

ACT ON DEMENTIA

FINAL REPORT
SUMMARY VERSION

WORK PACKAGE 7 **Dementia-Friendly Communities**



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Acknowledgements

Work Package 7 (WP7) produced the final report on which this summary is based, ***Final Report of Work Package 7 (WP7), Deliverable 7.2***, which will be available on the Act on Dementia website (<https://www.actondementia.eu/>).

The Department of Health and Social Care, England, was the WP7 leader and was responsible for overseeing and testing of dementia-friendly communities in the European pilot sites (Bulgaria and Greece) and the collaborator site (Italy). The Department of Health and Social Care also engaged with the collaborating partners, Alzheimer's Europe/European Working Group of People with Dementia, Imogen Blood & Associates Ltd and the Alzheimer's Society, England.

Act on Dementia

Act on Dementia is a 44-month European Union Joint Action which began in March 2016 and ends on 31 October 2019.

The aim of the Act on Dementia Joint Action is to promote collaborative actions among Member States to improve the lives of people living with dementia and their carers. It provides practical guidance for policy-makers developing and implementing their national dementia plans, policies and strategies, and provides cost-effective and practical examples of the core components of good dementia diagnosis, care and support.

Act on Dementia consists of seven work packages:

- Work Package 1: Co-ordination
- Work Package 2: Dissemination
- Work Package 3: Evaluation
- Work Package 4: Diagnosis and Post-Diagnostic Support
- Work Package 5: Crisis and Care Co-ordination
- Work Package 6: Residential Care
- Work Package 7: Dementia-Friendly Communities

For further information on the work packages, reports and other resources, access: <https://www.actondementia.eu/>

1. Introduction

The overarching objective of Work Package 7 (WP7) of the Act on Dementia Joint Action was to provide European Union (EU) Member States with clear, evidence-based and tested information and recommendations on how to effect change, improvement and support for people with dementia to live at home through the development and promotion of dementia-friendly communities (DFCs).

The WP7 co-ordinating centre, the Department of Health and Social Care, England, commissioned an ***Evidence Review of Dementia-Friendly Communities***,¹ which was the first deliverable of the Work Package. It proposed a model (the “four cornerstones model”) that identified four aspects of DFCs: people, place, networks and resources.

The second WP7 deliverable aimed to test and refine the DFC model in two pilot sites (Bulgaria and Greece), a collaborator site (Italy), and a partner site (England), where the DFC programme has been running for a number of years. The final deliverable was the report on which this summary is based, ***Final Report of Work Package 7 (WP7), Deliverable 7.2***. It sets out the lessons learnt from the testing of the DFC model at the pilot sites and makes evidence-based recommendations that could be implemented across all EU Member States.

Dementia-friendly communities

DFCs represent an ongoing process of learning and culture change, rather than a “state”. The activities and detailed structure of DFCs need to be defined locally and be informed by local residents who are living with dementia and their carers. The flexibility of this definition means that it does not attempt to determine the size or nature of “a community”, avoids specific descriptions of the type of barriers that need to be removed (and how), and confirms that the main mechanism for achieving change is the alliance between citizens, organisations and businesses.

At the core of the DFC model is an alliance (a Dementia Action Alliance, or similar), which is a broad network of organisations, businesses, groups and individuals, including those with lived experience of dementia, that provides leadership and vision. The Alliance should establish and communicate the core values underlying the DFC, which the *Evidence Review of Dementia-Friendly Communities* report suggests 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; and
- placing co-creation with people with dementia and carers at its heart.

¹ Access at: <https://www.actondementia.eu/sites/default/files/2018-02/Work%20package%207%20-%20Evidence%20review%20of%20Dementia%20Friendly%20%20%20%20%20Communities.pdf>

2. Pilot sites

The lifecycle of the pilots was 12 months (running from March 2018 to March 2019), during which time partners were required to continuously monitor the progress of the pilots and evaluate final progress at the end of the year against agreed indicators, with some limited support from the co-ordinating centre.

