia inclusive communities. The approach and experience of the UK was then used as the basis for the work in the test sites, which sought to examine the effectiveness on these in the pilot sites in Bulgaria, Greece and Italy.

The [Final Report of Work Package 7](#) was published at the conclusion of the Joint Action in October 2019, summarising the findings and evidence gathered throughout the duration of the programme. The text in the boxes outlined on pages 11 and 12 is taken from these reports and identifies some of the key points for dementia inclusive societies.



Defining Dementia-Friendly Communities (based on the WP7 Evidence Report)

Dementia-Friendly Communities represent an ongoing process of learning and culture change, rather than a singular “state”. The activities and structure of DFCs need to be defined locally, informed by people living with dementia and their carers, living within the communities. This flexible definition is sufficiently broad to accommodate a range of “communities”, thus avoiding specific descriptions of the type of barriers that need to be removed. In addition, it underlines the key aspect of driving change within communities in creating connections and understanding between citizens, organisations, groups and businesses.

At the core of the DFCs is an “alliance” between a broad network of different stakeholders, including those with lived experience of dementia, which should provide leadership and vision for the DFC. As part of this leadership role, the alliance should establish and communicate the core values which underpin the DFC, which should include:

- Being asset-based by building on local resources and the strengths of individuals, including people with dementia and their carers
- Removing barriers to mainstream services and provision for people with dementia
- Taking a rights-based approach
- Placing co-creation with people with dementia and carers at its heart.

Findings from the WP7 pilot sites

The key conclusions of the findings of the pilot sites:

- A robust network of key organisations with good levels of engagement and buy-in and from local stakeholders, including local authorities and politicians is essential
- Success of the DFC depends, to a large extent, on the development of the site itself, in terms of levels of stigma, resources available and existing networks. DFC sites go through a journey of development, and it is essential to consider what stage the site is at before establishing a DFC initiative. Different stages will require different approaches
- A one-year pilot scheme is not enough time to demonstrate real change. The most impact was demonstrated in Italy, which to some extent, is related to the longevity of the DFC site there, which has been established over a number of years
- A thriving network of volunteers grouped around a strong charitable sector is essential. Volunteers not only provide a human resource, but help to reduce monetary costs
- The nature of the site itself, particularly the strength of existing community ties, affect the success of the DFC – tightly knit communities can offer more support but also increase the risk of stigma associated with disclosing a dementia diagnosis
- Involving people with dementia is key, both at the development stage of what constitutes a DFC, and the delivery of DFC activities.

Key conclusions and recommendations for countries wishing to establish DFCs

At the conclusion of Act on Dementia, the WP7 final report created a number of recommendations for EU countries wishing to create their own DFC projects. They are grouped under the “Four Cornerstones” identified within the evidence report.

Place

- Draw on local cultures and traditions to help develop a truly context-specific approach, adapted to local need and want
- Use small scale, effective actions. Focus on the local people that you have the most influence over e.g. local branches of organisations rather than national chains
- Enable access to the wider community for PWD by making public spaces like gyms and libraries accessible and help to normalise the presence of PWD in their communities.

People

- Put people with dementia and their families at the heart of the programme – using their input to shape and guide the activities. Establish levels of understanding, knowledge and stigma about dementia at the outset
- Focus on a practical approach for training and use PWD as part of your activities
- Children and young people are generally enthusiastic and engaged with the topic of dementia; use intergenerational activities to raise awareness
- If not already in place, ensure that health and social care professionals receive high quality training to understand the importance of timely diagnosis, and post-diagnostic support
- Educate key members of the community to increase respect and understanding of PWD and their carers and enable them to access the community.

Network

- Create a wider network through the use of social media and online sites which can be used to share information about dementia
- Establish strong links with local administrations and political leaders. Buy in from the top is essential
- Develop a robust network of volunteers based on a strong charity sector organisation.

Resources

- Use volunteers throughout all activities to minimise cost and maximise involvement
- Train healthcare professionals and personnel in the initial stages, to maximise early intervention and increase sustainability of the DFC.

3.2 World Health Organization activities

3.2.1 WHO Global Action Plan on Dementia 2017–2025

In 2017, the World Health Organization (WHO) launched the “[Global action plan on the public health response to dementia 2017-2025](#)” which aims to improve the lives of people with dementia, their carers and families, while decreasing the impact of dementia on communities and countries.

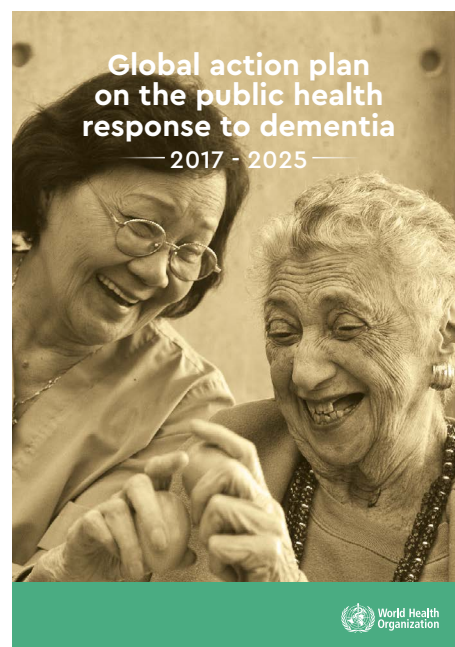
The global action plan covers a number of themes and includes actions (for Member States, the WHO Secretariat and other stakeholders) aimed at preventing dementia and improving the way in which people with dementia and their carers are supported. There are seven overarching “actions areas”:

- Dementia as a public health priority
- Increasing prioritisation and awareness of dementia
- Reducing the risk of dementia
- Diagnosis, treatment and care
- Support for dementia carers
- Strengthening information systems for dementia
- Research and innovation.

Action area 2 “Dementia awareness and friendliness” is most relevant to the topic of dementia-inclusive communities, with the defined rationale of the action area being that: “Increasing public awareness, acceptance and understanding of dementia and making the societal environment dementia friendly will enable people with dementia to participate in the community and maximise their autonomy through improved social participation”.

As such, the global action plan contains two specific targets in relation to dementia awareness and dementia inclusive communities which are:

- **Global target 2.1:** 100% of countries will have at least one functioning public awareness campaign on dementia to foster a dementia-inclusive society by 2025
- **Global target 2.2:** 50% of countries will have at least one dementia-friendly initiative to foster a dementia-inclusive society by 2025.



As part of the monitoring of this work, tools such as the [Global Dementia Observatory \(GDO\)](#) (which tracks the progress of countries against the measures in the global action plan) have allowed for implementation to be followed (amongst the 62 countries which had submitted data at the time of finalising this report). In addition, the [GDO knowledge exchange platform](#) has allowed for the sharing of resources and information which have been used in the implementation of policies (including relating to dementia-inclusive communities) across the world.

In September 2021, the WHO published the “[Global Status Report on the public health response to dementia](#)” which showed that, amongst GDO countries, two-thirds have at least one awareness-raising campaign (with 73% of these run at national level), whilst two-thirds of GDO countries have at least one dementia-inclusive initiative taking place in their country.

3.2.2 WHO toolkit on Dementia Friendly Initiatives

In addition, in September 2021, the WHO published “[Towards a dementia-inclusive society: WHO toolkit for dementia-friendly initiatives \(DFIs\)](#)”, which focused on the development and implementation of dementia inclusive communities.

The toolkit highlights that stigma and discrimination heighten the already significant psychological, social, emotional and financial impacts that dementia has on individuals, their carers, families and communities. The resource aims to support individuals, communities and countries in raising awareness of, and empowering people living with, dementia to remain in, and be a significant part of, their community.

It provides practical guidance and tools that can support efforts, including planning and implementation activities, to create dementia-inclusive societies.

Part I contains the underlying theory and objectives which support the concept of dementia-inclusive societies, as well as information on dementia, human-rights and global commitments, including the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD).



Furthermore, a conceptual framework is provided which aims to support the creation of dementia-inclusive societies and the implementation of dementia-inclusive initiatives. As part of this, specific principles are set out:

- Participation
- Multisectoral collaboration
- Coordination
- Sustainability
- Social environment
- Physical environment.

Part II contains the practical steps and exercises in relation to dementia inclusive initiatives, aiming to provide ideas and guidance for individuals working at the community-level to support the development of dementia-inclusive societies, including planning and implementing activities to achieve this. Specifically, it is intended to be used as a facilitation tool in group settings, amongst relevant team members and partners.

The section is centred around four modules, each featuring a series of practical steps and exercises, specifically focused on the implementation, monitoring and evaluation. There are four modules within this section, including:

- 1.** Starting a new dementia-friendly initiative (DFI)
- 2.** Integrating dementia into an existing initiative
- 3.** Monitoring and evaluation a DFI
- 4.** Scaling a DFI.

The modules can be used together or separately, offering guidance which can be adapted to suit local needs and settings.



3.3 World Dementia Council reports

In December 2018, the World Dementia Council (WDC) hosted a summit bringing together global experts from different disciplines in dementia to reach consensus on some of the global challenges the world faces in reaching the 2025 goals (set by the G8 in 2013). One of the priorities identified at the meeting was a better understanding of the evidence base for dementia inclusive initiatives, both in terms of what could be defined as a dementia-inclusive initiative, as well as the impact delivered by such activities.

Initially intended as a single report, the COVID-19 pandemic resulted in the findings of the WDC's work being published as two papers in 2020.

3.3.1 Defining dementia-friendly initiatives: promoting a global evidence base for dementia-friendly initiatives

The WDC's "[Defining dementia-friendly initiatives: promoting a global evidence base for dementia-friendly initiatives](#)", was based both on submissions and a literature review, and identified three main areas which dementia-inclusive initiatives aim to have impact:

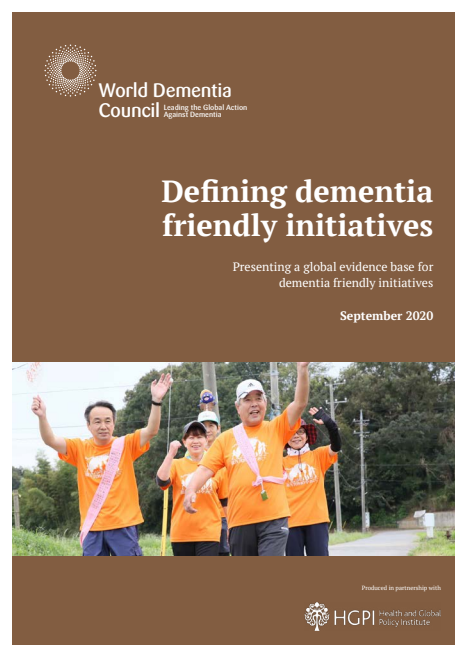
1. Raising awareness (with a focus on reducing stigma)
2. Enabling participation
3. Providing support – including in health and care settings.

As part of this review, the paper identified that different principles and toolkits are often developed, with methodologies such as “theories of change” often employed to determine the impact of activities and actions taken.

The paper further notes that defining exactly what constitutes a dementia-inclusive initiative can be challenging, as many actions which contribute to one of the aforementioned aims may be dementia inclusive in nature, but might not describe itself as such. Similarly, activities which aim to raise awareness, enable participation or provide support, pre-date the term “dementia friendly” and indeed, have been (and continue to be) undertaken in other areas, such as disability or old age.

Citing the overlap between oldest populations and the populations of persons with dementia, the report highlights the linkages between “age-friendly” initiatives, including the WHO Global Network for Age-friendly Cities and Communities, which was established in 2010. This network notes that “Age-friendly environments (such as in the home, community) foster healthy and active ageing by building and maintaining intrinsic capacity across the life course and enabling greater functional ability in someone with a given level of capacity”.

As part of their work, the WDC note that many of the dementia-specific examples submitted were delivered by the same organisations and individuals who were also involved with “age friendly” initiatives and movements.



The box below outlines some of the key conclusions from the paper which are of relevance to this yearbook, providing a broad framework to help contribute to the conceptualisation of a dementia-inclusive initiative.

- The greatest area of focus of dementia-friendly initiatives is awareness, across a range of actions, including raising visibility of dementia public discourse, reducing stigma about the condition, encouraging people to interact with people with dementia, as well as specific workplace training. Actions vary in scope, some covering national, regional, community, or local level – however, all primarily involving transferring knowledge about the condition to people not living with the condition.
- Programmes and initiatives focused on participation of involve activities which aim to allow individuals to continue to play an active role within in their community. This includes involving people in decisions about provision of housing, the design of the public realm, as well as accessibility and training in local shops. However, there is often a focus on organisations which have a strong local presence within the community.
- Finally, support involves providing a service to someone who has dementia, which may be in the form of community services, however, is also more broadly understood to also include the provision of health and social care services.

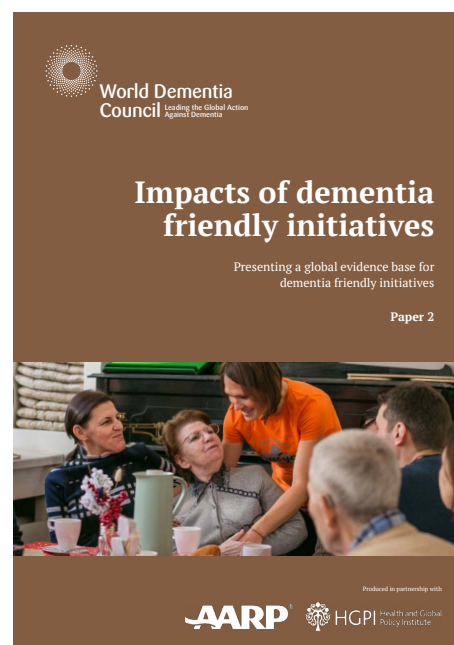
3.3.2 Impacts of dementia-friendly initiatives: promoting a global evidence base for dementia friendly-initiatives

In the second of its papers, [“Impacts of dementia friendly initiatives: promoting a global evidence base for dementia friendly initiatives”](#), the WDC explored the different areas of focus (based around impact, participation and support) of dementia-inclusive initiatives, whilst seeking to identify the evidence base for their impact.

Awareness

The report notes that most initiatives examined included time-limited interactions; however, due to the growing numbers of people living with the condition, more people have direct experience of dementia. Measured over a period of time, it becomes more difficult to identify the impact of a specific campaign, given the wider factors which may also raise awareness.

The paper notes that whilst stigma is commonly cited as a challenge for people with dementia and their caregivers, their systematic review highlighted the limited research evidence both on the extent of stigma and the evidence for interventions that address it.



Dementia-inclusive initiatives are aligned with other areas of awareness raising and anti-stigma training, e.g. those with mental health, with commonality in the areas of knowledge sharing, visibility and contact. This often includes areas such as prevention, improving access to and uptake of treatments, tackling stigma and discrimination, and promoting research.

