

Dementia-friendly communities



1

Edinburgh City Initiatives 2014 - 2015



Contents

Preface	3
Introduction	4
Methodology	5
What dementia friendly communities means	6
Activities undertaken to create dementia friendly communities	7
The four cornerstones	
Cornerstone 1 – Place	8
Cornerstone 2 – People	12
Cornerstone 3 – Networks	15
Cornerstone 4 – Resources	17
Recommendations For Action	21
Appendix A – About Dementia – facts and figures	24
Appendix B – Policy Drivers	25
References	26

Preface

Jenny Henderson, Associate Dementia Consultant, Faith in Older People, has written this report.

Thanks to all the staff and organisations who have contributed especially:

Sally Arnison, Pharmacist Barnton Pharmacy

Caroline Clark, City of Edinburgh Council

Jan Killeen, Portobello dementia friendly community

Theresa Staczynski, Alzheimer Scotland Dementia Advisor

Murryfield Dementia Club

Karen Ritchie and The Pioneer Group

Maureen O'Neill, Faith in Older People

And all the other people involved in dementia friendly projects in Edinburgh who gave their time and help in providing information for this report.

This report was funded through *A Stitch in Time*, a partnership project facilitated by Evaluation Support Scotland (ESS) and supported by the Scottish Government Third Sector Unit and the Joint Improvement Team.²

This report is for people with an interest in taking forward dementia friendly work in the future. This could include people who work for City of Edinburgh Council and its partners, third sector organisations and community groups.

'In the end it's not the years in your life that count; but the life in your years.'
Abraham Lincoln

Introduction

Dementia friendly communities together with high quality care services and a variety of supportive care settings play a part in helping people to live well with dementia.

Dementia includes a range of brain diseases that are typically of a chronic and progressive nature. There are almost 8000 people living with dementia in Edinburgh and this figure will increase 75% by 2031. The majority of these people will be over 65 years old often living with comorbidities (Appendix A). There are a number of key policy drivers, which have influenced the dementia friendly work and this report (Appendix B).

This report reviews the considerable work that has taken place in Edinburgh to create dementia friendly communities. Some of the initiatives described in the report pre-exist the specific dementia friendly work but never the less contribute to the overall picture.

The report will use the four corner stones (Place, People, Networks and Resources) of a dementia friendly community described in the report *Creating a Dementia Friendly York* to bring together evidence of change. Each section of the report will discuss the change that has happened and what could be focused on for the future.

Methodology: Approaches taken to assess the impact of the various initiatives

1. Listening to people with dementia

This included:

- The findings from a focus group involving 60 people with dementia their families and friends entitled 'Living with dementia; 'let's talk' which took place on 25 October 2014 in Portobello and provided a comprehensive view of what people with dementia would like from their community
- Discussions with members of the Murrayfield Dementia Club on how they feel about their community and what a dementia friendly community might look like to them. The conversations focused on Quality of Life indicators outlined in the Scottish Dementia Strategy 2013 -2016³ and the outcome indicators described in the *Stitch in Time* Indicator Bank for the third sector outcomes for older people and carers
- Feedback from the Pioneer group who worked on an anti-stigma campaign
- Experiences of people with dementia and their families expressed in wider research evidence.

2. Listening to key stakeholders

3. Reading background reports

4. Analysis of the Barnton Pharmacy project.

This included:

- A survey which was undertaken in the local parade of shops and services - nine shop workers helped by answering the following questions:
 1. Did they know about the local dementia friendly initiative?
 2. Did they have people with dementia visiting their shop/service?
 3. What experience did they have of people with dementia?
 4. Did they do anything special when they served people with dementia?
- In depth interviews were conducted with the key staff that have developed the work - the pharmacist and the dementia advisor
- A walk around of the area was undertaken to assess the environment.

Limitations

It has not been possible to measure accurately the impact of the various dementia friendly initiatives because there is no 'before' data available. However the report showcases examples of good practice and identifies areas where further progress can be made.

Statistical information was examined (For example Alzheimer Scotland's helpline statistics) but has not been referenced because you cannot attribute change to this on one programme.