The chosen sites were:

- Bulgaria, which was relatively inexperienced in relation to DFCs; and
- Greece, representing a more rural and suburban focus and areas of different socioeconomical status (Table 1).

Table 1. Characteristics of pilot sites

Country	Participating municipalities/towns	Urban/rural	Population	Country dementia prevalence (%)
Bulgaria	Ravno Pole	Urban	1,500	7.2
	Elin Pelin	Rural	7,430	
	Sofia	Urban	1,230,000	
Greece	Vrilissia	Rural /suburban	30,700	5.0
	Byron (or Vyronas)	Rural/suburban	61,300	
	Koukaki (Athens Acropolis area)	Urban	100,900	

The key collaborator, Italy, has been running a DFC pilot in Abiategrasso, a commune and town in the Metropolitan City of Milan with a population of 32,000, since 2016. The partner site, England, had several years' experience of DFC programmes and focused on the urban sites of Amber Valley (Derbyshire), Blackpool (Lancashire), Bradford (West Yorkshire), Alsager (Cheshire East), Telford and Wrekin (Shropshire) and Luton (Bedfordshire).

Bulgaria

The usual care for people with dementia in Bulgaria is provided by the family at home, with 95% receiving care at home and 5% living in long-term institutions. This has a great impact on families and informal carers, changing their lifestyle and reducing social contact, communication and activities in the community. Most family members and carers have insufficient support; society (at national, municipality and individual levels) is not prepared adequately for the significant challenge of diagnosis and post-diagnostic care for people with dementia.

Greece

Greece has a historically strong tradition of intergenerational and extended family ties, but the emergence of urbanisation and industrialisation has meant that younger people tend to seek economic solace in the big town and cities (with many leaving

Greece altogether in the wake of the economic crisis), leaving rural areas almost exclusively to older people.

A national dementia plan was approved in November 2014 and a national observatory for implementing the plan was established in December 2014. Greece was one of the first countries in Europe to introduce memory screening through elderly care centres in 260 municipalities co-ordinated by Alzheimer's associations and/or social services. Municipalities therefore are appropriate sites for developing primary-care dementia actions.

Italy

Italy has the oldest population in Europe, with the highest percentage of people aged 80 or over. More than 1 million people are living with dementia, but it is estimated that around 40% of all people with dementia have not received a diagnosis.

The first DFC in Italy was established in Abbiategrasso by Federazione Alzheimer Italia in early 2016. A core alliance or project group was set up at the beginning of the project to promote and monitor initiatives with representatives of the municipality and other partners. Abbiategrasso has a great culture and tradition of solidarity, as demonstrated by its high number of voluntary associations.

The site now has an extensive base of supporters representing a range of stakeholders, including decision-makers, businesses, people with lived experience of dementia and local volunteers, including young people. The Italian site therefore has had the opportunity to trial various initiatives and represents an invaluable source of learning and means of identifying best practices, resources and approaches, including successful stakeholder engagement and management experience.

Structural support for people with dementia is strong through the activities of the Golgi Geriatric Institute and the Golgi Cenci Foundation, a research centre that researches brain ageing and dementia.

England

By 2020, England's aim is to be the best country in the world for dementia care and support for people with dementia, their carers and families, and the best place in the world in which to undertake research into dementia and other neurodegenerative diseases. An estimated 850,000 people are living with dementia in the United Kingdom, of whom 676,000 are in England. Dementia is a key priority for both the National Health Service in England and the United Kingdom Government.

3. Pilot preparation

Phase 1: forming alliances

While the local contexts in Bulgaria, Greece and Italy are very different, the countries shared common approaches at the outset on forming alliances.

The initial focus of the pilot sites in Bulgaria and Greece was to form partnerships, build connections, secure resources and establish relationships with a range of stakeholders, including people with dementia, their families and carers, local businesses, municipality authorities, health-care organisations, public services and

academics. Both sites managed to secure official agreements with local authorities during Phase 1.