Participation

Initiatives focused on participation have a strong focus on both physical and social environments, with activities focused on a broad range of areas including involvement in the planning processes, the planning and decision-making processes, as well as ensuring accessibility within services and amenities in everyday life. This applies not only to venues but also within the public realm.

The review found little evidence that enabling participation leads to a better “quality of life” or better health outcomes, although there is a significant body of evidence on the negative health effects – both physical and mental – of isolation and loneliness. However, the paper notes that it is not necessarily essential to demonstrate this, as the case for participation is also important as part of human rights and equality-based approaches.

What is considered as “meaningful involvement” is often not specifically defined; rather the paper identifies that it relates to the involvement of professionals and people who use services, gathering and combining their collective knowledge and experiences, as well as relevant data.

The paper does not identify a single approach, noting that different methods will be more or less appropriate in specific contexts. However, it does note that gathering representative views particularly those which reflect specific characteristics (e.g. gender, socioeconomic status, ethnicity, sexuality etc) can be challenging.

Support

In the WDC’s first paper, a distinction was made between initiatives intended to provide support to someone because they have dementia and those that enable someone to participate despite the fact they have dementia.

The paper includes a variety of community services and supports, including memory cafes, singing groups, art and music therapy, a theatre company etc. The key commonality amongst the examples cited within the paper is social connection, which aim to reduce social isolation and loneliness. It is noted that not all the services provided are regularly described as “dementia friendly”, including assisted living, information services, befriending services, and respite services such as day care.

Furthermore, the paper notes that as the underlying disease progresses, more intensive health and social care supports and services are required to maintain an individual’s quality of life. A contrast is drawn between these and “dementia-friendly initiatives” which are predominately targeted at people in the earlier stages of dementia.

Kevin Quaid, Vice-Chairperson, European Working Group of People with Dementia and member of the Irish Dementia Working Group (IDWG)

I suppose we live in a world where words matter and whether or not you want to use the word dementia-friendly or dementia-inclusive communities, the important word here is community. There was an old saying “that it takes a village to raise a child”, well it can take a community to understand dementia and while there is still a stigma around dementia, I do believe that through the brilliant advocacy work been done by The Alzheimer Society of Ireland, the stigma is slowly drifting away, what is still in my view a very large problem is one of diagnosis.



If you have been told that you have a dementia or a touch of dementia, then you have not been given a proper diagnosis, when you consider that there are hundreds of different types of dementia, then unless you are given a proper diagnosis of what type of dementia that you have, then how can you get the proper treatment. Just like if you were given a diagnosis of cancer, the very second that you hear the word cancer, you want to know what type and what treatment is available for that specific type of cancer, then why should dementia be any different. The difference in symptoms between Lewy body dementia and Alzheimer’s disease, could not be greater so how could the same medication or treatment be used for both.

Dementia-inclusive communities are of vital importance to the person who has dementia as well as their carer. For the person with dementia it gives them a sense of belonging and a purpose, whether it is involved in a singing group or something like the men’s sheds, just to mention two. It also can give a much-needed break to the carer even if it’s only a couple of hours a week and they can meet their friends for a cup of coffee or just have time for themselves.

As a person living with Lewy body dementia, there is a lot of fear in my life so if I walk into a shop or supermarket that has a sign on the door saying that it’s a dementia-friendly community or a dementia-friendly shop, then I don’t feel as fearful and if I feel that I need help then I am not afraid to ask for it. For a person like me, that is a huge relief. However, if I go into a shop that’s busy and I am not sure whether or not they are dementia inclusive or dementia aware, then my fear levels just rise and sometimes I will avoid that shop altogether.

In the town where I live, which has a population of approximately 2,200 people we have a dementia café where we meet once a month and everyone there knows that I have Lewy body dementia and when people meet me, they just treat me like anyone else and always ask “how are you doing” and that’s it. So, in my community, because it’s a dementia friendly community, I feel completely safe and again I know that I can ask for help if I need it.

Our dementia café has had to go online because of COVID-19 but hopefully in 2022 we will be able to meet face to face again and we are like a small family where we talk about our different dementias as well as having some fun.

In the future I would like to see every city, town and village become dementia inclusive where people with dementia can feel safe and not afraid to ask for help and that everyone with dementia will know what type of this disease that they have – I do not think that is too much to ask.

4. Dementia-inclusive communities/ initiatives – concepts and models

As explored in the previous section, dementia-inclusive communities and initiatives are broad terms, encompassing many different ideas and aims, ranging from awareness raising, to empowerment of individuals and to accessibility in everyday life. Developing a concept or model is important, providing understanding of what dementia inclusive means, as well as providing information and guidance on how it can be achieved – this is particularly important for local initiatives or municipalities seeking to become dementia inclusive.

Each country operates within a unique policy context, with different levels of support and investment, involving different partners and organisations involved at a national, regional and local level, meaning the approach taken to developing a concept or model of dementia-inclusive communities varies significantly. In some cases, the focus is very much on individuals, groups and businesses, whereas other countries have a greater focus on municipalities and decision-makers.

This section provides an overview of the state-of-play, looking at where concepts and models have been fully or partially developed, as well as the different partners involved. Furthermore, the section also provides information (and links) about toolkits and guidance that have been developed, some of the common symbols and imagery used across Europe, as well as sharing the extent to which review processes are used in practice.

In many countries, the work done around dementia inclusive societies and Dementia Friends is interlinked, to such an extent that for some, Dementia Friends programmes are the foundation of their dementia inclusive models and work in this area, whilst for others their Dementia Friends programmes are related but separate pieces of work. For this section, we present the information as it has been returned within the survey. As such, where there is overlap between the two, we have included more detail in section seven, which is dedicated to Dementia Friends programmes.

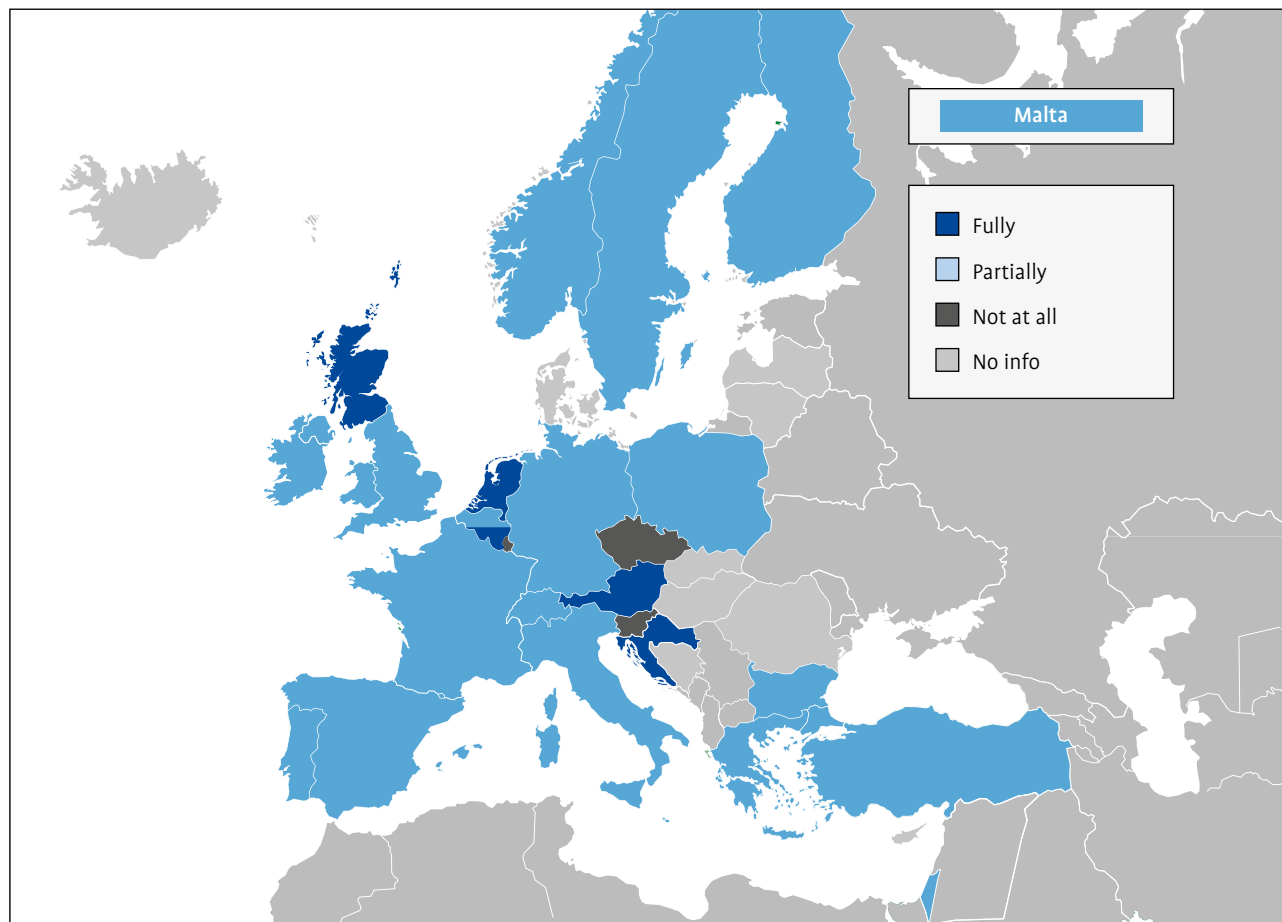
4.1 Responsibility for development

For the countries with a model or developed dementia-inclusive society, it is important to understand who is taking a lead on these actions, to gain some insight into the key actors who are both shaping and implementing this work.

Of the 24 who have developed a concept or model, a little over half (54%) reported that the Alzheimer associations were responsible for the development and coordination of dementia-inclusive societies/ initiatives, whilst nine (38%) reported a mix of organisations, which involved Alzheimer associations (8), governments (national/regional/local), other NGOs (3) and private organisations (1). The nature of these arrangements are highly specific to the countries, regions and localities; as such, it is difficult to draw out further analysis or conclusions from these.

There was only a single reported instance of a government leading on such a scheme (Malta), whilst there was also a single instance where the work was led by another NGO (Sweden).

Map 1 shows the distribution of countries which have developed (either fully or partially) a dementia-inclusive concept or models, with 24 respondents from 21 countries stating that these concepts had been developed to some extent in their country.



4.2 Provision of funding

In addition, our survey wanted to better understand how the concepts and models were being funded, to demonstrate how such policies and models are resourced. The funding models for such projects and programmes are often complex and involve multiple actors, however, we were keen to demonstrate the number of different actors involved.

As with the responsibility for development, Alzheimer associations play a key role, with 50% reporting that they alone fund(ed) the dementia-inclusive concept. A mix of funding sources were reported in 10 (42%) cases, with national/regional/local governments (9), Alzheimer associations (6), other NGOs (4) and private organisation (3) involved in these funding arrangements.

In only two responses were the initiatives funded purely by governments (one from a regional level [Belgium – Flanders, and one from a national level [Malta]).

4.3 Toolkit or guidance available

Around 60% of the countries with a dementia-inclusive model or concept reported that a toolkit or guidance had been developed, aimed at sharing information and spreading good practice about creating dementia-inclusive communities.

However, not all countries provided further details or information about these resources. Furthermore, some respondents referenced guidance and toolkits which form part of their Dementia Friends programmes, as these form the basis of their approach to dementia-inclusive societies. As section seven addresses Dementia Friends programmes across Europe, we will not include references to these documents in this section.

This section focuses on other examples in countries who have projects for dementia-friendly communities. These vary in nature, with a focus on different audiences, including municipalities, businesses and individuals, with some focused on a single audience, with others being multi-faceted and focused on different stakeholders. The following examples are not intended to be exhaustive, rather to give an illustration of different examples of work which has been undertaken

- Belgium (Flanders) – The Alzheimer Ligue Flanders, Centre of Expertise on Dementia Flanders, the Flemish Elderly council and the VVSG (the Flemish association of cities and municipalities) worked together to produce the [“Together for a dementia-friendly Flanders”](#) toolkit, which aimed to provide guidance, to help municipalities implement of dementia inclusive dementia
- Belgium (Wallonia) – Ligue Alzheimer was notable for its distinct campaigns focusing on different stakeholders:
 - The first campaign focuses on working with municipalities to implement its [“La charte Ville Amie Démence” \(The Dementia-Friendly City charter\)](#), which outlines the activities that municipalities must undertake to be considered dementia inclusive
 - The second, [“Ensemble Alzheimer est plus léger” \(Together Alzheimer’s is lighter\)](#) focuses more on businesses and groups, in relation to how they can support people living with dementia
- France – As part of a campaign launched by France Alzheimer in 2019, there are three main axes:
 - Raising awareness and training the major local actors (police, fire departments, etc.) with the help of the nationwide network of the association
 - Using a unifying symbol of recognition to signal support for people living with dementia
 - Inviting mayors of every French city to sign their pledge [“Ville Aidante Alzheimer \(Alzheimer Caring City\)”](#) and engage locally to create a dementia-inclusive approach within the city/town
- Germany – As part of work related to the National Dementia Strategy, the Federal Ministry for Family Affairs published guidelines aimed at municipalities, [“Living with dementia in a municipality”](#)
- Italy – Since 2016, Federazione Alzheimer Italia has implemented and adapted the Alzheimer’s Society model on the Italian territory thanks to the publication of a “Guide to create a DFC” and an “Agenda of commitments” that are shared with towns, villages or neighbourhoods of large cities who choose to work to become Dementia Friendly. Thanks to the website (<https://www.dementiafriendly.it/>), communities can meet each other known and exchange ideas and material to spread as much information and fight stigma
- Netherlands – In its work, Alzheimer Nederland offers three main tools or guidelines to support municipalities to become more dementia inclusive:
 - [Focus letters](#) aimed at municipalities, health insurers and care offices to advocate for better support and care for dementia

- “[Dementia scan](#)” for municipalities, which provides insights into how dementia inclusive a municipality is and how they can become more inclusive
- Publication of the “[Participate longer](#)” [booklet](#), which contains 10 examples that can serve as tools to make municipalities (more) dementia inclusive
- UK (England) – The Alzheimer’s Society worked with the British Standards Institute in the [development of a code of practice](#) for communities wishing to be recognised as dementia inclusive, whilst the Alzheimer Society has a [suite of resources aimed at different groups and businesses](#)
- UK (Scotland) – Alzheimer Scotland has developed [resources and toolkits aimed at both groups and towns](#), whilst funding bodies such as the Life Changes Trust have [also provided a specific toolkit](#).

