



**DEMENTIA
FRIENDLY
COMMUNITIES**



**CREATING
DEMENTIA
FRIENDLY
COMMUNITIES
– A Guide**







**THE ALZHEIMER
SOCIETY *of* IRELAND**



DEMENTIA FRIENDLY COMMUNITIES

To find out more about Dementia Friendly Communities in Ireland
please see www.alzheimer.ie or call **1800 341 341**

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-  Alzheimer National Helpline: **1800 341 341**
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Foreword

The Alzheimer Society of Ireland's vision is an Ireland where no one goes through dementia alone. This toolkit contributes to our vision as it focuses on how best we can support people with dementia to live well in our communities.

John Clifford

Chair of the Board of Directors
of The Alzheimer Society of Ireland



As a person living with dementia and a proud member of my community, I cannot overstate the role that a supportive community can play in our lives. At home in our community is where we want to be and this work plays a large part in enabling this.

Helen Rochford Brennan

Chair of the Irish Dementia Working Group



When I cared for my Dad, I saw the immense impact and difference that a community can play in supporting carers to continue to care for their loved one at home, as I did. I urge others to use this guide to work towards making their community more dementia friendly.

Judy Williams

Chair of the Dementia Carers Campaign
Network



Purpose of this guide

This guide has been created by The Alzheimer Society of Ireland (ASI) to support organisations, companies, groups and individuals that wish to make their community more dementia friendly.

This guide provides a practical framework based on our experience over the past three years in supporting communities to work towards becoming more dementia friendly.

It is not prescriptive or exhaustive in describing what to do to become more dementia friendly, as each local community is unique and will be at different stages. We hope you use this as a reference guide that outlines the key elements needed and examples of work that can be replicated.

The guide is informed by work carried out by a Dementia Friendly Community initiative that was led by The Alzheimer Society of Ireland and also by work being undertaken across Europe and the world.

What will you find in this guide?

This guide outlines:

- What is a Dementia Friendly Community
- The experiences and work undertaken by the projects involved
- The key elements needed to create a Dementia Friendly Community
- The things we learned about developing Dementia Friendly Communities along the way



What is a Dementia Friendly Community (DFC)?

‘A city, town or village where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a DFC people will be aware of and understand dementia, and people with dementia will feel included and involved, and have choice and control over their day-to-day lives’.

Building Dementia Friendly Communities – a Priority for Everyone – Alzheimer’s Society UK, 2013.

People with dementia are one of the most marginalised, socially excluded and highly stigmatised groups in society. In order to address the exclusion of people living with dementia, the DFC initiative has emerged.

63% of people with dementia live in the community in Ireland, so the concept of DFC focuses on transforming our villages, towns, cities and counties into better places to live for people with dementia. The goal is to facilitate local communities to enable people living with dementia to remain living in their own home and retain their traditional networks. It is not about setting up ‘new’ services, but instead supporting their community to be dementia friendly and inclusive.

DFC provide the opportunity to demystify dementia so that it is no longer perceived as something to be feared. DFC demonstrate a high level of public awareness and understanding about dementia. They are inclusive, and improve the ability of people with dementia to have choice and control over their lives.



63% OF PEOPLE WITH DEMENTIA CURRENTLY LIVE IN THE COMMUNITY

Cahill, S. & Pierce, M (2013) The Prevalence of Dementia in Ireland.
Genio Dementia Learning Event

Dementia Friendly Communities (DFC) in action

We worked with a number of projects across Ireland (see Appendix 1) that wished to make their community more dementia friendly. Common themes emerged from our DFC projects and you can get ideas from the examples presented here.

- 1 Dementia awareness for the general community
- 2 Dementia awareness for service providers
- 3 Volunteer engagement
- 4 Intergenerational learning
- 5 Improvements to the physical environment
- 6 Supporting people with dementia to stay active in their community
- 7 Supporting families and enabling them to empower their loved ones

1 Dementia awareness for the general community

Dementia awareness and education is a key intervention. People living in the community need to understand dementia in order to be able to respond appropriately. It is only through greater awareness about the impact of the condition that people can live well in their communities and the stigma of dementia can be broken down. All of the projects undertook work to raise awareness about dementia locally.

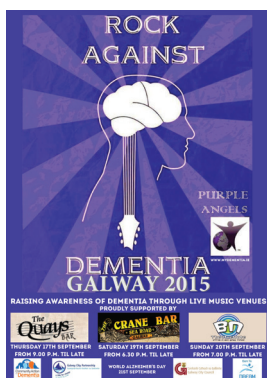
Examples include:

'Rock Against Dementia' – Galway City Dementia Friendly Community Initiative

'Rock Against Dementia' was a three day event based on the Purple Angels concept that aimed to raise awareness of dementia through live music venues in Galway. A number of music venues in the city got involved by putting on special musical performances to mark World Alzheimer's Day 2015.

Promotion included an editorial piece and advert in the Galway Advertiser, posters circulated through out Galway and the distribution of thousands of flyers that included key contact details such as the ASI free and confidential National Helpline Service.

This project was an opportunity to highlight the topic of dementia and raise it in a different setting with a new audience in a fun, welcoming and imaginative way.



Poster advertising the 'Rock Against Dementia' event in Galway



Members of the Kilkenny Age Friendly Alliance at the launch of the project Memory Matters (Callan)

Booklet on local services and supports – Memory Matters (Callan)

This project carried out a comprehensive baseline study and audit with local people to find out if they felt their town was dementia friendly. The main finding from this survey was that people identified a real lack of information about the services available to them in their community if they were affected by dementia. As a result the project developed a short and accessible leaflet for people with details and contacts for the main services available to them in the area.

Making Monaghan Dementia Aware

This project was run by the Monaghan branch of the ASI and involved collaboration between Monaghan Age Friendly Alliance and Monaghan County Council. They organised a Dementia Awareness Conference in September 2014 which attracted 180 participants. The project developed and launched a number of booklets at the conference including *Monaghan Dementia Awareness* booklet and their *Dementia Friendly Customer Service Guide*. Overall the project raised awareness about dementia locally and there was a lot of publicity generated from the conference. There have been a lot of requests for the brochures and these have been distributed throughout the county.