To set local priorities, the alliances consulted with people with dementia and those who support them to establish:

- how they currently use the community;
- how they would like to use it;
- what barriers they experience;
- how the barriers could be reduced or removed; and
- how people with dementia could be involved in making this happen.

Phase 2: implementation of activities

Phase 2 of the work was to design and implement activities using the DFC model to reflect country-specific needs. Common themes that emerged in the pilot sites in Bulgaria and Greece were:

- improving inclusion and community connections (including setting up regular support groups for people with dementia and carers, opening memory assessment clinics, providing cognitive enhancement services and launching a training programme for carers); and
- raising awareness and tackling stigma (including distributing brochures and other printed materials, publishing articles in local and scientific newspapers, holding awareness-raising sessions for the general public, local businesses and public services, implementing reasonable adjustments (including basic staff training for providers of services most used by people with dementia, such as various forms of transport, libraries, pharmacies, banks, post offices, police services and schools), and screening themed documentaries and feature films in local cinemas).

Phase 3: evaluating and analysing

The next stage within the pilot sites focused on evaluating and analysing the impact of their dementia-friendly initiatives while continuing to run regular activities and one-off events to strengthen and expand their reach. Examples include looking into the possibility of intergenerational work, further dissemination to academics working in the area, and exploring the possibility of making changes to the physical environment to provide better access for people with dementia.

4. Pilot site activity: examples

Bulgaria

Alzheimer Disease's Awareness Campaign and Cinema House (Sofia)

The Sofia Cinema House (capacity 270 people) screened four awareness-raising films for the general public between 12–20 September 2018. The Alzheimer's Disease Awareness Campaign was then launched on 21 September 2018 at the Department of Neurology of the University Hospital Alexandrovska, with screenings, discussions and audience surveys. The aim was to increase public awareness of, and empathy towards, people with dementia, change attitudes and behaviours, and reduce stigma and fear.

Carers support groups (Sofia)

Carer support groups were held twice monthly at the Memory Centre of University Hospital Alexandrovska in Sofia between September 2018 and May 2019. The groups included presentations, videos, case discussions, movies and discussion of models for managing challenging behaviour with the aim of improving carers' understanding of how practically to support people with dementia and increase their skills and confidence. Group stimulation sessions for people with dementia were held at the same time, twice monthly.

Greece

The Carers' School Programme (Vrilissia and Byron)

The Carers' School Programme started in Vrilissia and subsequently was rolled out to Byron. It consisted of regular two-hour meetings (every 15 days over two cycles of the programme (spring and autumn), comprising six meetings), including presentations by a health-care professional followed by discussion with other health professionals on issues such as the recognition and care of neuropsychiatric symptoms and financial counselling. The aim was to empower and educate carers, especially those who are unable to access local community services. The programme also provided a space in which carers could interact and learn about psychosocial interventions under the guidance of experts.

Intergenerational activities (Byron)

Intergenerational activities allowed older people, including those with dementia, and pre-school children to interact and undertake activities together. The activities presented an effective way of helping to reduce the stigma of dementia and educate the younger generation on becoming accepting and open-minded towards older people with and without dementia.

Open centres for older people (Athens, Byron and Vrilissia)

All three municipalities/town sites had open centres for older people, which were both referral points for patients and carers and venues for activities. The main objectives were to promote anti-stigma actions, involve patients and carers in meaningful activities in a social context, establish memory-enhancement groups that involved exercises for enhancing memory skills, and provide a place where older people could interact and socialise.

Italy (Abbiategrasso)

Video interview with Father Giancarlo Politi

Alzheimer Italia has published a video interview by Silvia Vitali, Medical Director of the Golgi Geriatric Institute, with Father Giancarlo Politi, who talks about his experience of living with dementia.² The video is part of a series of resources aiming to challenge common myths and assumptions about dementia created and disseminated as part of the DFC initiatives.