The approach of [Ireland’s Dementia: Understand Together campaign](#), a collaboration between The Alzheimer Society of Ireland and Irish Directorate of Health, is notable for its breadth and scope as a unified campaign. The campaign seeks to, amongst other things:

- Increase awareness of dementia and its impact on individuals, families and communities
- Help communicate the lived experience of people living with dementia and those caring for them
- Provide reliable information about dementia and signposting to services and supports to help those living with dementia, those caring for them, health professionals and the general public
- Promote the uptake of dementia awareness training and promote information about brain health and ways to prevent dementia
- Inspire and encourage individuals, businesses and organisations and communities to become involved in taking steps to create inclusive and supportive environments for people with dementia and their loved ones.

The work stemmed from an initial programme of work by ASI between 2013 to 2016, and is framed as a “social movement” involving many different actors and partners, emphasising the importance of each in creating a dementia inclusive Ireland.



Dementia: Understand Together project partners, the Alzheimer Society of Ireland staff (AS) staff, advocates and volunteers.

4.4 Review process

From the survey responses, 15 countries reported that there was some level of review process for dementia-friendly communities and initiatives. Almost half (7) of these were done by the Alzheimer's association alone, 20% were reviewed by government and 20% by a mix of organisations (in all cases involving the Alzheimer's association and governments).

There were fewer examples provided in this instance for how these work in practice, however, some examples provided included:

- Italy – Federazione Alzheimer Italia worked with representatives of the regions, associations and the Ministry of Health on a document for the dissemination of Friendly Communities in Italy. To date, the Federation recognizes the communities that are working to become more inclusive, thanks to an annual recognition process based on 7 points contained in the “Guide to creating a DFC”
- Netherlands – Alzheimer Nederland used different tools in monitoring and measuring impact of its various programmes, including:
 - A national survey Dementia Monitor of Alzheimer Nederland, which is conducted every other year including 4,500 family carers
 - A poll among the 48 regional departments on the degree of dementia friendliness of the municipalities in their area, as well as use of the [“Dementia Scan”](#) to identify how dementia inclusive municipalities are and areas where they can improve
- UK (England) – The Alzheimer's Society and the government works with communities that register for formal recognition as being dementia inclusive, and requires them to report on a six monthly and annual basis to detail the progress they have made
- UK (Scotland) – As part of its funding of dementia inclusive projects, [the Life Changes Trust produces evaluations](#) to help identify good practice.



4.5 Common symbols

18 countries reported having some logo to identify dementia-inclusive initiatives and communities. A number of these are related to Dementia Friends programmes and therefore make use of the Dementia Friends branding, which uses the blue and yellow forget-me-not flowers. Similar symbols exist for a number of other countries and initiatives (i.e. using a version of the “forget-me-not” flower).

Otherwise, symbols and motifs for dementia are specific to countries, regions or localities. We have included some examples here:



Row 1 (l-r): Ville Aidante Alzheimer (France), Ville Amie D mence (Belgium – Wallonia) and Dementia: Understand Together (Ireland)

Row 2 (l-r): Citt  Amica Della Persona Con Demenza (Italy), Forget Me Not Flower (multiple countries) and Dementievriendelijk (Belgium – Flanders)

Row 3 (l-r): Solidario Con El Alzheimer (Spain), Samendementievriendelijk (Netherlands) and Dementia Friendly Community (United Kingdom – Scotland)

4.6 Related concepts and other work

Whilst not all countries had a developed concept or model for dementia-inclusive communities and initiatives, some countries did report that related work and activities were planned or underway within their countries.

For example, in the Czech Republic, the most recent National Alzheimer Plan includes references and objectives related to dementia-inclusive communities, however, further details and information are not yet available regarding implementation.

In Italy, Alzheimer Uniti Italia Onlus has also started work on the development of dementia-inclusive communities, including in the Roman district of Garbatella. They have been engaging with and making presentations to Italian cities, providing directives and proposals with the aim of spreading key messages to service providers, caregivers and families of people living with dementia.

In Slovenia, the Alzheimer's association launched Dementia Friendly Points, a network of locations aimed at awareness raising and education, involving a wide spectrum of organisations in local communities. It helps create a dementia-friendly environment by providing information, ensuring social inclusion, acceptance and safety of persons with dementia and their families.

As well as the formal dementia inclusive work through Dementia: Understand Together, The Alzheimer Society of Ireland has a number of innovative community engagement projects. These include "Creating a Dementia Inclusive Generation" working with secondary schools to build awareness of brain health and "Football Memories" a partnership with a professional soccer club. Football memories takes its lead from the Sporting Memories format which aims to tackle depression, dementia and loneliness in older people through safe friendly sessions led by people with a passion for sport. The Alzheimer Society of Ireland are engaging with <https://www.cafefootball.eu/> to promote the inclusion of people with dementia in sport.

Helen Rochford-Brennan, member of the European Working Group of People with Dementia and member of the Irish Dementia Working Group (IDWG)

I live in Tubbercurry, County Sligo Ireland, I have always been passionate about the power of community. I have friends and family living locally. I tend the roses in my garden, go to the theatre and enjoy walking in the Sligo countryside.

I am a mother, an aunt, a friend, a dog owner and an active member of my community. My husband passed away in December 2020 and it has been incredibly difficult. But even with the restrictions of COVID-19 my community has supported me.

I was in my community the day before I was diagnosed, and I was still in my community the day I got my diagnosis. I am the same Helen; my eagerness of my community has not changed even though my memory has. My community did not abandon me and they have made a reasonable adjustment for me which is what I require.

I realise from social media that "finding your tribe" is very fashionable now. How lucky am I that I already have my tribe!

As my dementia progresses, I want to live at home surrounded by that tribe. I do not wish to live in an institution. Dementia villages are becoming more popular and while I understand their value I do not want to move to a specially constructed village when I already live in a real one. But I need my village to be dementia inclusive and so I am a passionate supporter for change and to create meaningful standards for dementia inclusive communities.



The Irish Standards Office are currently creating standards. I am grateful for their innovation in this work. It is a new way of working, there are not international standards like this – there is literature but not standards.

This is important because it democratises the knowledge and makes it more accessible – scientific literature is not always easy to interpret.

The standards are also important because of increased awareness – people must be aware of the problems before they can fix them. And this work makes the guidelines implementable – it provides a framework and a toolkit.

I was delighted to be the authentic voice on this project, together with professionals, family carers/ supporters and standards experts. My fellow committee members listened so carefully to my voice and believed it was important to include the voice of people living with dementia contributing to standards. We hope these standards will be used internationally.

We must remember that when we speak about community the built environment is a small part – education, awareness and services are all critical.

Here in Ireland, I am delighted to see the work of the Dementia: Understand Together Campaign in Communities to create dementia inclusive communities. It is my hope that through this work, shops and sports clubs and restaurants and coffee shops and community groups can all welcome people living with dementia. That people like me and our family and friends can live active engaged lives and be part of our communities not shut away.

COVID-19 has taught us all the importance of connection; we see the value of social connection and the loss when it is not there. People living with dementia need that connection, our memories might fade, our words get mixed up, but human connection can still bring great joy, this is one of the main reasons why our community matters.

Recently I went on a road trip to visit my friends with dementia in Scotland together with my travel supporter Carmel. We went to many places and felt fully included in the communities we stayed in, because all that we required and requested was adjustment whether it was noise level, visual, parking or mobility issues. Today communities are much more supportive whilst they may not all be aware of my rights under the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) they are willing to safeguard me and contribute to my enjoyment which gives me a sense of purpose, keep laughter in my life and most importantly that I have a quality of life.

As I said in the beginning, we are still the same people, and more than that we are people with human rights. Hopefully one day soon it will not be necessary for us to have this label, our rights under UNCPRD will be upheld.

As Nelson Mandela said, “to deny people their human rights is to deny them their humanity”. Standards have the potential to uphold the human rights of all people with dementia, honour their humanity and give them the quality of life they deserve.

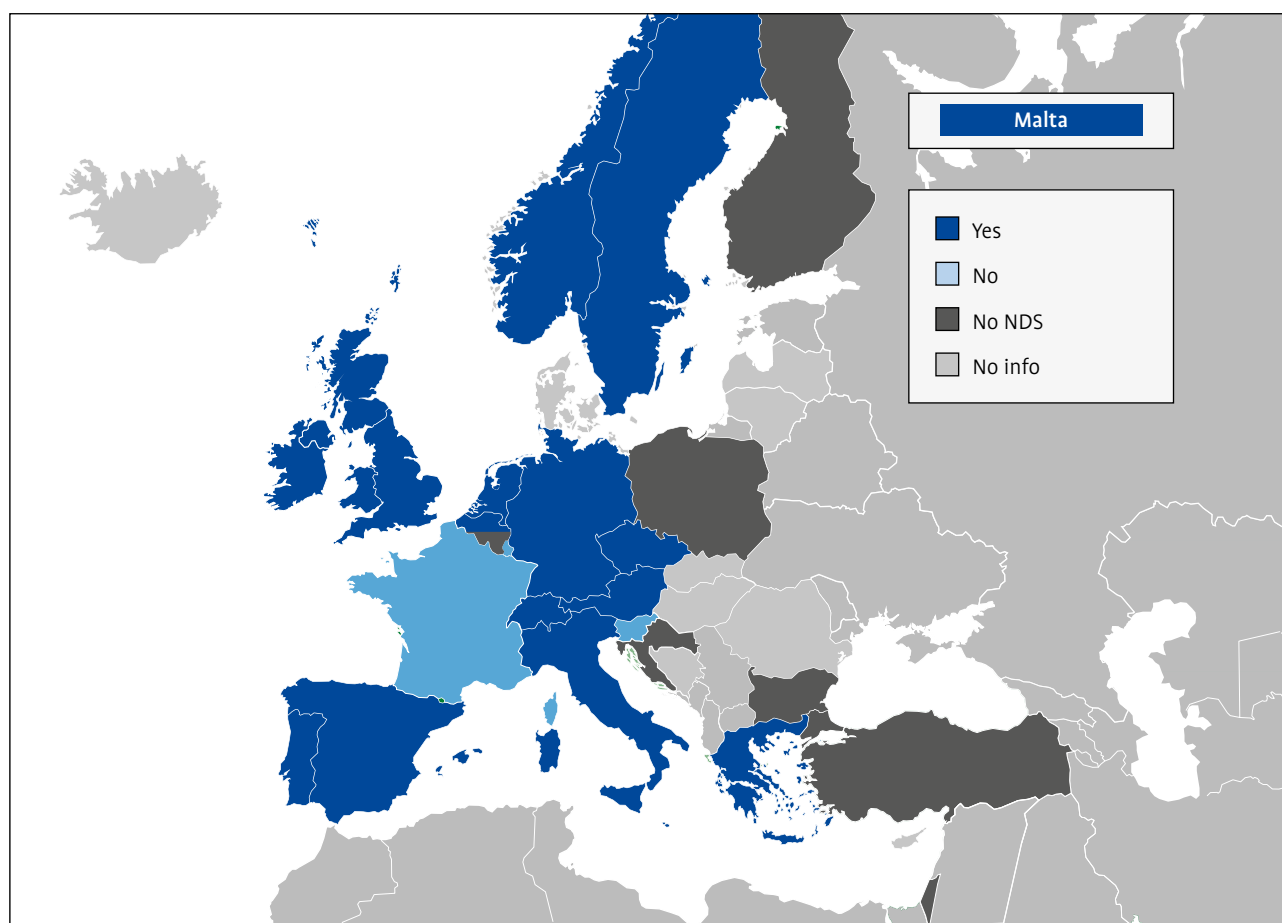
5. Governmental policies – embedding dementia inclusiveness

There has been progress over the past six years in raising the profile of dementia amongst governments and decision-makers, particularly in relation to policies and strategies at a national (as well as regional and local) level. Responses to campaigning from member organisations covers various themes and disciplines, including improvements to clinical and formal care, improvements to services and support, as well as work around dementia-inclusive communities and awareness-raising campaigns.

As such, we sought to understand the extent to which dementia inclusiveness is contained within national policy documents. In particular, we were interested in the extent to which the work of the EU Joint Action on Dementia and the WHO's Global Action Plan on Dementia were referenced and included within these documents. As such, in this section, we seek to provide a brief examination of the place of dementia inclusiveness in the policy responses of countries.

5.1 Dementia Strategies

Map 2 shows the breakdown of countries highlighting countries with a dementia strategy and those where the strategies reference dementia-inclusive communities or initiatives.



Of the 20 respondents who reported having a current national dementia strategy, 17 reported that it included some measure relating to dementia-inclusive work. This included examples of a broad range of commitments and workstreams. The following is intended to provide illustrative examples of the different areas of focus, however, it is not exhaustive:

- Ireland's [national dementia strategy](#) has six Priority Action Areas, one of which is Better Awareness and Understanding. The "[Dementia: Understand Together](#)" campaign and subsequent framework for a social movement to facilitate a culture change for dementia – both the movement and dementia champions continue to be supported
- The Dutch [national dementia strategy](#) focuses on three key areas, with two of the three pillars of the strategy a significant focus on dementia inclusiveness ("Persons with dementia matter" and "Tailor-made support when living with dementia")
- Germany's [national dementia strategy](#) has a focus on employers, including public transport staff becoming more dementia friendly
- Sweden's [national dementia strategy](#) has sections dedicated to "family and friends" and "society", whilst the mid-term review of its national dementia strategy identified the need for further work to improve understanding of dementia amongst work forces (e.g. transportation, retail sectors)
- UK (Scotland) developed a "[Dementia and COVID-19 Action Plan](#)" which included a specific commitment focused on ensuring community groups and businesses are dementia inclusive, in an effort to reduce social isolation and loneliness.

For countries which previously had strategies [Belgium (Flanders), Finland and the United Kingdom (England)], dementia-inclusive communities and initiatives were present within their strategies, whilst countries in the process of developing new strategies or who were awaiting government approval [Belgium (Flanders), Turkey and United Kingdom (England)] indicated that they expected dementia inclusiveness to be included in some form.

5.2 National/Regional policies and guidance

Nine countries reported that regional and national governments had additional policy documents or guidance in relation to dementia-inclusive communities and initiatives. The majority of these relate to the guidelines and toolkits mentioned in section 4.3, however, some additional examples were also provided:

- Ireland – Dementia Inclusive Communities work undertaken as part of the post-diagnostic pathways work package of the National Dementia Office (in partnership with The Alzheimer Society of Ireland)
- Norway – The national Roadmap on Dementia, the Strategy on Universal Design, as well as municipality plans for action related to dementia
- Portugal – Five Regional Dementia Plans are awaiting implementation and tie in to the overarching national dementia strategy, which includes a focus on public awareness and stigma reduction
- Sweden – The national government produced care facility housing design guidelines
- Switzerland – Alzheimer Suisse published guidelines on the creation of "living libraries", in person awareness events.