Attendees at the Dementia Awareness Conference in Monaghan

2 Dementia awareness for service providers

Each of the projects also had a strong emphasis on raising awareness and influencing businesses and other key organisations that work with people with dementia to become more dementia friendly. The aim was to ensure that local service providers including Gardaí, financial services, pharmacies and shops are more aware about how they can support a person living with dementia. In many cases it was the service provider's direct experience of dementia and an acknowledgement of the significance of the issue that opened the door for the projects.

Examples include:

Make my service more dementia friendly – Wicklow Dementia Friendly

The project researched and developed tailored workshops for specific service providers entitled 'Make my Service more Dementia Friendly'. This presentation was delivered to six areas across Co. Wicklow to a total of 242 people. Attendees included the general public (many of who had a family member with dementia and were keen to get information), a wide range of community groups, pharmacists, sports clubs, businesses, libraries, first responders, home helps and financial services.

Participants reported that the information provided about the signs of dementia and tips on communication were useful. However, the input from a person living with dementia who spoke about the issues that he faces on a day to day basis had the most impact on those in attendance.

"As a result of tonight I know the layout, signs and stuff and how body language can affect people with dementia. I will be passing on the information I got tonight to other staff members on how to approach and help people with memory problems."

Retailer in Co. Wicklow

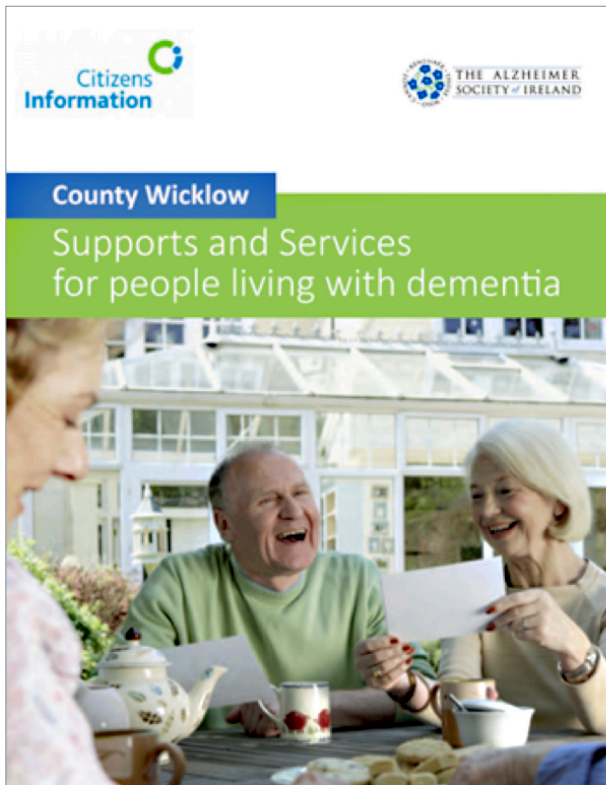


Wicklow Dementia Friendly sticker that was received by businesses that completed the dementia awareness workshops

In Arklow, retailers were invited to an event where the DCU Dementia Elevator programme piloted their online dementia awareness retail training module. Following the workshop all of the participants received a Wicklow Dementia Friendly sticker to display in their premises to indicate that they are there to help and support people with dementia. Representatives from all of the businesses signed commitment forms, stating their support and commitment for ensuring their service is more dementia friendly.

The project also developed key contacts with the Irish College of General Practitioners and the Mercer's Institute of Successful Ageing. An outcome from these key relationships was the delivery of a number of workshops to GP's in Co Wicklow. There were two key factors to the success of these workshops: 1) The input of a clinician; and 2) The workshops were accredited. A total number of 49 GPs attended the education workshops and 4 of the GPs signed the project's commitment form and displayed the sticker in their practices.

The five Citizen Information Centres (CIC) in Co. Wicklow had an opportunity to participate in the workshop 'Make my Service More Dementia Friendly' and nearly all the 50 staff and volunteers attended. As a result all of the CIC in Co. Wicklow are now more dementia aware. The Arklow CIC has become a centre of excellence for information in the community about supports available for people living with dementia and their carers. In partnership with the ASI, Arklow CIC developed a booklet about the dementia services available in Co. Wicklow and there has been a big demand for this.



Booklet of services and supports developed in Co. Wicklow for people with dementia

The project also hosted six workshops for Gardaí working in Co. Wicklow; a total of 40 Gardaí attended which accounted for 20% of the force working in Co. Wicklow. Following this, the project had an opportunity to meet with the Garda National Liaison Officer for Older People about the possibility of setting up a register where people with dementia and/or family members could give some details if they wished to contact local Gardaí in case of an emergency.

Ballina/Killaloe Dementia Friendly Community

Following a visit by members of the project's steering group to learn more about the awareness raising work they are undertaking in Motherwell, Scotland, it was agreed that a similar approach would be used for their project.

A member of staff with great knowledge of the local community was brought on board to support this work. The staff member was well known and respected among businesses in the community (as a business person themselves) and this meant there was an immediate trust and rapport in place when businesses were approached.

A total of 118 businesses have now signed up and given a commitment to work with the project to be dementia friendly. The project keeps them updated via regular e-mails about local news or events. The businesses involved traverse a wide range of services from barbers to the credit union and crèches to restaurants and estate agents. The only business that did not agree to sign up to become dementia friendly was the local bank. They were reluctant to sign anything that had not been agreed with their national body.

The project now hosts a weekly Cognitive Stimulation Therapy group for people with dementia in a local hotel. The hotel has been really keen to get involved and improve their service and make it more dementia friendly. They provide free tea and coffee and are very willing to accommodate the needs of the group. For instance they had a large event in the hotel and needed a bigger room to facilitate the numbers for this event. However, they did not give up the room for the Cognitive Stimulation Therapy group as they wanted to ensure familiarity for those involved. They have also been very friendly and accommodating towards people and any requests they have.