The video represents the first time someone with dementia has spoken publicly in this way in Italy, where the taboo surrounding dementia remains strong in many

² A version of the video with English subtitles can be accessed at:
<https://www.youtube.com/watch?v=XD1ddl6gGel>

communities. Father Giancarlo describes the challenges of his daily life since he developed dementia, but also describes the huge support he receives from his family and community. He asserts the ongoing identity of people with dementia and their right to come forward and be heard.

School project

A pilot project for training teachers and students (15 and 16 years) of two classes of a local high school was launched in Abbiategrasso in September 2017. The overarching aim was to overcome stigma, educate teachers and students and promote relationships between the students and people with dementia.

During the school year, each teacher included the theme of dementia in their own subject. In English classes, for example, students translated a questionnaire on knowledge of dementia into English; and in biology classes, students learned about what happens to the brain of a person with dementia. Students presented their parents with a questionnaire about the Abbiategrasso DFC that measured their knowledge of dementia, at the same time involving the students in DFC initiatives and making them advocates for people with dementia. In addition, a “flash mob” of students wearing gilets (waistcoats) with the DFC symbol in the centre of the town to raise awareness was arranged.

Gym classes

The gym classes gave people with dementia and their carers an opportunity to get out of the house and meet others in a pleasant environment. Attending the classes improved participants’ behaviour and mood. An analysis of the effectiveness of the experience was carried out through assessing a single participant with dementia. An initial assessment was made by expert personnel (a physiotherapist and a psychologist) who then conducted a follow-up interview after the activity to get feedback from the participant. The experience was welcomed positively, so it was decided to continue and expand the project.

Library

The public library in Abbiategrasso has been involved in co-ordination initiatives since February 2016. An initial training course was held in November 2016 and an exploratory intervention to make the library more dementia-friendly was undertaken in 2017.

People with dementia who visited the library made suggestions on how it could be made more dementia-friendly. Suggestions included replacing furnishings with armchairs and tables suitable for people with dementia, rearranging books and spaces to be more accessible, choosing appropriate books and dementia information, and establishing a room for small meetings and training courses.

Police training

Four training courses were held from July 2016 for local police officers and have since been carried out periodically. Participants were made aware of how to interact with people with dementia, and a post-training guide and helpline were established. The course was structured over two sessions: the first was on the nature, symptoms and progression of dementia, and the second on how to communicate and engage

with people with dementia. The sessions also included a visit to the special care unit of the Golgi Institute.

England

Face It Together (FIT) (Bradford)

The Bradford Dementia Action Alliance was launched in 2013 and is one of the first DFCs in England. It has worked over the past five years to engage with diverse communities, such as lesbian, gay, bisexual and transgender groups and the Sikh community. The diverse make up of supporters has led to 20 individual groups working to make Bradford dementia-friendly, from small groups holding awareness events to whole communities fundraising on specific activities such as health, education and social care.

The Alliance also facilitates the monthly FIT (Face It Together) group. Members of the group have dementia and contribute to dementia-friendly work by speaking at meetings, reviewing services and delivering dementia-friends information sessions.

Dementia friends and memory café (Alsager)

Alsager became the first town in Cheshire East to be recognised as “working to become dementia-friendly” in October 2017. A strong core group of 12 people meet monthly, all with the same vision of achieving “living well with dementia” in Alsager.

The group has run monthly dementia-friends information sessions since January 2017. The initial target was to make 100 dementia friends by the end of the year, and this was not only achieved, but surpassed. ID cards have been introduced for people with dementia and their carers so that a carer or other named individual can be contacted if the need arises.

A monthly memory café is run at the local library. Extensive information is provided through the café, which is attended by support providers and social visitors, including Cheshire Art for Health, young people’s groups (like the Beaver Scouts) and a local vet who brings along his trained dogs. The café is entirely free to customers thanks to the generosity of local businesses and services. Memory boxes, books and jigsaws are always available.

The DFC has also forged a close relationship with Alsager School, a co-educational secondary school and sixth form with academy status. The school’s Digital Art and Technology Lead produced a living memory box for couples to record their most valued memories. Year 9 students are paired with the couples, one of whom has dementia, and help them to create their memory box.