5.3 WHO Global Action Plan

In relation to the WHO Global Action Plan on the Response to Public Health, only eight respondents (30%) stated that policy documents or resources referred in some way to the WHO strategy or the resources it has developed in relation to this work.

The Global Status Report on Dementia, published by the WHO in 2021 showed that whilst many countries do not have national dementia strategies in place, 19 out of 24 Global Dementia Observatory Countries in the WHO European Region have had some form of public awareness campaign for dementia (measured between 2018 and 2020).

This distinction is interesting to note – it is unclear why, when many countries do have active awareness campaigns in place, they do not reference or link to the global work taking place. It is difficult to provide a definitive explanation, however, in line with the responses to the survey as a whole, it appears that:

- In some cases, strategies and policy work are long-standing in nature and may pre-date the WHO action plan – therefore this ongoing work may not reference the global action plan, even where the work still contributes to and is measured against the new framework
- As per section four, much work in this domain is undertaken by national, regional or local Alzheimer's associations, and does not always involve or receive funding from the state. As such, it may not be included in government policy documents.

5.4 Second EU Joint Action on Dementia

Alzheimer Europe asked countries if their national dementia strategies or other policy drivers made some reference to the second Joint Action on Dementia.

It was surprising that only two countries (Norway and Italy – who were part of the Joint Action) reported that the work of the second EU Joint Action on Dementia in relation to dementia-inclusive communities and initiatives, has been included in policy documents in their countries.

By way of explanation, some absences may be explained by strategies and other policy work pre-dating the conclusion of the second Joint Action (which concluded in October 2019) or by the absence of dementia policy work taking place in some countries.

However, even accommodating for such a delay between the project completion and the present time, it would appear that there is a considerable and concerning gap between the identification of good practice and policies (particularly at an EU level), and the adoption and implementation by governments into policy, practice and services for people with dementia, their families and carers.

5.5 Dementia inclusiveness in other policy areas

Alzheimer Europe asked members for examples of other initiatives where dementia-inclusive work or considerations may have also been included.

Of the 11 respondents who provided additional information, nine stated that policy responses were in place in relation to healthy ageing, age-friendly societies or ageing demographics, which linked into some aspect of dementia inclusiveness. In particular:

- Belgium (Flanders) – The VVSG draws strong links between dementia-inclusive and age-friendly communities, with the Flanders Dementia Expert Centre encouraging links between healthy ageing and support for informal carers, taking a holistic view of dementia
- Finland – noted two specific areas of work:
 - The [National Programme on Ageing 2030](#) is ongoing in Finland, with a strong focus on prevention of chronic diseases, as well as including references to memory related diseases (reflecting the terminology used in Finnish)
 - The [Action Programme for Housing for the Elderly 2020-2022](#) involved collaboration between national and municipal governments, as well as NGOs (including Muistiliitto – the Finnish Alzheimer's Society) to discuss how future housing can best support people as they age or live with conditions such as dementia.

Other themes which were directly referenced were housing, transport, awareness raising amongst various sectors (e.g. service sector) and prevention.



Petri Lampinen (Finland), member of the European Working Group of People with Dementia

Brain health does not just affect healthy people. People who are ill with dementia can also take equal care of it. Before I had frontotemporal dementia (FTD), I followed a healthy lifestyle, with my hobbies including hiking, picking berries and gardening. I had a great many social encounters as part of my work life.

Since I left work, I have had increased time to take care of my brain health. I have increased physical activity and attached even more concern to my diet. In addition, I am going to keep an eye on my sleep to ensure that I sleep for long enough and monitor my blood pressure. I also follow the medication given for this on a regular basis.



I have also developed my language skills whilst working with the EWGPWD. I experience joy in learning new things despite dementia. I would not be as good as I am now if I had not taken care of myself over the years.

Brain health is increasingly discussed in my country, Finland. The issue is discussed quite a lot in the press and has been widely highlighted by the Finnish Memory Association (Muistiliitto). Many other organisations are also concerned about brain health.

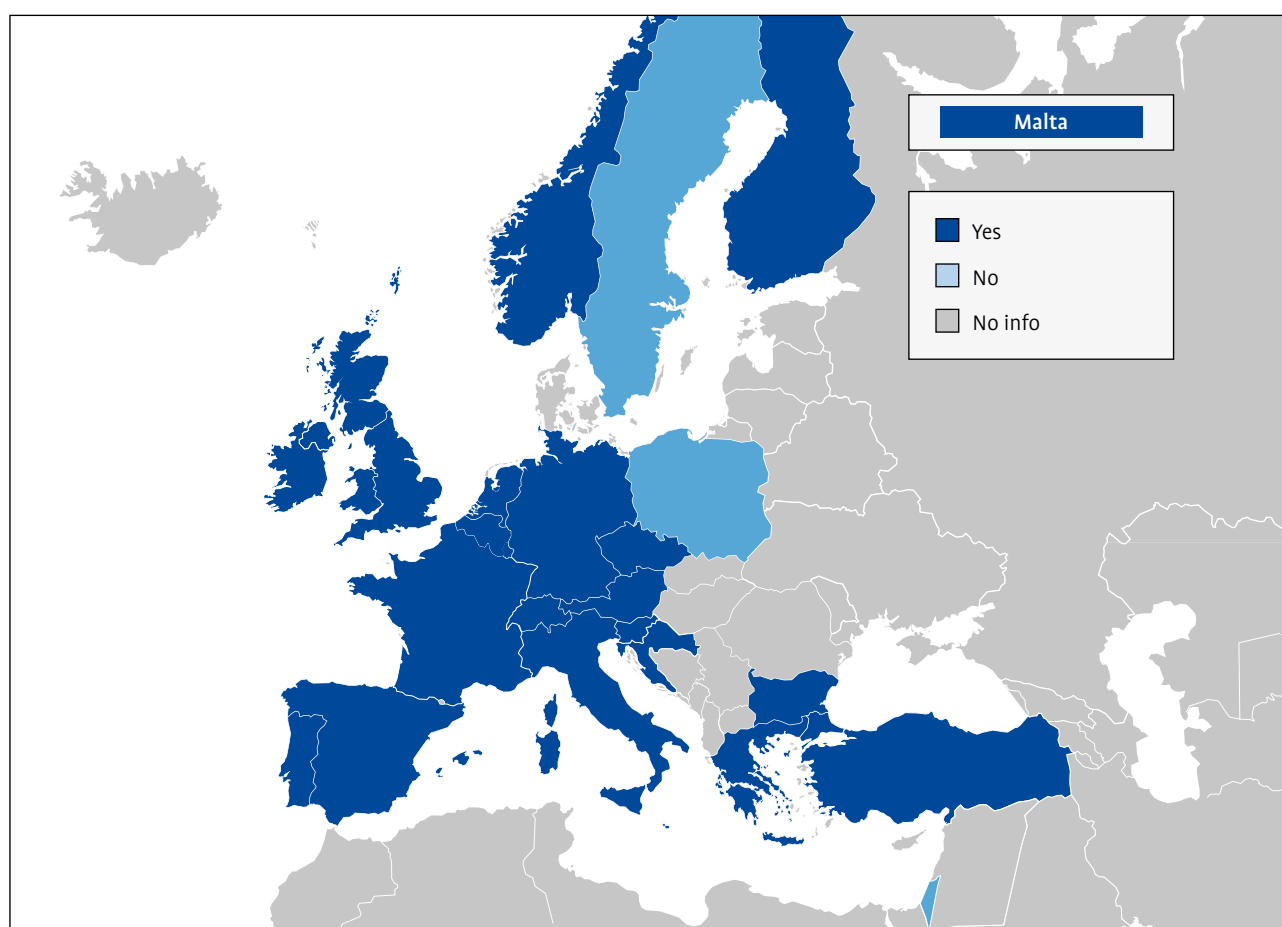
Brain health is a life-long thing and taking care of it should begin in childhood. Care should also be promoted at all stages of life. Children and young people studying, we should look at the functionality of the facilities in places of education, in particular, taking diligent care of school health care.

Working life is now terribly busy, stressful and a great deal is required of the employee. Work is strained and concentration can cause difficulties. It is also worth paying attention to the functionality of occupational health care and how it relates to the health of the brain.

Nurturing brain health is a worthwhile investment in the future and can help ensure that dementia becomes less prevalent in older people than it is at present. Somehow, people should be involved in brain-health life, regardless of their income level. This is something worth noting, as, unfortunately, there are health inequalities in lifestyles between people with lower and higher incomes.

6. Awareness raising campaigns – development and implementation

As part of our survey, we asked members if there had been an awareness-raising campaign in their country in the previous five years. As can be seen in [Map 3](#), the majority of European countries have had some kind of awareness raising campaign (24 respondents from 21 countries reported a campaign having taken place in their country).



From the additional information submitted by our members, it is evident that one of the most commonly developed and implemented elements of dementia-inclusive communities are that of awareness raising campaigns, aimed at improving knowledge and understanding of the conditions, primarily among the general public.

As noted from the policy overview in section three, the purpose of such campaigns can be varied, although they often have an overarching aim of combatting the stigma and stereotypes associated with the condition, removing misconceptions and encouraging people to seek support or further information.

In this section, a high-level overview of different aspects of the campaigns is provided, with relevant examples and information shared from specific campaigns.

6.1 Outline of campaigns' themes and targeted audience

National (as well as regional and local) awareness-raising campaigns are broad in nature covering a diverse range of themes and areas. Whilst these often reflect the national context in a country (i.e. reflecting the policy issues which affect people with dementia in those countries), a number of overlapping and common themes are evident. From the responses received, the most common themes of these campaigns include:

- Raising awareness and understanding about dementia
- Challenging the stigma associated with the condition
- Providing information on available services and support for people with dementia.

Other areas of focus for these types of campaigns include:

- The importance of timely diagnosis
- Upholding the rights of people with dementia
- Issues around the provision of financial support (particularly from government budgets)
- The risk factors related to dementia
- Links to existing policy issues.

In all cases, the awareness campaigns in each country were (partially or fully) aimed at improving the knowledge and understanding of the general public. However, more targeted audiences were the subject of some campaigns.

Roughly half of the campaigns also had some focus on policy- and decision-makers, to inform them about the experiences of people with dementia, whilst around about a third were also aimed at people with dementia and carers themselves. A small number of campaigns (five) also included health professionals and service providers as a target audience, demonstrating that for some countries, improving training and skills for professionals is still a key issue.

Other audiences for these campaigns included students, service industries, companies and the public sector.



Alzheimer Hellas members participate in the 1st European Sport Event Forum in Athens, 21 to 23 September 2018.



The Czech Alzheimer Association raising awareness during Memory Week, between 16 to 28 September 2019.

6.2 Involvement of people with dementia

The involvement of people with dementia varies by country, however, it is evident in the responses that the lived experience of people with dementia, their families and carers are the basis for all campaigns.

Only a small number of countries (four) stated that people with dementia were not directly involved in the campaign. All others reported that people with dementia were directly involved in at least one aspect of the campaign.

This ranged from gathering the experiences and knowledge of people with dementia, their families and carers (in the framework of the delivery of support and services) to dedicated engagement with groups, as the basis for the messaging and focus of the campaign. Flanders, Netherlands and Spain referenced the involvement of expert groups (including people with dementia) to inform the development of their campaigns.

France, Finland and UK (England), described using testimonies and lived experiences to build narratives and storytelling as a key part of their campaigns. In addition to this, Flanders, Ireland and Slovenia also highlighted that people with dementia, played more active roles as participants/ambassadors during the campaigns.

In Ireland focus groups with people with dementia, their families and carers informed the campaign. They also were part of the original steering group and today provide input into the working group, advise national partners and focus groups.



EWGPWD member Idalina Aguiar (centre) and daughter Nélida Aguiar (second from right), took part in the "Memory Ride" event organised by Machico City Hall, Madeira, Portugal, in 2019.

6.3 Funding

In the 21 countries which reported having had an awareness raising campaign within the past five years, slightly less than half of countries that the funding had been funded solely by the Alzheimer association(s) within the country (Belgium [Flanders and Wallonia], Bulgaria, Finland, France, Greece, Italy, Portugal, Switzerland, Turkey and UK [England and Scotland]).

More than a quarter of countries reported a mix of funding streams, with all of them reporting some funding mix between Alzheimer association and state funding (either from a national or local level), with a couple additionally reporting private sponsors. Finally, just under a quarter of organisations reported campaigns which were purely funded by the state (Austria, Germany, Malta and Norway).

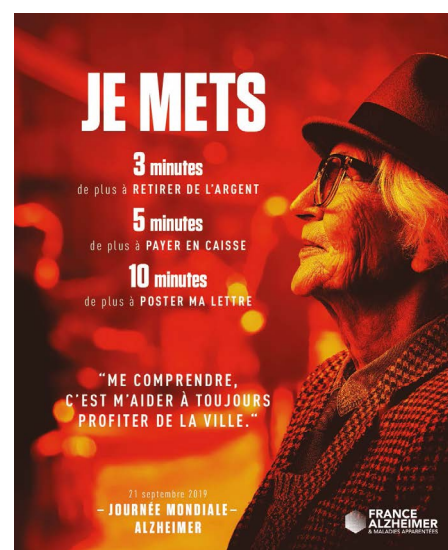


Alzheimer Luxembourg Association each year organises memory walks each year on World Alzheimer's Day to help raise awareness of the disease.

6.4 Mediums used

In keeping with the general public being the main target audience for awareness raising campaigns, the vast majority of campaigns adopted a mixture of different platforms throughout their duration. This included more traditional media such as TV and radio, as well as newspapers, flyers and brochures. Furthermore, campaigns have recognised the importance of an online presence in sharing messages and raising awareness, with all campaigns having incorporated the use of social media, as part of their activities.

Less common were in-person events and activities, such as conferences, however some countries reported holding such events as part of their awareness raising campaigns. Despite the increasing importance and growth of social media and online resources, it is interesting to note that only a single country (Switzerland) reported a purely online campaign.



Around World Alzheimer's Day 2019, France Alzheimer focused its messaging on inclusiveness and the necessity for all citizens to take into consideration people living with dementia and their caregivers.

6.5 Coordinators and other involved stakeholders

Around 70% of respondents reported that responsibility for the coordination of the awareness campaigns described resided solely with the Alzheimer associations themselves. Around 20% reported a mix, primarily between Alzheimer associations and governments (varying between national, regional and municipal level), with other elements of civil society and national foundations having some active role in such awareness-raising campaigns. Only 8% reported that governments had responsibility for the coordination of the campaigns described.