3 Volunteer engagement

Social isolation is a key difficulty for people with dementia across all communities both urban and rural. The “drifting away” of friends and networks following a diagnosis of dementia can be distressing for the person and their families. As a result the need for low level one-to-one support by a volunteer was recognised as a key area to address for the projects involved. A volunteer scheme that supports and encourages a person with dementia to stay involved through a volunteer who knows and understands their needs can play a really important role in the person’s life.

Examples include:

Good Morning Inishowen - Dementia Aware Donegal

The project invested a lot of time and energy into the development of befriending services across Donegal and with a particular focus on the more rural, isolated areas. A key partner was Good Morning Inishowen, an initiative that makes contact with older people by telephone a few times each week to check in with them and have a chat. The isolation and loneliness that was apparent to the volunteers who ran the telephone service prompted them to extend the service to home visits and befriending.

The project provided the volunteers with dementia awareness training which gave them the skills to continue working with people with dementia. There are now 22 befriending relationships supporting people with dementia and the only limitation on expansion of the service is sourcing more suitable volunteers to befriend people. There are two other rural befriending services in Co. Donegal (Glencolumbkille and Dunfanaghy), and the professional experience of Good Morning Inishowen together with the enthusiasm of the two small rural services are visible, practical examples of what can be done elsewhere in the County.

“One experience taught us an important lesson about making the assumption that we knew what a person with dementia wanted. A farmer who was forced to retire when he developed dementia had handed his farm over to his son. We proposed to provide training to his family and friends to enable him to continue with some of the farmyard activities such as feeding calves and bringing in the cows for milking.

We had located an agricultural safety consultant and would have provided him with dementia awareness training to conduct a safety audit of the proposed activities until we put the idea to the farmer. He promptly advised us that he had only become a farmer because he was the eldest son and it was expected of him. He did not care if he never saw another cow in his life – so we abandoned our plans, identified what his other interests were and provided opportunities to do the activities that he had always wanted to do.”

Alastair McKinney, Dementia Aware Donegal Project Leader

4 Intergenerational learning

In order to create DFC that have a lasting impact and genuine sustainability it is essential that we encourage young people to become dementia aware and create a dementia friendly generation. This would mean that young people are familiar with the condition and it would not hold the same fear or anxiety for them if they encounter it. They would recognise it in their grandparents and parents and understand how to help them to live well with dementia.

Examples include:

Ballina/Killaloe Dementia Friendly Community

A group of 75 transition year students visited the Waterman's Lodge Day and Respite Centre over a full school year which involved weekly activities with the clients with dementia. These interactions enabled them to have a better understanding of dementia and an increased awareness of the condition. As a result of the students involvement many continued to visit the Centre and some even brought their unusual pets including snakes to visit!

Transition year students from St Anne's Community College attend the Christmas party at Waterman's Lodge



An Ordinary Man – Dementia Aware Donegal

The project was keen to engage with secondary school students to educate them more about their awareness and understanding of dementia. Talks were given to over 500 transition year students in secondary schools in Co. Donegal. All the students involved were then invited to attend a play titled 'An Ordinary Man' and over the two performances 200 students attended. The play was performed by a solo actor and here is a brief synopsis provided by Beeznee (2013) theatre productions:

"An Ordinary Man takes us on the life journey of the protagonist through births, deaths and marriages with a bit of football and ballroom dancing thrown in just for 'craic' until, ultimately, we realise that while there may be an ordinary man, there is no such thing as an ordinary life. An Ordinary Man will live long in the memory of anyone lucky enough to catch this show."

Beeznee Theatre Productions

The purpose of the play is to show the students that dementia is just a small part of the person's life and that it is more important to see the whole person with a life story. The play was followed by a questions and answers session with the actor at the end of the play.

The project found that this performance resulted in many of the students sharing their experience of living with a family member with dementia with their classmates for the first time. It is hoped that in years to come the increased awareness and understanding of the next generation about dementia will ensure that as a community they are better equipped to face the challenges.



5 Improvements to the physical environment

The physical environment, from streetscape to individual shops, plays a key role in determining the extent to which people with dementia find their community dementia friendly. People with dementia have said that a physical environment in which they can find their way around, know where they are, and that makes them feel safe, is a huge advantage and an ideal gateway to their communities.

Examples include:

Signage at Mallow Primary Healthcare Centre - The Crystal Project

Work was undertaken by the project to make the local primary healthcare facility a more dementia friendly building. A researcher from University College Cork sent surveys to all staff working in the facility and a focus group was held with key businesses and services to ascertain their views on how the building could be improved. The aim of these consultations was to identify plans for making the building more dementia friendly.

The consultations resulted in the project developing dementia friendly signage on the HSE floor – which had mixed success. There is now signage where previously there was none and this signage has reasonably good colour contrast and the inclusion of illustrations to represent each area. However, it was necessary to include the Irish translation on the signs which means there is an abundance of text and also that the English text is smaller than ideal.

Councillor Joe Carey (pictured far left) unveils the dementia friendly town signage along with staff from the ASI



Town signage – Ballina/Killaloe Dementia Friendly Community

Ballina in Co. Tipperary and Killaloe in Co. Clare are two towns that are separated by one bridge but situated in different counties. A key aim of this project was to develop an activity that both towns and councils could work on with a shared outcome. It was decided that they would erect signage at the entrance to both towns to let people know that they are entering an area that is working to be dementia friendly.

The two relevant County Councils were key stakeholders in this and the project had varying degrees of success with them. The project found that after initial interest and engagement from County Council officials the quickest way to progress the work was to deal directly with County Councillors. After the intervention of the County Councillors the process was very fast and the area engineer came out to assess where would be suitable to mount the signage incorporating dementia friendly design principles.