Dementia-friendly buses (Blackpool)

The Blackpool Dementia Action Alliance (DAA) was launched in 2015. One its key aims was to improve the lived environment for people living with dementia, an essential part of which is the ability to travel with confidence.

People with dementia in Blackpool struggled to use buses, as they felt transport providers neither understood nor catered for the complexities they faced. This

caused isolation and left people feeling unable to be an active part of their own communities.

Blackpool Transport, the leading provider of bus services in Blackpool, incorporated the Alzheimer's Society's Dementia Friends programme into their annual staff training programme (for all staff and new employees). Blackpool Transport's training team then became Dementia Champions so they could deliver dementia-friends information sessions, creating over 600 dementia friends. They also implemented a yellow-card scheme for passengers who might need more time to get on or off a bus: the card enables drivers to identify those who might have dementia.

Dementia Action Alliance (Telford and Wrekin)

Successes of the Telford and Wrekin DFC include the "Safe Place" initiative, which was rolled out by West Mercia Police with dementia friends; various locations can now sign up as safe and dementia-friendly places. Shropshire Fire and Rescue Service has signed up as a member, and staff use their dementia awareness to provide more and appropriate support for people they rescue and work with.

Dementia-friendly places (Amber Valley)

The Amber Valley Health Partnership identified dementia as a key health priority in 2016. Amber Valley Dementia Action Alliance is made up of organisations and individuals who have come together to make the Amber Valley a better place to live for people with dementia and their carers.

Several projects have been developed to enable the community to become more dementia-friendly, including a dementia-friendly town centre that will include a dementia-friendly garden, large reminiscence boards in the local library and training for shop workers. There is also a sporting reminiscence group, dementia-friendly cinema screenings and a dementia-friendly checkout at a supermarket.

The Alliance has run training sessions for local people to become dementia friends, and nine general practitioner surgeries have signed up to become dementia-friendly.

Dementia Action Alliance supporters (Newport)

A new dementia-friendly supporter process is being piloted in Newport. The supporter process allows small businesses and organisations to sign up to show that they support the local Alliance, without actually becoming full members.

Luton Town Football Club (Luton)

Luton Dementia Action Alliance approached Luton Town Football Club to join them in December 2015. The club has been part of the Luton community for 130 years and has average attendances of over 8,000 for home matches, meaning it could play a key role in raising awareness and understanding of dementia.

A dementia-friendly match against Exeter City took place on Saturday 18 March 2017. Luton Town invited the Dementia Action Alliance and offered an executive box for people with dementia, each accompanied by a friend, to attend the match. Feedback was very positive. The dementia-friendly match was felt to bring people in the community closer together and show the positive impact of sport.

5. Outcomes

The full results of the evaluations from all the pilot sites can be found in the *Final Report of Work Package 7 (WP7), Deliverable 7.2*. This section provides only a brief summary.

Evaluation methods

It was agreed that the pilot sites would adopt relevant indicators suggested in the *WP7 Evidence Review of Dementia-Friendly Communities* as evaluation criteria, but also develop their own additional measures to reflect local priorities. This enabled a collaborative approach to establish what a successful DFC would look like in the respective countries.

Bulgaria

The effectiveness of activities to increase public awareness of people with dementia and carers in the three municipalities was assessed using different outcome measures and analysed through questionnaires, scales and other data, including discussions from focus groups and questionnaires distributed before and after the pilot activities.

The most effective activity was found to be training sessions for staff of municipality services, such as libraries and pharmacies. Surveys showed good increases in knowledge levels after training. Rates of satisfaction reported by carers regarding knowledge levels also increased, but there was little improvement in levels of stigma reported after the activities, which remained low/average. Satisfaction rates for training were high among carers and community workers, with the highest rating going to the impact of the training.