What does 'dementia friendly communities' mean?

The concept of a Dementia Friendly Community isn't new. As far back as 2001, Alzheimer Scotland's Dementia Awareness Week focussed on how to reduce stigma, raise awareness and create more dementia-friendly communities. The 'dementia friendly' movement is worldwide with examples of innovative work as far afield as Japan and Australia. In March 2012 the Prime Minister, David Cameron, launched the Prime Minister's Challenge on Dementia and this included 'creating dementia friendly communities that know how to help'. This has led to many cities in the UK seeking to become 'dementia friendly'.⁴

Defining dementia friendly communities is problematic for a number of reasons: -

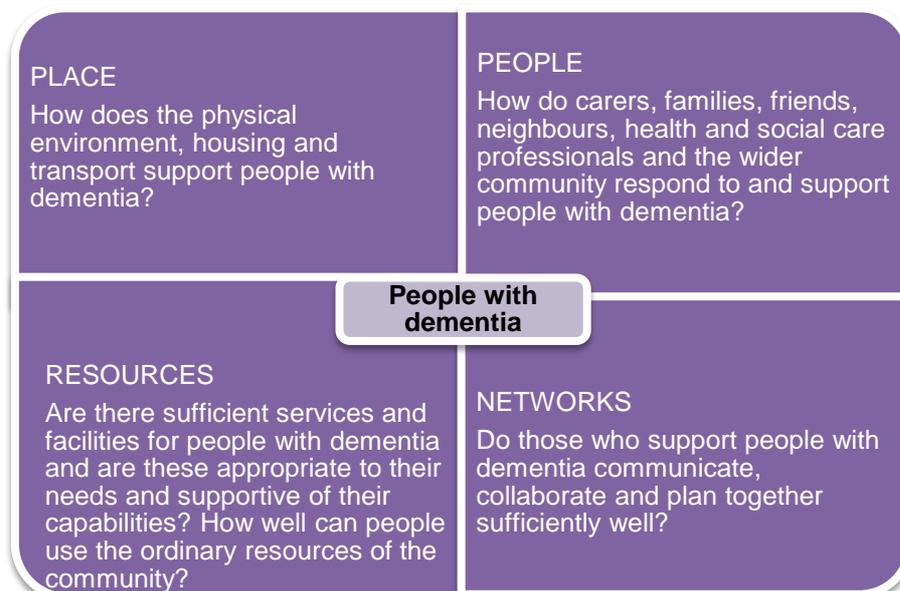
- The comparative newness of the concept
- The lack of research and peer reviewed literature on the subject
- The diverse ways in which the idea has been used
- The word 'community' itself is not easy to define - the term encompasses not only geographical boundaries but also an ethnic, spiritual or specific interest group or clubs etc.

The concept of dementia friendly communities could be seen as an overarching programme of work undertaken to improve the lives of people living with dementia or equally as something distinct from but complementary to other initiatives. Alternatively it could be seen as a new focus that overlaps with existing initiatives to enhance the lives of people living with dementia.

However often outcomes include

- an increased public understanding and awareness about dementia
- increasing support for people living with dementia to remain active and independent members of their communities for as long as possible.

A useful framework is described in the report describing York City's experience of developing dementia friendly communities. It suggests that with the voices of people with dementia at the centre of the process, communities need to consider four cornerstones:



Adapted from
CREATING A
DEMENTIA-
FRIENDLY
YORK: Joseph
Rowntree
Foundation⁵

Activities undertaken in Edinburgh to create Dementia Friendly Communities

'let a hundred flowers bloom' Mao Zedong

This maxim has much resonance when considering the variety of initiatives, which are being undertaken in Edinburgh to make the city dementia friendly. There has been 'a top down and bottom up' approach to organising and contributing to creating dementia friendly communities.

Some of the initiatives have been promoted by Edinburgh City Council in partnership with NHS Lothian and Alzheimer Scotland. Other projects have been led by a variety of Third Sector organisations or churches, museums, art galleries etc. Individuals who are passionate about improving the lives of people with dementia are also having a significant impact on providing services and raising awareness.