Outside of the responsibility for the coordination, our members reported on the diverse range of other organisations and bodies which were involved in some capacity in the campaigns. Just under half of the campaigns involved other associations or organisations. The types of organisations varied significantly by country and included:

- Municipalities, regional level organisations and umbrella bodies
- National health and social insurance schemes, pension schemes
- Other civil society organisations (including those for older people)
- Academic institutions
- Private organisations and sponsors.

6.6 Timeframes

Perhaps unsurprisingly, almost all of awareness raising campaigns are timed around World Alzheimer's Day (21 September) or World Alzheimer's Month. In the case of long-term or ongoing campaigns, activities often peak or are aligned to make the most of these global focal points each year.

Approximately half of the campaigns included by respondents were described as being continuous in nature, with awareness raising and activities taking place throughout the year.



The Alzheimer's Society (UK – England) holds annual Memory Walks during World Alzheimer's Month to help raise awareness for dementia.

However, for a small number of campaigns, uniquely amongst those funded by Alzheimer's associations, a number of other factors dictated the approach to campaigns, such as availability of resources and finances, responding to local contexts etc.

The campaigns for Belgium (Flanders), Ireland and the Netherlands have a number of features in common, notably that they are linked and originated as part of previous/current dementia strategies in their countries/region. The ongoing nature of the campaigns, both as a means of raising awareness within society, as well as a way of ensuring the involvement of people with dementia as experts with lived experience, is distinct. In its response, Ireland described this as a shift in approach towards a “social movement”.

For campaigns which were specifically time-limited, there was a significant range in durations. The shortest was four weeks (split into two periods of two weeks), with the longest being scheduled to continue for two years (though the Irish campaign had originally been scheduled to last for three years).

Both UK respondents were distinct from other European countries as their dedicated Alzheimer's awareness weeks (which take place annually) fall during May (England) and the first week of July (Scotland).



In South Park in Sofia, Bulgaria, Alzheimer Bulgaria and Foundation Compassion Alzheimer organised a 5 km run, to mark World Alzheimer's Day with the message: “Health promotion and disease prevention through sport”.

Carmel Geoghegan, supporter of Helen Rochford-Brennan, member of the European Working Group of People with Dementia

My first experience of dementia came when my beautiful mum got a very late diagnosis for vascular/frontotemporal dementia in January 2011. It was a shock but as we had no idea what it meant, leaving the neurologist with no information or any guidance as to the supports available.

We arrived home and continued on with life as normal as possible. We continued to go out for coffee, lunch, socialise but as people got to hear of Mum's diagnosis it was them who changed towards Mum.

They stopped speaking to her directly, spoke about her in the third person in her presence. It was very frustrating to witness, I was so hurt for my Mum to have to hear this. The clinicians we encountered all spoke about the ageing process which I knew was not the answer but it was very difficult to argue with so called 'experts'.

Services and supports were non-existent in our rural area and internet supports were unheard of at the time. By self-educating i.e., attending a course on social gerontology, going to conferences about dementia I learned a good understanding about what we were dealing with.

This at least gave us some solace, we continued to engage in our community for as long as possible and after my mum passed away, I decided to speak out about our experience and try to change attitudes as it is the misunderstanding around the diagnosis that is the main issue.

We have to realise that dementia in any form will manifest differently with each individual and no two persons will have the same experience much like any other life-limiting disease. Starting to introduce the conversation at a young age in schools is really important so dementia is not misunderstood and those who receive a diagnosis can continue to contribute and participate in day-to-day life. They can also continue to remain in the workforce if they so wish.

Communities should be open and welcoming to all, we should not be labelled or partitioned into groups, we all have a lot to contribute and everyone's life is a valued part of the community.

Going forward I hope to see communities just being open and understanding and not having to have constant campaigns to be reminded to include a certain cohort of human beings.

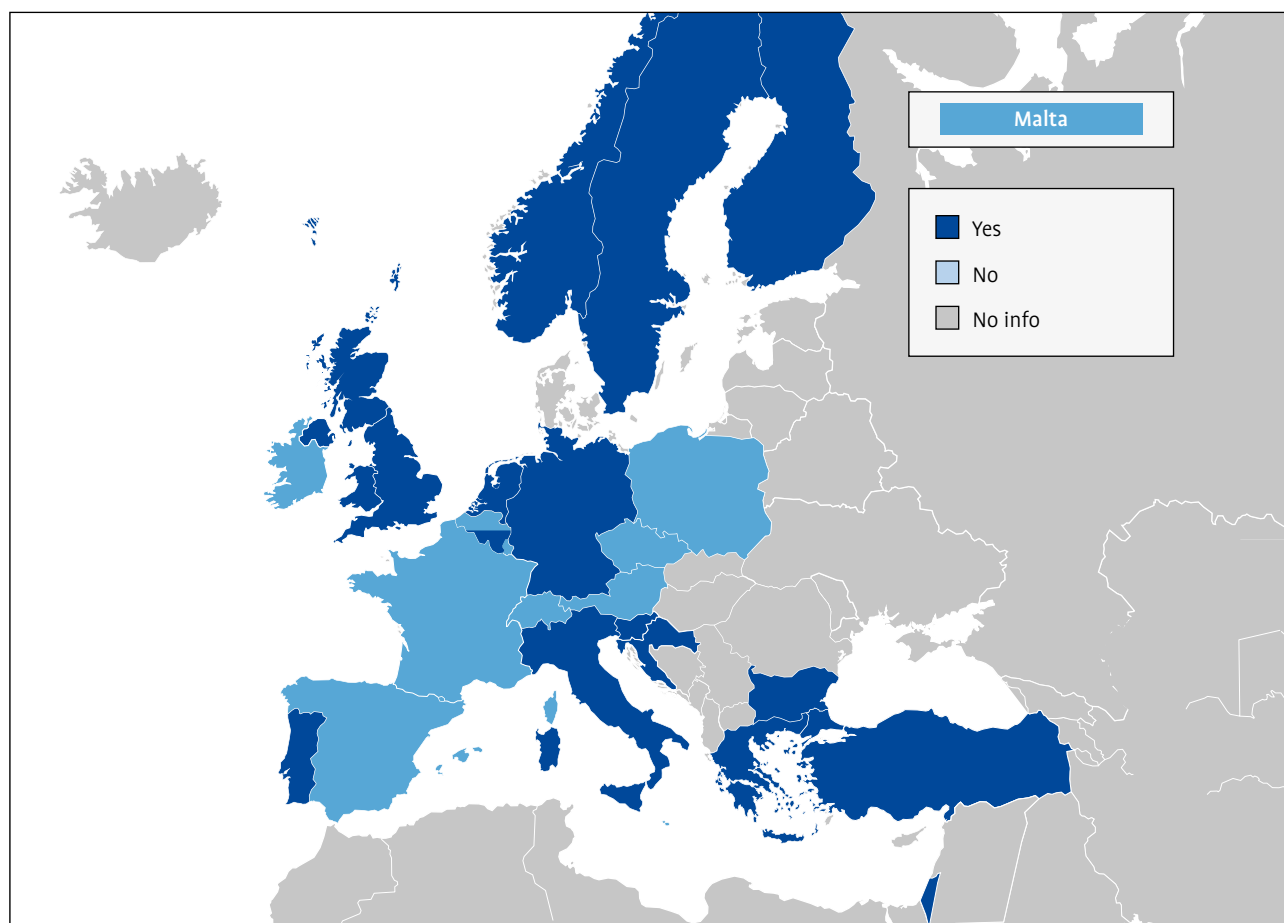
The last number of years has brought many positive changes to communities and those living with a diagnosis, we have the right to residential care but not to remain in our own homes. During COVID-19 it became evident that residential home care has to be monitored and made accountable.



7. Dementia Friends and other training programmes

As part of our survey, we asked members about the presence of Dementia Friends programmes in their countries, as well as other courses or programmes which aimed to improve the knowledge and understanding of different societal groups (specifically those not working in health and care settings) about dementia. These programmes are usually short, low-intensity courses, which aim to provide a baseline of information about dementia, some examples of challenges with people may encounter in day-to-day life, how individuals can help and where to find further information.

As can be seen in [Map 4](#), the majority of respondents have some kind of Dementia Friends programme in place (16 respondents from 15 countries reported the programme being developed in their country).



As with other sections of the report, providing clear delineation between certain programmes and activities is challenging, as it is evident that there are often areas which overlap in this work, particularly in relation to dementia-inclusive community work and dedicated Dementia Friends programmes (as well as other areas of work undertaken by our members).

In this section, we examine some of the key features of these types of programmes, including their organisation, funding, target audience and how they tie into other areas of dementia inclusive work.

7.1 Global Dementia Friends Network (GDFN)

The origins of the Dementia Friends programme can be found in the work of the Alzheimer's Society (UK - England). As part of the Prime Minister's Challenge on Dementia 2020, the Alzheimer's Society was committed to "turning Dementia Friends into a global movement including sharing its learning across the world and learning from others".

Between 2016 and 2020, the Alzheimer's Society hosted and coordinated the [Global Dementia Friends Network \(GDFN\)](#), fostering a global network of countries to raise awareness of dementia and challenge stigma through Dementia Friends programmes.

At the conclusion of the programme in April 2020, there were 67 Dementia Friends programmes (or national equivalent) launched or in development in 56 countries, across the world.



7.2 Coordination and funding of programmes

In all countries with a Dementia Friends programme, the programme is coordinated by the Alzheimer's association of that country. However, the funding sources vary, as follows:

- Ten (63%) are funded purely by the Alzheimer's association themselves
- Two (13%) were funded jointly by Alzheimer's associations and national governments
- Two (13%) were funded jointly by Alzheimer's associations and regional governments
- One was funded jointly by an Alzheimer's association and private funding
- One was funded purely from a private source.

7.3 Target of programmes

In all cases, the programmes were reported as being targeted at the general public (either as individuals or as part of community groups) to increase their awareness and understanding of dementia, with programmes being delivered various ways (whether completing in-person training from the Alzheimer's association or through the completion of an online course).

However, it was also reported that other sectors and populations were the specifically identified and targeted by the campaigns, including:

- Nine organisations (56%) also target businesses (e.g. service sector, banking etc)
- Six organisations (38%) deliver sessions to care services or professionals in the field
- Other organisations targeted civil servants, students and schools.

Owing to the nature of Dementia Friends programmes, it is surprising that they are used in care services and professionals working in the field, especially in countries where policies, services and practice may generally be regarded as being more well-established. Without further detail as to the exact nature of the trainings and the broader context, it is not possible to explain the reason behind this.

7.4 Evaluations

Slightly more than half (56%) of the respondents with programmes reported having some level of evaluation for their Dementia Friends programme. From the responses, we identified three specific areas which the evaluations cover (in some cases only a single issue is covered, others cover multiple issues):

- The experience of the programme itself
- The motivations to become a dementia friend
- Changes in understanding of, and attitudes towards, dementia.

A recent study from Alzheimer Nederland, involving 500 people who had become dementia friends, showed that 85% of dementia friends reported having greater recognition of dementia, whilst 82% reported having greater confidence to interact with a person with dementia.

In addition, some of the evaluations also track the additional activities of those who have become Dementia Friends.

7.5 Involvement of Dementia Friends in other areas of work

To maximise the potential impact from engaging with the public, many Alzheimer associations seek to build on Dementia Friends programme to encourage participants to take on a greater role, including contributing to the work of the associations or in their localities, attending meetings or events, as well as invitation to support the associations through fundraising activities.

In doing so, the potential of Dementia Friends extends beyond its initial purpose of raising awareness and challenging stigma within society, moving towards an engaged and informed population willing to actively contribute and act to ensure that people with dementia, their families and carers are supported.

This approach was reflected in eleven countries (69%) with Dementia Friends programmes, who noted that they attempt to involve their dementia friends in other areas of work, including:

- Invitations to attend Alzheimer's Cafés and other events
- Invitations to meetings and networks of Dementia Friends
- Involvement in awareness raising, especially during World Alzheimer's Month
- Connecting Dementia Friends with existing dementia inclusive societies
- Provision of further resources e.g. newsletter
- Encouraging further training to proactively spread awareness (see 7.6)
- Invitations to participate in fundraising for the Association.

7.6 Other courses and training programmes

Both countries with or without Dementia Friends programmes shared other examples of other (non-clinical) training and courses available in their countries, which similarly aimed to raise understanding about dementia amongst different sections of the population.

The focus and audience for the training varies across countries, with some building on the Dementia Friends programme described above to provide additional training to engaged volunteers or businesses and services to allow them to support further awareness raising or. A number of responses highlighted programmes for providing support and advice to carers of people with dementia to allow them to effectively support the person with dementia. Some training programmes were also aimed towards care settings and professionals, though they were fewer in number.

Some specific examples include:

- Belgium (Flanders) – the Alzheimer Ligue Flanders provides additional training for informal carers, whilst the expert centre provides training for professional carers
- Belgium (Wallonia) – the Alzheimer Ligue launched [“Ensemble Alzheimer est plus léger” \(Together Alzheimer's is lighter\)](#) in 2015, which focuses on the person with Alzheimer's disease as a full citizen and actor of his community. Starting in Bastogne, the initiative provided training, by way of a conference, to raise awareness of dementia among citizens, associations and local shopkeepers to encourage and practice hospitality, communication and quality of support for people with Alzheimer's disease or other forms of dementia

- Ireland – Dementia: Understand Together has undertaken “walkability audits” in community and primary care centres to inform best practice and improve understanding about how design in the public realm and health centres can affect people with dementia. Dementia inclusive design training is offered to local councils, town planners and national partners and elements are part of the Age Friendly Ireland training. Dementia Awareness Training for national partners and local community groups is provided by the campaign’s partner The Alzheimer Society of Ireland
- Portugal – In 2019 Alzheimer Portugal trained about 200 Dementia Friends Ambassadors to provide informative meetings about dementia, using specific toolkits and following a common manual. Their mission is to inspire others to learn more about dementia and to accept a commitment to actively promote the daily life of people with dementia
- UK (England) – The Alzheimer Society outlined two of its additional training programmes:
 - Dementia Friends are encouraged to volunteer as Dementia Friends Champions and deliver sessions in their own communities and networks
 - The Carer Information and Support Programme (CRISP) which aims to enable carers to have increased knowledge of dementia, provide practical information that they can use in coping with living with dementia day-to-day and help them feel better informed. And there are several more detailed training courses the public or non-health and social care professional can pay to attend.