Reminiscence Walk/Boithrín na Smaointe (Cavan town)

The main aim of this project was to construct a reminiscence-walking trail in Cavan town. As the work involved a park owned and managed by Cavan County Council a key task was to get their permission and support to develop the walk. The work was enthusiastically received by the key decision makers.

Once the relevant partners were on board the team met with local artists to put their 'vision' on paper and then prepare the site for work. The County Council sourced workers via the Gateway programme which is a work placement scheme designed to provide short-term working opportunities for unemployed people. The work they undertake is intended to benefit the local area and is primarily focused on the outdoors. Their involvement and co-operation was crucial as they carried out the following activities: preparation of the site, planting of shrubs, trees and flowers along the route and essential maintenance on the walk.

The project then identified suppliers of suitable artefacts for the walk. These included replicas of well-known items from the past such as a post box

and an old milk can that people would engage with as they strolled along. They also hired a person to design, create and erect the selected 'silhouettes' and finally a graphic design and signage specialist to erect the sign at the entrance of the walk and the addition to the central bandstand.

An important feature of the walk is the opportunity to engage with and see at first hand the natural environment and also to engage with the artefacts and silhouettes as the person strolls along, providing them with an opportunity to share a 'story' from their past.



Some images capturing the Boithrín na Smaointe Reminiscence Walk

6 Supporting people with dementia to stay active in their community

Providing people with dementia and their families with meaningful opportunities to meet and engage with each other was identified as a key aim as great strength can be gained from meeting with others. However, the direct involvement of people with dementia and their families in the development of the project structures and activities remained a challenging aspect of the work. One of the main challenges of involving the person with dementia was the progression of their condition.

The other main challenge was the stigma of dementia; it means there is often a reluctance to get involved in dementia related activities. As a result, a number of the projects decided to mainstream the involvement of people with dementia into existing services rather than creating one specifically for people with dementia. Existing services need to be more educated and supported to integrate people with dementia into the activities they run in the community. This is also more sustainable in the long run and meets the needs of people with dementia as there are outlets for them to get involved but they are not stigmatised by the label of dementia.

Examples include:

Singing for the Brain – The Crystal Project

The project ran a weekly singing group, Singing for the Brain. The group was initially piloted for 6 weeks and due to its popularity is now going strongly into its second year. The average weekly attendance is around 20 people and one of the main advantages of the group is that it is not dementia specific - it is open to all, thus truly representing the concept of people with dementia being included in society.

“Singing for the brain was a life saver for us when Mam was dying. Dad sang the songs he had done at the sessions on the drive to Cork University Hospital to see Mam. It was a wonderful distraction for us all and Dad never missed the sessions – he was even there three days after Mam was buried.”

Family Carer

Participants of the Singing for the Brain group in Mallow, Co Cork



Finding out what people with dementia want in their community – Wicklow Dementia Friendly

The project was keen to find out the thoughts of people with dementia and their carers about the types of things they felt would make their community more dementia friendly. Collecting this information about the lived experience from the various geographic areas highlighted the almost complete absence of supports in some parts of the county.

People with dementia were engaged in the project in a variety of ways:

- In Carnew, the Co. Wicklow Network for Older People's local ambassadors sought people with dementia and family carers' perspectives on living with dementia in that area and finding out ways that would make their community more dementia friendly. Their feedback informed workshops on the practical ways people with dementia and family carers can be supported.
- In the Arklow area, seven people with dementia took part in a focus group. The Co. Wicklow Network for Older People ambassador facilitated this and the need for a befriending service for people with dementia to enable them to go about their daily business was identified.
- In north Wicklow, people with dementia attending the Wicklow Dementia Support social club gave their views on what would make their area dementia friendly. They spoke about the benefit of having a befriender through Wicklow Dementia Support service and thought more people with dementia should have access to this.

There were a number of specific outcomes for people with dementia from this work also:

- Five people with dementia are now being supported by Activity Pals to attend the Carnew Community Care Centre.
- Family Carers Ireland have now established a befriending programme in Arklow and is in the process of setting up one in Bray.

- Wicklow Dementia Support now receives some funding from the HSE to expand their AlzPals befriending programme in north Wicklow.

Past Times Community Choir – Naas, Co. Kildare

The choir is open to all, but particularly welcomes those living with dementia and their carers. The first rehearsal took place in January 2015, and they strive to provide a secure, fun and stimulating environment for those participating. Their membership consists of a core group of volunteers, residents from several Kildare nursing homes and their carers, people living with dementia in the community and their carers, and active retirement groups.

Each rehearsal is carefully structured to maximise the feeling of security while also creating space for spontaneous fun and reminiscence. The performance schedule (including a performance launching the Culture Night for Kildare and the Dementia Elevator Award Ceremony) provided clear and realistic aims for the group as a whole and gave momentum to the entire project.

The combined impact of the choir's openness to visitors, a public Christmas sing-along and their performance for Culture Night, has led to greater awareness among the local community about the choir and has also broken down many traditional stereotypes people held about dementia.

Past Times Community Choir perform at the launch of Culture Night at Naas Town Hall





Performer at the Tea Dance Tunes

Tea Dance Tunes – The National Concert Hall (NCH)

The NCH wanted to provide an opportunity for people with dementia to come into the NCH and participate in an interactive event called ‘Tea Dance Tunes’. The event took place in February 2015 and enabled access to cultural activity for people with dementia and provided the staff and musicians of the NCH with more awareness and understanding of dementia.

The event was a great success with almost 80 people participating in a repertoire of music and singing and even some dancing. The interest in the event was so great that the NCH had a waiting list of 40 people. Given its success Tea Dance Tunes continues at NCH. It is hoped that the event has also inspired people with dementia and their families to return and use the NCH to attend concerts or other activities.



Participants of an Azure facilitated art session

Azure around the country

Azure is an initiative exploring the greater inclusion of people with dementia in galleries and museums across Ireland. The project is inspired by the ‘Meet me at MoMA’ programme, which is based at New York’s Museum of Modern Art. Azure aims to practically explore the application of the ‘Meet me’ model in Ireland. Training has been delivered to build the capacity of staff from museums and galleries across Ireland to be more dementia friendly and to provide them with the skills and knowledge needed to facilitate dementia inclusive arts events.