Key activities revolved around

The Dementia Friendly Campaign (launched January 2014) which aimed to raise awareness of dementia and tackle discrimination. This included training for employees, and proactive work by local shops.

The anti-stigma Campaign (From February 2015) includes posters, leaflets, pub mats, bus adverts and radio adverts to highlight the importance of reducing stigma. This work was led by Edinburgh City Council. People with dementia have been a key part of developing the slogans used in the materials and overall aim was to engender hope by using the message: 2015)

'We have not had to pressurise anyone to do anything – the ideas, time and commitment has come from them. It has not just been a positive response, it has been overwhelming'
Edinburgh City Council Staff member

Pioneer Group: an example of co-production of campaign materials



1. LEARN THE FACTS

Find out about dementia and how it affects people who have it. That way you will know what to do to help them. Share your knowledge with friends, families and workmates. The more people there are who know about dementia, the easier things will become for the people who have it.



2. HELP ME JOIN IN

Don't write someone off because they have dementia. Dementia affects everyone who has it in a different way. It does get worse over time but, with a little help from others, people with dementia can live good lives and keep their daily routines going for many years.



3. USE KIND WORDS

People often joke about dementia. They forget it is a fatal condition. They make light of dementia. Using words such as 'losing their marbles' or 'going gaga' can be hurtful. It also causes people to hide their dementia.



4. TALK TO ME

Not knowing what to say to someone with dementia can stop people talking to them. Many people say that they become invisible as soon as they tell others they have dementia. This can be hurtful. So, don't be afraid. Give it a go and keep on talking!



5. BE PATIENT

There are little things everyone can do to help someone with dementia. Giving someone a bit more time in a queue is one. Giving a person time to find their words if they are having problems speaking is another. Help them keep doing the things they do every day.



6. BE A FRIEND

Keep in touch. Social contact can help slow down the progress of dementia. The support of friends and family helps someone with dementia stay connected and part of their community. Show your support by becoming an Alzheimer Scotland 'Dementia Friend'.

"We can't cure dementia yet but we can cure the stigma"

The Pioneer Group are a group of people with dementia who helped with the stigma campaign and are open about their diagnosis and are keen to be involved in helping with other events and supermarkets.

Anti-Stigma poster

It made me feel worthwhile that someone was asking my opinion

Member of the Pioneer Group

Cornerstones

In the following sections we highlight the four cornerstones for creating a dementia friendly community. We use these cornerstones to present evidence of change as a result of the programme in Edinburgh.

CORNERSTONE 1 - PLACE

How does the physical environment, housing, transport support people with dementia?

The environment is a key aspect of helping people with dementia to cope with everyday life. Small environmental changes can provide clues to assist the person with dementia to make sense of a confusing world. These could include clear signage, good light, low noise and use of colour to create a contrast.

The focus of dementia friendly communities in Edinburgh has mainly been on raising dementia awareness, reducing stigma and good customer care and there has not been a specific focus on environmental change.

Views of people with dementia

The areas of environmental concerns for people with dementia were mainly about signage, toilets and transport. No housing issues were raised although this is an obvious area for good dementia friendly design.

1. Signage

The Portobello focus group concluded that the street signs are often too high and lettering too small

None of the Barnton shops had particularly clear signage or anything visible that identified the shops as being dementia friendly. This is something that could relatively easily be improved.

2. Shops

Little has been done so far within shops to improve the environment for people with dementia, although the Barnton Pharmacy had worked to reduced noise levels.

A suggestion from the Portobello group was that that there should be seats available in shops for people with dementia or the elderly to be able to use.

The Murrayfield group relied on their families to take them shopping. Some of the group used the Internet for shopping and found it very convenient to have frozen meals delivered to the house. No one was able to use the Internet themselves and instead relied on their families to place the orders.

One gentleman described enjoying going to the supermarket with his daughter where he was able to lean on the trolley to get round.

3. Toilets

Many people with dementia are assumed to be incontinent when in reality it is often simply that they are unable to find the toilet or fail to get there in 'time'. Family members find it stressful when they can't find a toilet or go into a toilet with the person.