We also wish to highlight the “[Samen dementievriendelijk](#)” (Dementia Friendly Together) programme of the Netherlands, which is run collaboratively between Alzheimer Nederland and the Dutch Ministry of Health. The programme covers a number of themes (including those on dementia-friendly initiatives and communities, awareness raising and dementia friends). We have included reference to the programme here, as there is a significant focus on training within the programme, particularly in relation to improving the understanding of dementia amongst the public, businesses and workers in service focused roles (e.g. supermarkets, transport etc.). This compares to the Irish approach, but has a more specific focus on training. However, the programme also seeks to involve and work with municipalities to improve the experience of people with dementia, their families and carers, as well as linking people to volunteering opportunities to contribute to dementia-inclusive initiatives within their communities.



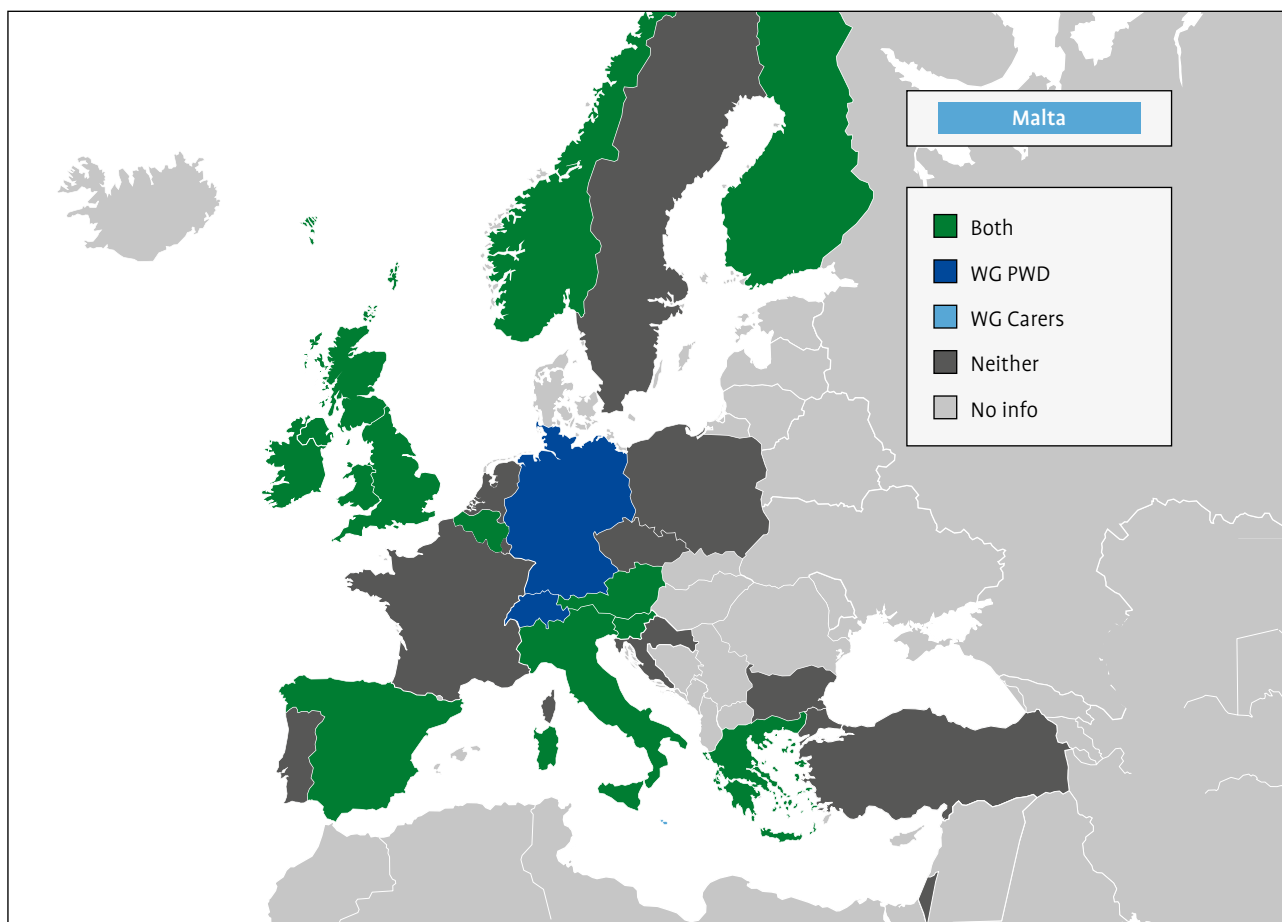
8. Involvement of people with dementia and working groups

Involving people with dementia, their families and carers in the decisions which affect them is an essential part of any rights-based approach to the care and support for people with dementia, their families and carers. Whether these are decisions concerning matters which directly impact upon an individual in their day to day life (such as different types of care and support) or relate to broader policy decisions (such as dementia strategies or legislation), ensuring that their views are heard and acted upon is crucial if a country and a society is to be considered as truly dementia-inclusive.

As such, this section will provide an overview of some of the ways in which countries involve people with dementia, by governments and decision makers, our members and other stakeholders.

8.1 Working groups

Alzheimer Europe was interested in finding out how many countries had “working groups” of people with dementia or carers, brought together specifically for the purpose of involving people in policy-making processes. [Map 5](#) shows the distribution of working groups across Europe.



From our survey, 14 respondents indicated that they had a working group of people with dementia, whilst 13 countries had a group for carers. 12 countries reported that the groups are financed by the Alzheimer's association themselves, whilst others reported a mixture of financing, involving the Alzheimer's association, national and local governments.

The Flemish Working Group of People with Dementia was reported to have created two manifestos setting out their views, the [“Hand in Hand Manifesto”](#), setting out the ten topics which matter most to people with dementia, as well as a [sports manifesto](#) on the subject of exercise, conveying the importance of allowing people with dementia and their loved ones to stay socially active as long as possible and enjoy what they like doing. This approach was distinct from the work reported from other working groups.

Whilst sections 8.2 and 8.3 are primarily concerned with the activities of these working groups and are based on the responses as to the activities of these groups, it is important to recognise that the absence of formally established working groups does not mean that people with dementia or carers are not involved in the work of associations or are not engaged with policy and decision-makers in their countries and communities.

8.2 Involvement in Alzheimer's associations

Alzheimer Europe asked members with working groups about the natures of the activities and involvement within the organisations. From the responses, seven countries (Finland, Germany, Greece, Italy, Malta, and the UK (England and Scotland)) reported that the working groups were involved in some way in the governance of the associations, including on boards and/or committees of the organisations. In addition, seven described engagement with the specific purpose of helping to set the aims and objectives of the organisations.

Amongst other organisations, responses varied in their approaches to involvement, however, the commitment to ensuring the voices of people with dementia, their families and carers were heard, was a recurring theme of the work of organisations. Other ways in which these group were involved in the associations included:

- Active engagement in campaigns and public affairs work of organisations
- Dedicated meetings and focus groups throughout the year to gather feedback and input into the work of the organisation (including services)
- Online engagement through groups and forums related to the work of the organisation.

8.3 Involvement by government and decision-makers

We were also keen to understand the extent to which governments and decision-makers involved these working groups of people with dementia and carers in their policy work. 11 respondents (Austria, Belgium [Flanders], Finland, Germany, Ireland, Malta, Norway, Spain, Switzerland and the UK [England and Scotland]) noted that there was some level of engagement by governments and decision-makers. Three of these responses were for the regional or local government only, whilst the others were a mix of national and local engagement. Involvement with the work of governments included meetings with officials and decision-makers in health directorates, as well as involvement in the development and monitoring of national dementia strategies.

The Scottish Dementia Working Group and the National Dementia Carers Action Network are long-established groups supported by Alzheimer Scotland, which are frequently involved by the Scottish Government

and national bodies to ensure that the voices of people and carers help shape policy responses. For example, both groups meet with the relevant Scottish Government minister at least once per year (although this has been disrupted by the COVID-19 pandemic), whilst also contributing to National Dementia Strategy Implementation and Monitoring Group, engaging with the national bodies for health and social care workforce development, as well as being involved in ongoing work on the oversight and reform of mental health and capacity legislation. Alzheimer Scotland has also focused in more recent years in the development of a Local Active Voice Network to ensure the meaningful participation of a greater diversity of lived experience to inform policy and practice at a local and national level.

8.4 Other examples of involvement

It is not only working groups of people with dementia and carers which provide ways for people with dementia and carers to be involved. As part of our survey, we asked respondents to share other examples of the ways in which people with dementia and carers were involved, regardless of whether their country had a working group or not.

Some examples have already been provided in relation to the involvement of people with dementia in awareness raising campaigns, which can be found in section 6.2.

Frequently cited examples of activities which also involve people with dementia and allow them to share their experiences and views include:

- Attendance and speaking opportunities at events and conferences held by other organisations and groups
- Involvement in the development of brochures and written resources
- Working with local authorities in relation to the provision of dementia-inclusive services
- Providing feedback and evaluation on the services and supports (of the Alzheimer Association)
- Participation in media (e.g. written articles, interviews etc.)
- Inclusion in research projects.

Alzheimer Portugal shared that it is in the process of implementing a programme “[Na primeira pessoa](#)” (“In the first person”), which aims to empower people with dementia, enhancing their wellbeing, autonomy and active participation in society with a strong focus on the involvement and participation in society. It has five overarching areas of work:

1. Portuguese Working Group of People with Dementia
2. Training on legal rights
3. Individual and group support
4. “Marcar lugar” (schedule a visit to the Museum)
5. Community awareness on the rights of people with dementia through online training sessions.

The approach of Alzheimer Nederland was also somewhat distinct, involving people with dementia and carers in two ways:

- Through the programme [Samen dementievriendelijk](#) (Dementia Friendly Together), a “Group of Friends” was formed consisting of 46 people, including professionals, volunteers, students, informal carers and people with dementia, who provide feedback on aspects such as training courses, campaigns and communications. The group is contacted by email and meets twice per year
- The Alzheimer Nederland Panel is an online platform which gather the views of over 2,000 people with dementia, their informal carers and care professionals who are dealing with dementia in their work.

8.5 Resources

A number of associations shared resources which have been produced to support the inclusion of people with dementia, including considerations when establishing groups for people with dementia or involving people with dementia in decision-making processes.

For some organisations, these were materials for their own staff and volunteers, to support the involvement of people with dementia and their carers. Others have publicly available resources, for example:

- Belgium (Flanders) – The workbook referred to in previous sections, [“Together for a dementia-friendly Flanders”](#), contains general principles on the involvement of people with dementia and their carers
- Germany – The German Alzheimer Association (Deutsche Alzheimer Gesellschaft) produced a brochure about how to set up groups for people with dementia and providing an overview of some of the considerations that should be made: <https://shop.deutsche-alzheimer.de/broschueren/35/gruppen-fuer-menschen-mit-beginnender-demenz>
- Ireland – The Alzheimer Society of Ireland launched the [“Hear our Voice”](#) publication in 2020, which provides guidance on how to involve people with dementia and carers, including in policy processes or as part of committees or advisory boards
- UK (England) – The Alzheimer Society produced the [“Dementia Experience” toolkit](#) detailing how to measure the experience of people with dementia when commissioning, improving, or creating new services and products. This resource was developed with people affected by dementia, commissioners, health and care professionals.



9. COVID-19

Since the onset of the pandemic in early 2020, the majority of our members have reported that work on dementia-inclusive initiatives and communities (both their own and that of governments etc.) in their countries has either been delayed or halted. The pandemic has created additional barriers in the delivery of services and support for people with dementia, as well as creating additional challenges in maintaining dementia as a priority issue in the eyes of policy and decision-makers.

In this section, we provide a brief summary of some of the key points which have been conveyed by our members in this regard. Although many of the points within this section pertain to the broader issues caused by the COVID-19 pandemic on services and support for people with dementia, it is helpful to refer to them, as they highlight the additional challenges which people with dementia have faced. This includes prolonged periods of social isolation, which emerging evidence is showing worsens the progression and symptoms of dementia. Furthermore, many carers experienced negative effects on their health and well-being, as a result of isolation and a lack of services and support during periods of lockdown.

As such, this section underscores the importance of communities and initiatives which are dementia inclusive, helping to maintain the social connections and activities which are a vital component of the health and wellbeing of people with dementia and their carers.

9.1 Delays and disruption to services, projects and programmes

A number of our members shared that they reduced or suspended their services as a result of the pandemic and the restrictions which were introduced in all European countries. This included Alzheimer's cafés, day care centres and other support services.

Many of our members created online support systems, providing the opportunities for people with dementia and their carers to socialise with their peers, whilst also having the opportunity to ask staff and volunteers for information, guidance and support, particularly in relation to COVID-19 measures. Members highlighted the variation in activities, some more socially focused, other times more focused on discussions and advice about measures and rules in relation to lockdown etc. The importance of providing activities and engagement, particularly during a time where routines had been disrupted was highlighted as being crucially important for people with dementia and their carers.

However, we are aware that it is not only services provided by our members which were disrupted, with services such as memory clinics, GP visits and other clinical appointments often delayed or cancelled as staff were deployed elsewhere. Furthermore, care homes across the continent experienced extremely high mortality rates as a result of the virus infecting older and frail populations, including high numbers of people with dementia. Even as measures were gradually lifted in society, more restrictive measures often remained in care homes with outside visits not permitted or severely restricted.

In relation to community-based actions and initiatives, many national Alzheimer's associations were active in outreach programmes, actively making contact with people in their communities through phone calls and email, ensuring that connections were maintained, even where people were unable to meet in person.

Our members also made use of their Dementia Friends and dementia-inclusive communities, particular in the earlier stage of the pandemic in 2020, when measures were at their most restrictive for vulnerable persons (i.e. those at higher risk of serious illness or mortality as a result of the virus) who were encouraged or required to stay at home. Support from volunteers included visits to deliver meals, medicines, groceries and other activities to help lessen the burden of the restrictive measures.

The COVID-19 pandemic significantly altered dementia-inclusive initiatives in many countries, which not only delayed the implementation of these projects, but also proved to be a significant financial challenge to national Alzheimer's associations, as project funding was also not continued or reduced to a minimum, whilst donations and funding were substantially reduced for many associations.

As well as individual services, our members have also reported that projects to create dementia-inclusive villages and open new services were slowed down as a result of the pandemic restrictions.

During the first six months Alzheimer Uniti italia Onlus focused on proactive outreach to its members through telephone and video calls, as well as by sending videos as a guide for cognitive, motor and occupational activities to support and maintain their quality of life. To assess the impact, they followed up with a questionnaire conducted by psychologists to caregivers by telephone, which showed that caregivers viewed this support as useful and significant, with only 10% describing having felt abandoned.

Alzheimer Nederland moved its training for dementia-inclusive work online, training smaller groups intensively to become more dementia-inclusive. In the online group training, participants learn how to properly support people with dementia. The first part is about dementia and specifically how to recognise someone with dementia, whilst in the second part, the participants receive information through their ["Doe GOED"](#) ("do good") training method, which operates around four themes:

- Geruststellen (To comfort)
- Oogcontact maken (Make eye contact)
- Even meedenken (Let's think along)
- Dankjewel (Thank you).