Following this training the ASI sought applications from the museums and galleries involved to compete for an award to facilitate them to undertake this work. The successful museums and galleries are: Irish Museum of Modern Art (Dublin), The Lab Gallery (Dublin), the Butler Gallery (Kilkenny), Highlanes Gallery (Drogheda), the Hunt Museum (Limerick) and Galway Arts Centre. The network continues to grow and a number of these projects have had great success in their work and are aiming to continue the work as part of their own arts programme.

Case Study

The Hunt Museum, Limerick

Azure at the Hunt Museum was viewed as a first step in making the museum more dementia friendly. The Art Conversation Programme invited people living with dementia and a loved one to come and enjoy learning and talking about the art and artefacts in the Hunt Collection.

The first step in the development of the project was to train the staff who volunteered to deliver it. The training programme briefed participants about the “Meet Me at MoMa” model, the Azure Project, the development and characteristics of a dementia friendly museum and input from the ASI.

A session was also delivered by Bairbre-Ann Harkin, Education Curator from the Butler Gallery, Kilkenny on programme planning and facilitation skills and strategies. For the latter part of the training volunteers broke into sub-groups and each prepared a theme for one session. Each sub-group in turn presented their theme for evaluation and the whole group worked together to finalise how the theme would be presented.

Following on from the training, information about the Art Conversation Programme was sent to a list of local services provided by the ASI. The Dementia Adviser for the Limerick region was hugely helpful in advising them about who would benefit from the programme and also helped pass on the relevant information to the support services in the area.

The programme ran for a period of six weeks and was presented by the same facilitator every week. Each session started with tea/coffee and scones in the restaurant. Museum volunteers were there to welcome people and chat to all involved. The sessions focused on objects which were likely to evoke discussion. Objects were also chosen taking into consideration their accessibility and the mobility levels of those attending. People contributed by verbalising their experiences, ideas and memories.

The whole museum community was informed as to the nature of the programme – this included all volunteers, staff, Friends of the Hunt Museum, security and restaurant staff. None would have been previously involved in a similar programme and all were wholeheartedly supportive and willing to assist in any way. What came to light was how many people’s lives had been and are affected by dementia, just within the museum community alone.

It would be helpful for other projects embarking on this type of work to receive the necessary training and take enough time to prepare and put the programme together. This strategy proved most helpful in developing the programme at the Hunt Museum and aided the quality of the project and the level of volunteer engagement. However, as a result one of the main challenges was the amount of working hours the development and delivery of the programme involved. Another challenge was funding for this programme and acquiring funding to continue and develop the programme in the future.

7 Supporting families and enabling them to empower their loved ones

We know from carers that peer to peer support is vital and often the information they gain from other carers is more valuable and relevant than information provided by health care professionals. People respond well to the opportunity to share positive and negative experiences with those who understand. As a result, a key goal of a number of the projects was to provide these types of opportunities to family carers.

Examples include:

Alzheimer Café Naas, Co. Kildare

This project developed an Alzheimer Café that opened in September 2013. It now meets monthly with guest speakers covering topics such as managing dementia, legal considerations and information about rights and entitlements. The Café has received positive feedback from people with dementia and their families. People with dementia enjoy attending the café and their carers access relevant information from the speakers.

Pat Kenny at the launch of the Alzheimer Café in Naas, Co. Kildare with members of the Steering Group



Participants attending the dementia awareness training in Co. Donegal

Family Carer Training – Dementia Aware Donegal

Family carer training was delivered in four locations across Donegal and in total there were 257 family carers trained. There was also a broad mix of people invited to attend the training and these included volunteers, academics (Transition Year students, FETAC nursing students, Letterkenny Institute of Technology law and nursing students), health care professionals and community organisations (family resource centres, parish councils, Gardaí and a local development company).

The training was so successful that the HSE in Co. Donegal are now funding the project to continue. It is hoped that local nursing homes, health forums and FETAC training providers may fund additional courses for their staff or students at which family carers may also be included.

10 key elements needed to create a Dementia Friendly Community



Taken from *Building dementia-friendly communities: A priority for everyone*, Alzheimer's Society, UK 2013

If you want your community to become dementia friendly, there are ten key elements to consider. Remember, communities can be a geographic village, town, city or county but it may also be a community of service providers, a workplace, club or business. No matter where the ‘community’ is, each of the elements remain relevant but they may need to be applied in a different way depending on the setting.

1. Community development approach

2. Direct engagement of people with dementia and their families

3. Strong leaders

4. Partnership

5. Local champions

6. Activities that are achievable

7. Avoid replication

8. Learning and sharing

9. Funding

10. Evaluation

1. Community development approach

Creating a DFC must be grassroots and community-led. Community development uses an asset based approach. This means that a DFC is not about setting up 'new' services, but instead supporting the existing community to become dementia friendly and inclusive. The composition of steering groups and the various activities of DFC projects must be designed to include the various components or stakeholders that make up any community – health, education, faith, business, sports and cultural.

2. Direct engagement of people with dementia and their families

In order for a DFC to succeed the person with dementia must be at the centre of all activities and decisions taken. The aim of any work undertaken must be to put the person at the centre of the overall vision as they are the experts in their journey and they will bring the expertise to identify the change that is needed. This may take time and present different types of challenges but the project structures must continually explore the opportunities for this to develop. The type of services developed for people with dementia may not always need to be dementia specific as often integrating people with existing services can have more success.

3. Strong leaders

You will need two or three strong leaders to drive the development of the project. These leaders must have a clear vision of what they want to do and how they would like to achieve it. Preferably it would be a core responsibility (but not exclusive) of an agreed designated organisation on the steering group to ensure continuity should people move on to new roles.