Greece

Greece used various metrics to collect data to analyse activities piloted in the three municipalities, including attendance numbers at activities, results from the Dementia Attitudes Evaluation Questionnaire, activity evaluation questionnaires, and outputs of focus groups and meetings. The final results of the evaluation of the pilots in Greece are awaited.

Italy

Two measures were adopted. The first was the number of activities undertaken, and the number of participants from the target population. The second recorded the participant responses and any reported impact of the activity.

Overall, the most successful activities for increasing the participation of people with dementia and their families were reported to be engaging people with dementia in planning of the DFC, the gym classes and education meetings for families. Training for police officers and other community members, intergenerational school activities and the “flash mob” were the most successful for reducing stigma.

England

The DFC programme in England has been running for a number of years. It is not an official EU Joint Action site, so no quantitative results are available to measure

outcomes. Some qualitative achievements of the DFCs in England can, however, be identified.

The DFCs in England have been successful due to strong leadership, usually formed around a dementia action alliance. They have placed people with dementia at the centre, seeking their input to identify community needs and make activities truly context-specific. People with dementia often have been key in the establishment and success of the DFCs, with key organisations and leaders, such as businesses and local authorities (councils), also engaged.

Challenges

There was some overlap in countries' findings around challenges. These included difficulties in engaging, or maintaining contact with and participation from, the private sector (such as local businesses like banks, supermarkets and shops). Italy surmised that this could be due to a lack of practical messages and training, and that more active involvement of people with dementia could have made a difference. This idea is reinforced by more general findings of the DFC and Bulgaria's analysis of intergenerational activities. Greece found that the participation of larger private institutions was difficult to manage due to bureaucratic reasons, finding it easier to organise smaller training events at local level through local branches. This feeds into another common observation shared by all pilot sites: scaling down activities is often more effective, from both logistical and impact perspectives.

Issues related to timings and organisation were identified. Italy, for example, cited long lapses between meetings and training sessions for local businesses, or delays in implementation of initiatives (such as assessing how to improve access to the town centre). Bulgaria referred to lack of time and resources and difficulty in co-ordinating carer meetings as obstacles to co-ordinating activities.

6. Conclusion

The *Final Report of Work Package 7 (WP7), Deliverable 7.2*, on which this summary is based, synthesised findings from implementation of the DFC model in the European pilot sites. It found that the key conclusions from the findings of the pilot sites were that:

- a robust network of key organisations, with good levels of engagement and buy-in from local stakeholders (including local authorities and politicians), is essential;
- the success of the DFC depends, to a large extent, on the development of the site itself, in relation to 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, as different stages will require different approaches;
- a one-year pilot scheme is not enough time to demonstrate real change: the highest impacts were seen in Italy, which to some extent is related to the DFC site having been established over a number of years; and
- a thriving network of volunteers grouped around a strong charitable sector is essential.

The *WP7 Evidence Review of Dementia-Friendly Communities* stated that DFCs are most sustainable when:

- they are based on broad and strong alliances, which includes people with dementia, and in which responsibility and leadership is shared;
- activities are mainstreamed into local plans, strategies and training initiatives;
- there is a long-term commitment (including political) to the agenda and recognition that a DFC cannot quickly be achieved;
- evidence is gathered to build a business case for activities;
- opportunities to learn and share experiences from other projects and nations are maximised; and
- the focus is on bringing the dementia-friendliness agenda in line with the disability rights agenda.

The findings from the pilot sites reinforce these recommendations.

The conclusion of *Final Report of Work Package 7 (WP7), Deliverable 7.2* is that the DFC model can work in a variety of contexts across the EU, as demonstrated in the pilot sites. The model must, however, reflect local culture, levels of resources and networks, and existing levels of stigma.

DFCs may not demonstrate measurable change in the short term, particularly in sites that have less robust networks, fewer resources and higher levels of stigma. The levels of improvement and impact varies dependent on the context, but DFCs have been shown to be effective and to have had a positive effect across the pilot sites.

Recommendations for other EU sites that wish to establish DFCs are presented in the *Final Report of Work Package 7 (WP7), Deliverable 7.2*.