The Barnton shopping parade had one toilet available in the parade of shops and this had poor signage, this could be typical of many shopping experiences.

Views of people with dementia (from Portobello and Murrayfield groups)

- There are not enough toilets
- More unisex toilets would be helpful
- Signage should be clear and consistent

✳ Good practice example:

The Kendal Community Toilet Scheme provides members of the public with clean, safe and accessible toilets in convenient locations across the town. Participating businesses have agreed to let members of the public use their toilet facilities during normal opening hours, without the need to make a purchase. Several of the participating premises offer wheelchair access and baby changing facilities. The location of the toilets is widely advertised. This type of scheme could be adopted in Edinburgh with the added benefit of making it dementia friendly by using good signage and contrasting colours for toilet seats.

4. Transport and mobility

The Barnton Shopping Parade

The environment around the Barton Pharmacy demonstrates the challenges of creating suitable transport solutions, as there is a bus service, a busy road to cross, limited disabled parking and a limit of half an hour for normal car parking.



Views of people with dementia (from the Murrayfield group)

- I carry a stick when I'm out because it makes people more helpful
- The green man at the traffic lights is too short to cross safely
- The traffic lights with voice instructions are confusing
- Uneven pavements and unnecessary steps affect balance and mobility

Traffic lights with a voice system have been designed to help people with visual impairment and this highlights the difficulties of supporting different disability needs – there is not an easy answer. However, consideration could be given to less complicated instructions and using short simple sentences.

Council staff involved in planning, roads and transport department could also undergo dementia awareness training.

Public Transport

There are a number of things to consider when thinking about the environment of bus and train stations. Train stations are often very busy, noisy and confusing - quiet areas can be difficult to locate.

The complexity of the timetables and platform information may also be a challenge for people with dementia to follow and this [YouTube clip](#) clearly demonstrates the difficulties. The impact of not being able to use public transport restricts freedom and quality of life.

Views of people with dementia

The Murrayfield group did not use public transport because they were too frail and were reliant on taxis, which are expensive, or family and friends. One lady needed a taxi to visit her doctor's surgery only three streets away.

The Murrayfield group also described the loneliness of being housebound. The dial a bus scheme was not used by the Murrayfield Club because of difficulties with access - it required planning and the times were not always suitable to fit in around care packages.

*** Good practice examples:**

First UK Bus – Rotherham have introduced training for all their employees as well as 'safe journey cards' to alert staff that someone has dementia and may need more time and help.

SWESTRANS has introduced a Thistle Assistance card that identifies people with mobility and sight problems and has a message of 'please wait for me to sit down' this could be further developed to include people with dementia.

5. Clubs and groups

The same environmental challenges as described above will also apply to all other initiatives, which often take place in rented or borrowed facilities – for example art galleries, museums, clubs, and cafes. One member of staff noted that it can be difficult to have good signage in rented premises.

Churches and other faith communities have a number of constraints and will need guidance to make changes. There are particular problems as the buildings are often old and there may be restrictions on providing contrasting doors or increasing lighting.

However there are simple interventions, which would be helpful, for example ensuring the person sits in the same seat when attending church or providing additional lighting. Environmental changes to church halls are simpler and will reach a greater number of people. Ideas could include contrasting colours on the doors and good clear and consistent signage.

Specific tools for helping churches and other faith groups to adapt to meet the needs of people with dementia are in the process of being designed by Faith in Older People.

Areas for more work

- An environmental audit involving people with dementia should take place. This should look at each of the individual shopping areas. The ‘individual’ village feel that Edinburgh has is a real advantage as the City can be broken down into ‘bite sized’ areas for easier auditing.
- To help with the audit in shops Alzheimer Scotland has produced a helpful poster
http://www.alzscot.org/assets/0001/2899/Environmental_Hints_Tips.pdf
- An Edinburgh City Charter Mark or a dementia friendly shopping ‘app’ should include evidence of good environmental practice, for example having chairs and easily identified toilets.
- Changes could be made in identified areas: eg the green man stays on for longer, provision of more toilets, better signage and so on.
- A review of transport needs for people who cannot use public transport.