People should be highly committed to the project and willing to do all of the tasks required (ranging from going from shop to shop distributing leaflets to writing funding applications). These people would be the consistent drivers behind the initiative and would be responsible for delegating and also keeping the momentum going. Delegation of roles and responsibilities is critical to ensuring the sustainability and effectiveness of the project. Steering group members must take on responsibility where appropriate and this needs to be effectively delegated by the designated organisation/leader.

4. Partnership

To bring about change you need to have the right people on board in order to create a DFC. A strong team of diverse individuals with the necessary expertise and influence to guide the change must be established. This will be critical to the development of the project and you must consider how the steering group can be sustained.

It must be made up of key stakeholders in the community but also new partners that would not be directly involved in traditional dementia care. Contributions will differ, some partners may require clear direction as to why they are there and what they can offer. Invest energy in utilising the capacity and resources of the partners involved and up skill them around their awareness and understanding of dementia. The steering group may benefit from the presence of the ASI or other local dementia service providers. This guidance will bring the

dementia related knowledge necessary and the local information about existing services that would guide the other partners in identifying local needs and priorities.

Keep your project team small so that it is easily managed and people can communicate effectively with each other about their progress. It is important that there are strong and effective partnerships forged between people living with dementia and those in the statutory agencies, dementia services and other bodies working at a local level in order to develop and implement a 'joined-up' approach.

5. Local champions

Identify dementia champions in the local community that have a vision for change. Local buy in is key to success. Getting local people interested in the work that are trusted and well known locally will develop opportunities for relationships to flourish. These local champions may come from a range of backgrounds. Arrange to meet key decision makers in an environment that they are comfortable in and work at a pace that suits them even if this can be frustrating at times, as it is very important to gain the trust of those involved.

6. Activities that are achievable

The key thing is to keep it simple and start small. It is really important to identify a number of key activities and remain focused on the task at hand. The tendency can often be to work on lots of different activities whereas it might be more advantageous to concentrate on just a few.

However, it is hard to know if activities will be successful until you try them out. Over the lifespan of any project, priorities and activities may change and the people involved must be responsive to this. If something is found to be working put the effort into maintaining, sustaining and developing this rather than just moving on to the next one.

All of the projects involved cited that they had to amend their original plans for various reasons. This can sometimes be difficult and cause unexpected delays but is worthwhile and necessary in the long run so review and amend as you go along. Ensuring that the project is responsive and open to change will lead to more meaningful outcomes for all involved. Be prepared to think 'outside the box' on how things can be done, rather than viewing your activities narrowly this will allow for new ideas and proposals to emerge.

It is important to know from the outset that the time involved in developing this work is very significant and should not be underestimated. A lot of time may be spent planning, making connections, holding meetings and it may then all come to nothing. It takes time to build a reputation and for people to become familiar with the work being undertaken.

This all means that momentum can ebb and flow but it must be maintained throughout. Try to go for small, easy wins in the beginning. Be consistent with your branding and advertising so that the project can gain recognition. It is important to remain focused despite the setbacks. Having a strong and committed team in place will ensure that the work continues to get the best out of people.

7. Avoid replication

If you can identify an organisation or a person that is already undertaking work in this area, explore if there are opportunities to tag your work on to theirs. For instance, by aligning the work being undertaken to one of the existing stakeholder's operational plans or advocating for them to include the activity in their future plans you can ensure that the work stays on everyone's agenda.

By identifying local links and building relationships with project partners you will have access to a wide range of local community resources. This focus has proved an invaluable asset for stitching in the DFC project into community structures and the mind sets of those involved. This has meant that there is an enhancement of existing local capacity to raise awareness and to understand dementia.

8. Learning and sharing

There are a whole range of reasons why developing a network of support is important – it gives you an opportunity to spread the word about your work, provides encouragement, identifies new opportunities and allows the project to learn from others experiences.

Keeping yourself informed about other work being undertaken in this area is fundamental to ensuring that the project will be successful. Often times the resources/information that is required is already in existence and may just need to be adapted for a local context. Likewise you may be able to offer key hints and tips to others just embarking on this work.

9. Funding

Do not wait for funding to move the vision forward. The work can be progressed by bringing together many of the existing resources and key stakeholders in the community. Identify activities that tie in with the strengths of the partners involved and reflect the needs and wishes of people with dementia and their families. Responses must be built around local need and the resources/opportunities available.

10. Evaluation

Evaluation structures and parameters must be set out from the beginning so that projects can measure their progress, identify their challenges and perhaps explore new opportunities. Although this work is time consuming it will reap benefits as the project develops.

Building on successes and overcoming challenges

As with any project development, there were key successes and challenges for the DFC projects along the way. Each of these also created opportunities for future communities working in this area. This section outlines a table of the key successes and challenges and the opportunities these presented.

Overview of the key successes and challenges from the DFC projects

People with dementia

Successes	People want to meaningfully engage with people with dementia and try new things.
Challenges	Direct involvement of people with dementia and their families can be really slow and may not happen at all. The stigma of dementia is a major factor in this.
Opportunities	<p>To address the stigma of dementia this work may have more success by incorporating people into existing services available in the community.</p> <p>Through perseverance and the right approach the involvement of people with dementia can become a reality.</p> <p>As the work becomes more established, “organic” opportunities to meaningfully include the person with dementia will emerge.</p>

Working in partnership

Successes	There is strong support from community stakeholders to get involved in this work.
Challenges	<p>Ensuring that partners understand that their role contributes equally and in an appropriate way must be clearly outlined from the beginning.</p> <p>Partners will change and people will lose interest particularly when progress is slower than anticipated. As well as this, people will move on to other roles and this may mean adapting the programme of work.</p> <p>The restructure of the ASI presented challenges for a number of the projects as it meant there were often gaps in their dementia expertise.</p> <p>Building on the initial interest and buy in from local businesses and others in the community is challenging, as you must find ways to sustain their involvement often based solely on goodwill.</p>
Opportunities	Partners that may not be identified at first will come forward with ideas and suggestions for activities as the work progress and awareness of the initiative grows.