There are exercises and practice sessions with interaction between the participants and the trainers at various times, allowing for questions to be asked. The group training takes place online and lasts approximately 1.5 hours. A maximum of 15 participants can participate (minimum 10) with two trainers (trained by the association) delivering the training.

9.2 Advocacy and campaigning

Some of our members have expressed the view that the pandemic has underlined the importance of campaigning and advocacy work, noting that it had exposed the inequalities faced by people with dementia and their carers and at times exacerbating them (e.g. access to supports and services, triage decisions on treatments etc.)

In addition, some members have noted that there has been comparatively little media focus on how the pandemic had disproportionately affected people with dementia and their carers (whether at home, in a residential setting or in hospitals) whilst policy and decision makers have had a very narrow focus in their response to the pandemic, failing to acknowledge or address their specific needs and challenges. However,

as society has opened up and services and support resume, our members have identified that it is now imperative to campaign and undertake dedicated advocacy work to ensure that dementia is prioritised as a policy and public health issue.

As part of this, some members have highlighted that they are making use of online seminars, speeches etc., in their advocacy work, whilst noting that for some work, it is easier to prepare and implement campaigns on a more regular basis, often with the participation of people around the country who otherwise would not have been able to take part. Indeed, the European Working Group of People with Dementia (EWG-PWD) has continued much of its work in patient involvement during the pandemic, despite no physical meetings taking place. Whilst this undoubtedly brings its own challenges (including technological literacy, infrastructure etc), it has been a clear demonstration that with innovation and dedication, involving people with dementia and campaigning can be continued.

In Scotland, the COVID 19 pandemic delayed the development of the country's fourth national dementia strategy. However, in response to the pandemic, the Scottish Government consulted on and developed a specific dementia related action plan, the ["Dementia And Covid-19 – National Action Plan To Continue To Support Recovery For People With Dementia And Their Carers"](#).

The plan contains 21 commitments, including:

- Recognising the huge impact of the pandemic on people with dementia, their families and carers and the wider community
- Recognising that people living with dementia and their carers often feel alone, vulnerable and anxious about COVID-19
- Recognising the particular worries families have about what the future holds for their loved ones with dementia
- Using the experiences of people with dementia and their families to inform responses respond to their needs during the pandemic
- Setting out how the Scottish Governments plans to help people with dementia and those that love and care for them to live well with dementia across the whole journey of the illness – as well as how to reduce the risk of dementia
- Setting out the actions of the Scottish Government so far and ongoing actions to respond to the pandemic
- Reinforcing the shared human-rights based and person-centred approach to supporting people with dementia and their families and carers.

Of particular interest in the context of this Yearbook, commitment 11 states that the Scottish Government will continue "Working with local health and social care partnerships and the third sector, community groups and businesses [to] support and enhance local dementia-enabled communities and reduce social isolation and loneliness, as part of our shared action to strengthen and recover resilience in our communities".

10. Good practice examples

In the survey to members, Alzheimer Europe asked members if they would like to share good practice examples of activities and programmes taking place in their country. In doing so, we explained that it would be helpful to have detailed examples of campaigns, programmes or initiatives that they considered as having been effective in their countries.

As such, this section sets out some of the examples we have received, with information, details and links which we hope will allow others to gain inspiration and ideas for work which may help to make their communities, region and county more dementia-inclusive.

Some of the examples below touch upon examples and programmes already referenced in previous sections, however, we have included them here as they provide further detail and information on the more specific context of the initiative or programme.

10.1 Belgium (Flanders)

Regional Expertise Centre on Dementia – Foton

The regional expertise centre on dementia Foton is the hub of the dementia-inclusive movement in Bruges. The pillars of this organisation and its approach are as follows:



- A walk-in house: People can turn to Foton without professional referral. The threshold is low and one can register in a conversation at home. The clients themselves choose who is present during the conversation.
- Collaboration with and embedding in the neighbourhood: An open and constructive cooperation culture is paramount, both with the local government and many caregivers from the region. Each from their own expertise. Foton improves perceptions of people with dementia and is strongly committed to organise encounters between people with and without dementia such as powerful medium to break the taboo. For this, they work together with competent “mediators”, who deal with dementia from a consistent attitude of equality, or who have gradually learned it through trial and error. They act as role models in dealing with people with dementia.
- Holistic: Foton goes for a total concept that focuses on a dementia-friendly care and welfare sector and a dementia-friendly society. After all, people with dementia are more than just consumers of care. Collaboration with schools, museums, shopkeepers, sociocultural associations etc. is just as important as cooperation with healthcare.
- Dementia consultants: Dementia consultants (case managers) specialise in caring for people with dementia at home and are key figures in Foton’s work. They come home for a good chat, they empower the informal caregivers as much as possible and attune themselves as much as possible to the actual needs and questions: “no one has to follow a mapped-out route, but in dialogue and consultation together with the dementia consultant we look for the most suitable form of support.”
- Empowerment: If one person can indicate which actions meet their needs, it is people with dementia and their immediate environment themselves. Foton considers it important to have that expertise and tries to hear their opinion on each project.

More information on the centre in Foton can be found at: <https://www.dementie.be/foton/>

10.2 Belgium (Wallonia)

Ville Amie D  mence (Dementia Towns) in Wallonia, Belgium

The concept of Ville Amie D  mence and the charter of dementia-friendly communities were developed by the Ligue Alzheimer ASBL. They were first presented in 2011 at the World Health Organization (WHO) European Healthy Cities Network Conference.



By becoming a dementia-friendly city, the signatory city commits to encourage the inclusion of people with dementia and their relatives in their community. The signature is a partnership between the interested city, which is perhaps already active in the field, and Ligue Alzheimer which gives its development tools and a support for the implementation of concrete initiatives. The signature is the proof of the moral commitment of the city. For Ligue Alzheimer, it is the completion of prospective and preparation work and a long-term investment. The Charter is available to all local authorities and to the Provinces.

There are two rules to sign the charter:

- Designate a Proxitem agent
- Organise at least one activity among activities proposed by Ligue Alzheimer.

The “Proxitem agent” 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. Their mission is also to encourage and look deeper into the support activities (medical, psychosocial, cultural, interpersonal, administrative, etc.). It is essential to allow patients and their carers to remain independent in their lives.

By becoming a dementia friendly community, the signatory commits to develop activities which contribute to the improvement of the quality of life of people with dementia and their relatives and/or carers e.g. support for one of the following initiatives:

- The ‘Alzheimer Caf  s’
- The ‘Fighters Group’
- ‘Guest homes’
- Touring conferences cycle
- ‘Auxiliaires de vie’ (life assistants)
- Intergenerational work.

As of 2021, 47 municipalities had signed the charter, pledging to work towards becoming more dementia friendly. In 2019, there were 64 Proxitem agents.

More information on the programme can be found at: <https://alzheimer.be/nos-projets/ville-amie-demence/unecharte-unengagement/>

10.3 Bulgaria

Dementia Friends and awareness raising

In Bulgaria, the provision of social services and support to people living with dementia and their carers still requires a great deal of improvement.

The main vision of the Dementia Friends in Bulgaria is to improve the quality of life for people with dementia and their families. Alzheimer Bulgaria Association (ABA) is working towards building a dementia-friendly society where everyone is aware about the difficulties people with dementia are facing on everyday basis. As part of the global Dementia Friends movement, the goal of ABA is to:

- Improve the public policies and attitudes towards dementia
- Disseminate information in order to make the general public informed and aware about the problem of dementia, as well as its societal costs and implications for family members
- Conduct training and information sessions.

The Dementia Friends Bulgaria movement was successfully launched in 2018, following information sessions with undergraduate and Masters students from psychology and social work disciplines, as well as professionals from various backgrounds. The following outcomes have been achieved thus far: 1) more than three general information sessions with students were held raising awareness on dementia; 2) more than 141 Dementia Friends are created already and 20 of them also completed six months of volunteering as dementia befrienders in two nursing homes in Bulgaria.

The Association has already created partnerships with companies, such as Hewlett Packard Europe (HPE) Bulgaria, and organised a charity dementia mini-marathon with another Bulgarian NGO to raise awareness on dementia prevention through sports in October 2019. After 2019 ABA will organise a mini-marathon every year in Sofia, with an additional mini-marathon in Plovdiv in 2021.

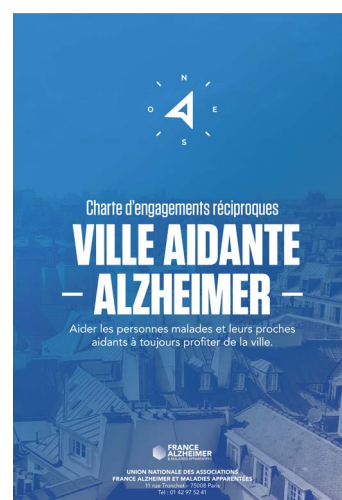
10.4 France

Alzheimer's at the heart of local public policies – “Ville Aidante Alzheimer”

France Alzheimer's notes that people with Alzheimer's are still largely reduced to sickness, disqualified speech and forgotten skills. So how can they hope to keep their lifestyle, their hobbies, their friendships or family as long as possible? It is fundamental for them and their families not to abandon public space and to continue to carry out their daily activities, surrounded by attentive and reassuring people, in towns and villages that are open and concerned by their issues.

France Alzheimer and related diseases encourages reflection and collective action aimed at making public spaces more welcoming and inclusive.

By adhering to the dynamic “Alzheimer's Caring City”, local communities, villages, towns or departments, are asserting their desire to make public



space a space that is opening up again. They are committed to facilitating knowledge and the deployment of actions in favour of people with dementia and their families.

Thanks to the combined mobilisation and enthusiasm of its 101 local associations and their volunteers, the dynamic launched by France Alzheimer, supported by the Association of Mayors of France (AMF), is growing stronger every day. Initiatives are springing up on all sides, in every department in France and overseas, and appointments are being made at town halls, ARS (Agence régionale de santé) and CCAS (Centre communal d'action sociale). Just about everywhere, the “Ville Aidante Alzheimer” (Alzheimer’s Caring City) is flourishing and with it, new contacts and new opportunities.

To ensure that families do not abandon the public space and continue to carry out their daily activities surrounded by attentive and reassuring people, partnerships have been formed with the national federation of French firefighters and the national police force. The challenge is to enable France Alzheimer associations to raise awareness and train them about the disease. Local shopkeepers have also been approached and, once trained, will be able to display the “Commerce Aidant Alzheimer” sticker in their windows.

Additional information on the “Ville Aidante Alzheimer” work is available at: <https://www.francealzheimer.org/notre-vision/batir-ensemble-societe-inclusive/dynamique-ville-aidante-alzheimer/>

10.5 Ireland

Men’s Sheds Dementia Guidelines project

The Irish Men’s Sheds Association is one of the 40+ partner organisations of the Dementia: Understand Together campaign. Men’s Sheds are at the heart of communities with over 450 sheds throughout Ireland. They offer friendship, support and social interaction also for people with dementia.

As part of their work developing the Sheds for Life well-being programme, the topic of dementia had been regularly raised by Shed members as something about which they would like more support and advice.

Focus groups were held with Shed members, where content for a dementia awareness training and a handbook for members on dementia and the inclusion of people with dementia in the sheds was discussed. Dementia awareness training is now a fixture of the Sheds for life programme. The training is provided by The Alzheimer Society of Ireland.



Their new manual [Your Shed & Dementia](#) was launched in August 2021. It is aimed at raising awareness of the condition, as well as offering advice for “Shedders”, their families, carers and supporters on supporting a member with dementia. It has been distributed to all Sheds and can also be ordered free of charge.

Additional information on the Men’s Sheds project is available on the website of the scheme at: <https://menssheds.ie/irish-mens-sheds-in-campaign-to-raise-awareness-of-dementia/>

10.6 Italy

Federazione Alzheimer Italia – “non scordare di volermi bene” campaign

For Federazione Alzheimer Italia (FAI), the focus of the September 2021 World Alzheimer Month was the “non scordare di volermi bene” campaign.

The campaign began thanks to the meeting between FAI, Lorenzo Baglioni, Tuscan singer-songwriter and family caregiver, Paolo Ruffini, famous actor. The main objective was to communicate to as many people as possible the importance of not forgetting people with dementia.

Music was chosen as a dissemination channel as it represents a preferential channel in the relationship with people with dementia; it often connects them to their past, helping them to awaken memories and emotions that the disease tends to keep hidden.

The two artists thus chose to donate the song entitled “Non scordare di volermi bene” (Don’t forget to love me) to Federazione Alzheimer Italia. From this gesture, a campaign entitled #Nontiscordaredivolermibene started to be planned with the aim of raising awareness and inviting more people to become “Dementia Friends”, creating a group of citizens who are aware and informed about dementia and create a more inclusive society for all those who live with this condition and for their families.

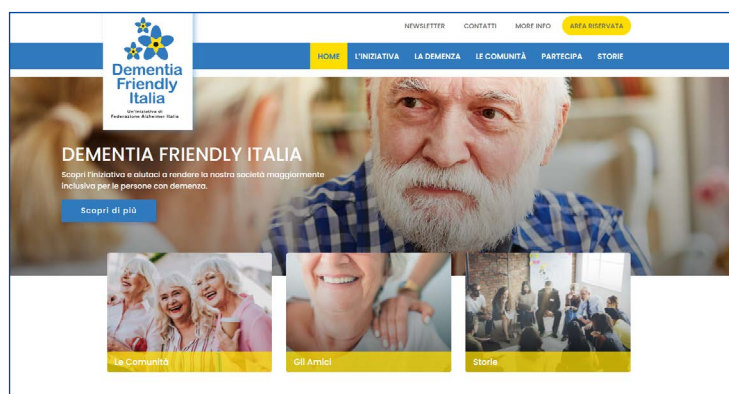
The poster features a photograph of two men, Paolo Ruffini and Lorenzo Baglioni, standing on a balcony with a stone balustrade. In the background, there are buildings and trees under a cloudy sky. A large white play button icon is centered over the image. In the top left corner, there is a logo for 'Dementia Friendly Italia' with the text 'Un'iniziativa di Federazione Alzheimer Italia'. At the top, a blue navigation bar contains the following links: LA CAMPAGNA, LA DEMENZA, GLI AMICI DELLE PERSONE CON DEMENZA, and CHI SIAMO. At the bottom, a blue banner contains the hashtag #NONTISCORDAREDIVOLERMIBENE, followed by the text: 'In Italia 1.200.000 persone hanno la demenza', '"Isolamento" la parola giusta per descrivere la loro condizione.', and '"Amicizia" la parola giusta per scrivere una storia'.