Delivery of activities

Successes	There is a lot of work already underway in communities and the DFC award gave them a real momentum to grow.
Challenges	Some activities will be slower to develop and some may need to be scrapped altogether. This may be due to lack of interest, difficulty getting the right partners involved or the time intensive nature of the activity. Putting in place the structures and resources to harness the energy and enthusiasm generated through the work needs constant attention.
Opportunities	Allowing the work to be flexible is critical to success as unanticipated activities may evolve.

Learning and sharing

Successes	Learning and sharing from others working in the area is so important for the development and support of the whole initiative.
Challenges	Fully capturing and documenting the work is difficult as outcomes are often difficult to quantify and report on. There is a need to constantly reassess how projects are supported and facilitated to evaluate their work.
Opportunities	Unanticipated partnerships will evolve particularly into the future as awareness grows about the work.

Funding

Successes	A strong focus on using existing resources and bringing key partners on board is critical. This minimises unnecessary costs and ensures that the work can continue beyond the lifespan of any funding arrangement.
Challenges	Potential funders often do not account for the time that goes into the planning and development of this work. Availability of money is often not the problem but time can be! Building sustainability remains a challenge. There needs to be solid leadership consistently driving it on and with people's limited resources and time this is extremely challenging.
Opportunities	Budgets must be flexible (but always transparent) to respond to the needs of the work. Many of the projects worked hard to redefine their structures to ensure that are sustainable into the future.

Final checklist

Each DFC is as unique as the communities in which they operate in but before you start to build your own DFC here is the checklist of the ‘must dos’:

1. Involve people with dementia and their families in the process
2. Incorporate awareness raising and education
3. Include a diverse range of people and organisations
4. Remain flexible
5. Find a good leader (or be one yourself)

You are now equipped to build a DFC. The Alzheimer Society of Ireland will back you 100%.

Good luck!



NOTES

Appendix 1

Background to The Alzheimer Society of Ireland (ASI) work on creating Dementia Friendly Communities (DFC)

The ASI is at the forefront of the creation of DFC. In 2013 the ASI received grant support from the Atlantic Philanthropies which allowed us to provide financial and capacity building support to a number of communities across Ireland to enable organisations, local communities and businesses to play their part in becoming more dementia friendly.

There were four key selection criteria applied in the application process for communities:

A. Commitment to working with and including people with dementia

Improve attitudes to dementia and promote inclusion by supporting people with dementia and their families to stay better connected to the services and supports available in their community.

B. Partnership

Work in partnership with other organisations by providing evidence of existing structures and strong collaboration with a wide range of stakeholders.

C. Activities that would be undertaken

Demonstrate an ethos of community development by identifying organisations, community resources, key personnel and stakeholders that are available and have a proven track record of work in this area. The activities also needed to focus on enabling people with dementia to make an active contribution to their local community.

D. Evaluation and sustainability

Sustain the work through the existing community structures after the funding has ceased by having a clear, realistic and structured approach to the project paying particular attention to the budget and timelines.

There were two strands to the funding support provided by the ASI:

1. Community of Interest Awards

This award was to enable communities across Ireland to become more dementia friendly. The awards granted ranged from €15,000 - €25,000 distributed over the course of three years up to the end of 2015.

Initially eight communities of interest were granted an award and funding commenced in September 2013 for six of them with a further two awarded funding in December 2013. However, in mid-2014 it was agreed that one of the projects granted an award in December 2013 (the Daisy Chain project in Rathfarnham, Co Dublin) would not proceed due to structural changes in the ASI at the time.

The ASI held overall responsibility for the delivery and support of this initiative but the awards granted were distributed amongst a wide variety of organisations from across Ireland. Some of the projects were led by the ASI but many of the organisations came from diverse backgrounds often with a focus on community development.

The details of the projects involved were as follows:

Name of project	Lead organisation/s	Amount awarded
Galway City Dementia Friendly Communities Project	Galway City Partnership	€25,000
Dementia Aware Donegal	ASI Donegal Branch and HSE	€25,000
Crystal project (Mallow)	HSE and ASI	€20,000
Wicklow Dementia Friendly	Co Wicklow Network for Older People	€20,000
Ballina/Killaloe Dementia Friendly Community	ASI Waterman's Lodge	€20,000
Memory Matters (Callan)	Kilkenny Age Friendly Alliance	€20,000
Reminiscence Walk/Boithrín na smaointe (Cavan town)	ASI Cavan Branch	€15,000

Galway City Dementia Friendly Communities Project

This project aimed to facilitate the social inclusion of people living with dementia in Galway City. The goal was to enable people living with dementia to maintain their identity as much as possible within the context of their own community. This was done through a consortium of key local agencies that implemented a series of awareness raising events with local communities and service providers.

Dementia Aware Donegal

This project sought to engage people with dementia and their carers across Co. Donegal in both urban and isolated rural settings. The project addressed the different aspects of the everyday lives of a person with dementia and the roles they play as parents, sports enthusiasts, members of faith communities, people involved in various hobbies and community activities. The aim was to maintain the inclusion of people with dementia and their carers in the activities they had always enjoyed.

Crystal Project (Mallow, Co. Cork)

This project facilitated a number of initiatives which supported and promoted the inclusion of people with dementia and their families. The project also worked to increase awareness of dementia in North Cork by hosting public information evenings, erecting information stands in prominent public places and linking with community groups to promote the inclusion of people with dementia in their work.

Wicklow Dementia Friendly

This project worked across Co. Wicklow to develop and deliver targeted awareness and educational workshops to the wider community including businesses, Gardaí, GPs, Citizen Information Centres, Active Retirement groups and second and third level education centres.

Ballina/Killaloe Dementia Friendly Community

This project worked to increase awareness and reduce stigma surrounding dementia in the towns of Ballina and Killaloe with an overall aim of making the two towns more dementia friendly. Many diverse groups were targeted including private businesses, retirement groups, sports clubs and schools. The project also identified the need for signage to signify that the towns were working towards becoming more dementia friendly.

Memory Matters (Callan)

This project is a Kilkenny Age Friendly Initiative and focused on ensuring that the town of Callan in Co. Kilkenny was more dementia friendly. The project undertook a comprehensive baseline study and audit of the area and the needs of people living there followed by a corresponding action plan which included a focus on the following area: - communication, intergenerational activity, social participation and the built environment.

Reminiscence Walk/Boithrín na Smaointe (Cavan town)

The aim of this project was to construct an engaging reminiscence walking trail in Cavan town. The walk has significant reminiscence features, talking points along the route and the project is aiming to identify ways to encourage people to frequently use the walking trail.

2. Targeted initiatives

As the project progressed we recognised that there were many exciting initiatives that wanted to be part of the dementia friendly movement. Therefore, the ASI sought applications from organisations across Ireland to undertake a dementia friendly project for an award of up to €1,000. We had four rounds of applications and they focused on two particular themes of interest:

- A. Age friendly towns becoming more dementia aware
- B. Promoting the participation of people with dementia in the area of the arts, performance and music

Over the various rounds of applications the following projects were awarded funding:

1. Alzheimer Café Kildare
2. Making Monaghan Dementia Aware
3. Dementia Awareness Open Day in Foxford
4. Skerries Town Park – Upgrading and development proposal
5. West Cork Arts Centre
6. Purple Pops Performance - The Alzheimer Society of Ireland, Bessboro, Co Cork
7. Tea Dance Tunes – The National Concert Hall
8. Memory Lanes – Crumlin Centre for Music and Arts
9. Past Times Community Choir, Naas
10. Azure at the Butler Gallery, Kilkenny
11. Azure at IMMA (Irish Museum of Modern Art), Dublin
12. Azure at the LAB Gallery, Dublin
13. Azure at the Highlanes Gallery, Drogheda
14. Azure at the Hunt Museum, Limerick
15. Burning Bright ‘Music and Memory’ – Galway Arts Centre

Appendix 2

Further resources

There are many other organisations that provide information and key resources about developing DFC and tools that can be used to support this work. These include (but are not limited to) the following in alphabetical order:

ACT on Alzheimer's – www.actonalz.org

This organisation is based in the USA in Minnesota and works with nonprofit, governmental, and private organisations along with hundreds of individuals through a statewide collaboration to foster collective ownership and accountability in preparing Minnesota for the personal, social and budgetary impact of dementia. They have produced a DFC Toolkit that outlines the four phases for communities to adopt dementia-friendly practices.

Age Friendly Ireland – www.agefriendlyireland.ie

Coordinates the national Age Friendly Cities and Counties Programme by providing guidance to the Alliances created, developing tools and methodologies for age-friendly practitioners and offering access to valid, reliable and timely evidence on the lives of older people in Ireland.

Alzheimer's Disease International – www.alz.co.uk

Produced a report entitled 'Dementia Friendly Communities: New domains and global examples', which documents DFC examples from all over the world, demonstrating the potential these programmes have to improve the lives of people living with dementia and their carers. The booklet was produced in conjunction with the first World Health Organisation Ministerial Conference on Global Action Against Dementia in March 2015.

Alzheimer Europe Yearbook – www.alzheimer-europe.org

The 2015 yearbook focused on a dementia friendly Europe. Alzheimer Europe compiled the information from European countries in cooperation with its member associations. A member of the European Working Group of People with Dementia also participated in the project. The end result was a comparative report and a national report for each country.

Alzheimer's Society UK – www.alzheimers.org.uk

Their website contains information about their recognition process, the Prime Minister's Challenge on Dementia, resources and guidance for creating DFC and their dementia friendly awards.

Alzheimer Scotland – www.alzscot.org

There is lots of useful information on this website including details of their award winning project in North Lanarkshire where a partnership between Alzheimer Scotland, North Lanarkshire Council and NHS Lanarkshire has resulted in Motherwell becoming Scotland's first dementia-friendly town centre along with many other helpful resources.

Dementia Elevator – www.dementiaelevator.ie

This is an education and empowerment programme to help individuals, communities and health systems engage with and support people with dementia. They provide a range of free training including programmes

specifically for retailers, financial services and transport providers among others, which can be used to learn more about supporting people with dementia.

Dementia Without Walls – www.dementiawithoutwalls.org.uk

This website shares resources such as: images, videos, stories, blogs, audio diaries, reports and toolkits about DFC. The voices and views of people with dementia themselves resound throughout.

European Foundations Initiative on Dementia (EFID) – www.efid.info

This is a group of European Foundations that recently commissioned a report undertaken by the Mental Health Foundation looking at DFC and similar initiatives across Europe. The aim of the report is to provide practical information, guidance and examples to support good practice around inclusive and supportive environments for people living with dementia and their carers. The report is accompanied by an online collection of case studies that illustrating DFC activity in Europe.

Genio Dementia Learning Network – www.genio.ie

The dementia learning network contains a number of resources including research and evaluation papers, learning and briefing papers, films, podcasts and presentations, all of which have been informed by the learning that has occurred across twelve demonstration sites involved in the HSE and Genio Dementia Programme.

Innovations in Dementia – www.innovationsindementia.org.uk

This organisation works with people with dementia, partner organisations and professionals with the aim of developing and testing projects that will enhance the lives of people with dementia. They aim to work collaboratively with people with dementia in all their work and provide advice and training to others to help them develop more positive care and support services for people with dementia.

The Institute of Public Health Ireland - Dementia research resource hub – www.dementiaresearch.ie

This site provides an overview of data, research and policy on dementia across the island of Ireland (between 2010 and 2014). It allows users to search by keywords or undertake a more specific advanced search with the results providing information about where to access further details.

For more information about this guide

If you want to learn more about the DFC initiative or any of the resources or projects outlined here please contact,

Avril Easton, Project Leader – Dementia Friendly Communities,

Tel: 01 2073802 or email avril.easton@alzheimer.ie.

Please see www.alzheimer.ie for more information.



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