PAOLO RUFFINI
LORENZO BAGLIONI

#NONTISCORDAREDIVOLERMIBENE

In Italia 1.200.000 persone hanno la demenza
"Isolamento" la parola giusta per descrivere la loro condizione.
"Amicizia" la parola giusta per scrivere una storia

The press office, the social media manager of FAI and a digital agency worked on the campaign, preparing materials for communication with the press, graphics for social media, web pages and managing relationships with well-known and public persons. Thanks to the collaboration with the main national television broadcaster RAI, the campaign was presented on TV in various programmes and time slots during World Alzheimer's Month 2021.



The song “non scordare di volermi bene” remained available for the entire month of September on all major streaming platforms and the proceeds from the sale of the song were donated entirely to FAI.

Word of mouth between local associations, the mailing list managed internally by FAI and a budget allocated for adverts on Facebook made it possible to reach almost 3 million people in Italy, who in turn shared the song on their Facebook pages, resulting in 8 million views. As a result, people who are far from the issue have decided to get involved for the first time and start a training path to become “Dementia Friends” by visiting the website www.dementiafriendly.it

The website was created specifically to bring as many people together and provide them with simple and useful information on how to recognise, behave and relate to a person with dementia, with the aim of implementing inclusive initiatives throughout the Italy. The new website intends to be a place where Dementia Friendly Communities, already active throughout the Italian territory, can initiate an exchange of experiences and good practices.

It acts as a portal where people can learn about inclusive communities, their conception and development, the path needed to join the initiative and an interactive map showing the 35 communities and their projects already active. One section is entirely dedicated to telling the stories of the communities through the voices of people, volunteers, shopkeepers, representatives of institutions and law enforcement agencies, teachers and students who, with passion and dedication, carry out initiatives and projects of inclusion for people with dementia.

Finally, the site aims to be a training resource that addresses the main medical and behavioural issues related to dementia, explaining how everyone can become a Dementia Friend and demonstrate that it is possible, with knowledge and closeness, to concretely give help to those who face the disease. A quiz also allows testing the knowledge of dementia and at its conclusion, to receive a certificate that certifies one's commitment as a Dementia Friend.

The strength of the campaign was, above all, the song that narrates the progressive loss of memory and the choice of two important testimonials which, alongside FAI, turned the spotlight on the hope that more and more people understand how important it is to learn about dementia and to work to fight the loneliness and stigma that often surround the condition. Knowing that you can count on someone who “does not forget to love me” with small daily gestures, can make a difference in the life of a person with dementia.

10.7 Netherlands

Samen dementievriendelijk programme – transport campaign

The programme Samen dementievriendelijk works together with 550 companies, especially companies in which employees have customer contact. Because a lot of people with dementia who still live at home are dependent on public transport, they decided to launch a special training for employees in public transport.



Alzheimer Nederland developed a training with and for employees in public transport: the bus driver, the train conductor etc. The goal was to create more awareness, recruit more Dementia Friends and help people with dementia who still use public transport. The target group of this campaign were people who use public transport and public transport employees. Alzheimer Nederland, the Ministry of Health, Welfare and Sport, the pension fund (PGGM) and two large transport companies (Dutch railways (NS) and a national bus company (Connexxion)).

The vice-prime minister launched the campaign in Holland's largest train station in Utrecht with the CEO's of the involved companies. This was a very good PR moment, but more important were the stories of the bus drivers and train conductors, which were broadcast. These stories show that being dementia friendly is relevant for the bus driver, the train conductor and for all of us. The campaign last for four-weeks, launching in September 2019 and achieved the following results:

- Display of our promotional video in 5,000 national trains and 1,500 buses
- 13,222 new Dementia Friends, of which 6,751 followed the online training (51%)
- 8.5 million people were reached by media.

As part of the programme:

- An online training was developed
- A promotion video was produced
- A promotional PR stand was provided by the NS.

The campaign and development of the online training was funded by the programme Samen dementievriendelijk. More information on the campaign can be found at: <https://www.samendementievriendelijk.nl/nieuws/campagne-ov>

10.8 Slovenia

Dementia-Friendly Points

The Dementia-Friendly Points (DFP) network is a national awareness raising and education programme involving a wide spectrum of organisations in local communities. It helps create a dementia-friendly environment by providing information, ensuring social inclusion, acceptance and safety of persons with dementia and their families. Member organisations provide friendly and accessible use of their services for persons with dementia, sharing information and knowledge about dementia and promote the dementia friendly principles in the community.



As a response to the needs of persons with dementia living at home, in 2016 Spominčica – Alzheimer Slovenia started developing a training programme for employees in organisations providing services accessible to the public. The basic idea of the programme is to train the employees about dementia, communication with the person with dementia, post diagnostic support and rights of persons with dementia and their caregivers.

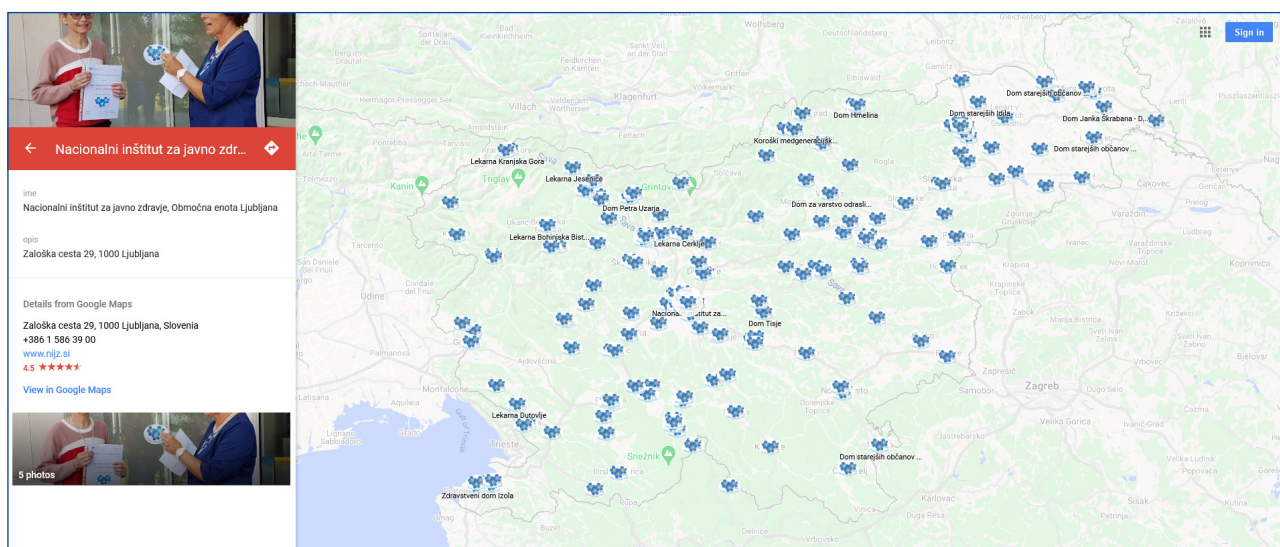
The first DFP was opened in July 2017 at the Human Rights Ombudsman office after the employees' training. The opening was covered by national media and a member of the European Working Group of People with Dementia (EWGPWD) presented his experiences with dementia and stressed the importance of building a dementia-inclusive society.

Before becoming a DFP, the organisation applies with an expression of interest stating their motivation in joining the DFP network and, upon invitation, the employees of the candidate organisation attend training.

The opening of DFP is designed as an awareness raising event involving a cultural programme, important stakeholders from the local community and media. Each DFP is marked with a label of three Forget-me-nots, has informative materials about dementia, related services and support in a visible and accessible place. Furthermore, DFPs can be found on an [interactive map of Slovenia on the Spominčica website](#), making them easier to find.

Spominčica performs regular programme evaluation and provides for permanent members' education. As of 2021, there are more than 220 DFPs, including government ministries, care homes for older people homes for elderly, community health centres etc.

The DFP network has resulted in increased awareness about dementia and recognition of the warning signs. Accessibility to information about services and support is widely spread in the communities, whilst policy-makers increasingly recognise the urgency of properly addressing dementia.



Within the DFP programme, the association has produced materials and resources about the concepts of dementia-friendly design, as well as an information leaflet for carers about what measures can be taken to prevent wandering and what to do if a person with dementia goes missing.

The training programme for employees is partially supported by the Ministry of Labour, Family, Social Affairs and Equal Opportunities, the Ministry of Health, the Municipality of Ljubljana and the FIHO Foundation, whilst the DFP network is financed through fundraising.

10.9 United Kingdom (England, Northern Ireland and Wales)

Dementia Friendly action from a local bus company in Brighton and Hove, England, UK

A staff member working in accessibility for Brighton and Hove Buses attended a Dementia Friends Information Session. As part of the session, they learned that dark flooring can be challenging for people with visual perception issues and as a result one of their social actions was to influence change across the fleet of buses in the city.

The company have installed lighter flooring across the entire fleet. This provides colour contrast against the seats and is more accessible for people living with dementia. Additionally, all their bus drivers are Dementia Friends and they have even committed to highlight this work in the buses with interior panels that read: “To ensure a more inclusive and accessible travelling experience for all, in partnership with Alzheimer’s Society, our drivers are Dementia Friends, and our buses all have dementia friendly flooring.”



Taking this one step further, the Alzheimer’s Society has linked Brighton Buses with Brighton and Hove council to re-launch their Dementia-Friendly Community programme. They have created a video to show how their action have a positive impact for people affected by dementia here: Shirley’s journey: <https://youtu.be/9ok9HyBqo-A>

Dementia Action Week events

Get involved to make Brighton & Hove an age and dementia friendly city



11. Conclusions and recommendations

Drawing together the policies and practices from across Europe, it is evident that there has been significant progress and development in many countries since the publication of the last Dementia in Europe Yearbook dedicated to the topic in 2015.

The examples and case studies presented throughout the report demonstrate the excellent range of initiatives which, in the vast majority of cases, are driven by the knowledge, innovation and dedication of our national member organisations. Without their commitment to the cause of improving the lives of people with dementia and their carers, it is evident that much of this work would not be possible and would not have taken place.

Furthermore, the examples illustrate the diversity and breadth of work which falls under the banner of dementia inclusive, ranging from specific initiatives at a community level, overarching awareness raising campaigns at regional or national level and work of cities and municipalities to become more accessible and accommodating to people with dementia. This progress is to be celebrated. However, it is also clear there is much to do, even where successful and established initiatives are in place.

Involvement of people with dementia and carers

The contribution of members of the European Working Group of People with Dementia is a vital perspective in identifying the issues and areas for future prioritisation within policies and programmes. An evident thread running through their contributions is the importance of involvement, in these projects, ensuring they reflect the needs and views of people with dementia, especially the recognition that people wish to remain active and engaged in their communities, without the stigma of dementia.

We see that in a number of countries, there are initiatives and opportunities involving people with dementia, however, these vary significantly in scope and nature. Only a handful of countries reported specific measures or initiatives by governments (at any level) to ensure that people with dementia or their carers are involved in the policy decisions which affect them.

Funding

From the responses provided by our members, a picture emerges of the lack of reliable and sustained funding from governments for such projects.

Whilst the majority of projects and initiatives report some mix of funding (by national Alzheimer associations themselves, government support or private funders), the primary source of funding often comes from our member organisations themselves, many of whom rely on fundraised income or other forms of income.

It is therefore imperative upon governments (at a local, regional and national level) to ensure that such programmes and projects have access to secure and guaranteed resources.

Political and societal prioritisation

Despite dementia-inclusive initiatives being a cornerstone of international policy documents and initiatives (from the EU Joint Actions on Dementia, WHO and World Dementia Council, amongst others), there continues to be a lack of commitment and political prioritisation of such programmes. One example of this can be seen in the low number of countries reporting that the Joint Actions or WHO policy documents were referenced by any of the documents produced by governments in relation to dementia-inclusive communities or initiatives.

Even in countries where there are strategies or policies in place, implementation remains variable and commitment from other stakeholders also varies. This includes a number of associations commenting that only Alzheimer's associations fully commit to undertaking their role across different areas.

Monitoring/evaluation

The monitoring and evaluation of dementia inclusive communities and initiatives continue to present a challenge. As noted in the World Dementia Council reports, the breadth of approaches across different domains, coupled with the range of actors who may be implementing an initiative (e.g. an individual, a municipality) and the context in which the work takes place, make evaluation difficult.

However, it is evident that some level of consistency is required, particularly for municipalities and cities who may describe themselves as dementia inclusive, with little monitoring or evaluation to determine this.

As part of the work of the second Joint Action on Dementia, the Work Package on "Dementia Friendly Communities" examined this issue and was exploring the possibility of an ISO standard for this, which would provide the parameters for a dementia-inclusive community. At the time of writing, an ISO Framework for dementia-inclusive communities (ISO/DFIS 25552) was under development, however, very little information about this is in the public domain. In addition, the publication of the dementia-inclusive toolkit by the WHO is likely to offer some help in this regard, as it includes specific modules in relation to this. However, it still remains to properly being applied by different stakeholders.

Other considerations

There was also recognition of the impact on organisations following the wrap up of the Global Dementia Friends Network (GDFN) in 2020 (which had been led by the Alzheimer's Society). Some organisations expressed the need for a dedicated platform which can support organisations in the development, use and adaptation of existing resources (such as brochures, videos etc). Many organisations had relied on the sharing of information and resources through this network, particularly for the Dementia Friends programmes.

Amongst some members, there were comments relating to the need for dementia-specific resources and actions, both in relation to social inclusion and the specific individual needs of people with dementia. It was noted that younger populations with dementia also have distinct needs. As such, it is necessary to distinguish between the two groups and to offer initiatives that correspond to each population.

Dementia in Europe Yearbook 2021 recommendations

Based on the information gathered in the Dementia in Yearbook 2021, Alzheimer Europe makes the following recommendations:

- People with dementia and carers should be involved in the development, implementation and monitoring of dementia-inclusive initiatives and societies
- National, regional and local governments should provide sustainable and ongoing funding for projects and initiatives to create dementia-inclusive societies
- National, regional and local governments should utilise the findings from existing work in the development and implementation of their own dementia inclusive-societies and initiatives, including that of the WHO, the second Joint Action on Dementia and World Dementia Council
- Structured and continuous monitoring and evaluation of dementia-inclusive societies should be undertaken, particularly for cities and municipalities who self-describe as being dementia inclusive etc. using a universal or at least European evaluation framework
- The European Commission should, through its work under the EU4Health and Equalities programmes, dedicate funding for projects which empower people with dementia and their carers including for dementia-inclusive societies and initiatives.



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