CORNERSTONE 2 - PEOPLE

How do carers, families, friends, neighbours, health and social care professionals and the wider community respond to and support people with dementia?

There are many people involved in helping people with dementia in many different ways. People are the most important resource and without their hard work and dedication Edinburgh City's drive to become dementia friendly would not be so developed. It is also important for continuity and sustainability that there is support available for these individuals; this might take the form of advice and guidance or financial help.

People working in shops and services

Dementia friendly Edinburgh started in January 2014 as a campaign to raise awareness of dementia and to tackle associated discrimination. This has included training for employees, and proactive work by local shops.

Cameron Toll Shopping Mall has become the first 'dementia friendly shopping mall' in Edinburgh after lending its support to a citywide awareness campaign. More than 30 organisations including supermarkets, the emergency services, pharmacists and retailers have signed up to the scheme and are actively involved in developing it.



✳ Evidence of good practice from the Cameron Toll initiative:

Sainsbury's has been particularly involved in becoming dementia friendly; they have had 'listening sessions' for their staff and have developed a number of actions including: -

- A 'slow' shopping lane
- Disability/dementia training for all staff



The Barnton Sainsbury's store demonstrated the impact that dementia and disability induction training had had on staff. One employee who was interviewed stated that they saw it as 'just good customer care - if someone needs help then that's just what we do'

Another corporate initiative has been the Bank of Scotland who working with Alzheimer Scotland to deliver awareness-raising and information resources to branch colleagues, which will help them provide a more Dementia Friendly service to people with dementia, their families and carers. Bank of Scotland have also committed to further train staff on the issues around dementia and to improve practices on an ongoing basis.

This was evident in the Barnton branch where the counter staff had completed on line training and were aware of how to protect people with dementia from potential fraud.

Visits to the Barnton shops showed that: -

In most of the shops, staff were able to describe the steps they would take to support the person. This included taking time and if necessary helping them to select the goods they were purchasing. They stressed that knowing the individual was really important - one sales person noted 'we look after our own'. These staff were aware of the difficulties that people with dementia face and how best to help them. However most of them had not attended awareness raising sessions and this is perhaps an indication of staff turnover since the completion of these sessions eighteen months ago. This raises concerns about the on-going need to keep up momentum to ensure the sustainability of such dementia friendly community initiatives.

The impact of this project is difficult to measure but the experience of the staff is that it has been valuable and they feel they are offering a better service to people with dementia. There are much better channels of communication within the local health services and they are far more responsive to the needs of people with dementia

The Barnton Hairdressers said they knew their customers extremely well and have had regular contact with them over a long period of time. This meant they are well placed to be supportive if a customer developed dementia.

There was a notable difference in shops where disability/dementia training was part of company induction i.e. the branch of the Bank of Scotland and Sainsbury's

This was in contrast to another shop when a disappointing interaction with a customer in a shop was observed during the visit; the member of staff working on the checkout was dismissive with an elderly gentleman who appeared confused about the amount of change he was given. This shop reputedly had a high turnover of staff and no disability and dementia induction although it was part of a national chain.

Views of people with dementia – council support services

One of the Murrayfield Group described his frustration when trying to get his refuse collected through the Council 'Access" scheme. He experienced a confusing phone system and when he eventually spoke to someone he found the staff member unhelpful and was still waiting to have his refuse collected.

✿ Evidence of good practice from a local pharmacist

The Barnton Pharmacy initiative demonstrated that the people involved in this project were enthusiastic to improve the lives of people with dementia living in their community.



This has included changes in practice for the pharmacy: -

- The pharmacy provides assessments on the appropriate use and content of Dosset Pill dispensers and is proactive in trying to ensure people take their medication.
- The pharmacist recruited a student pharmacist to investigate poly pharmacy (when there are 4 or more medications prescribed that can cause unexpected side effects).
- Barton Pharmacy delivery driver has been trained in Medicine compliancy assessment and can report any problems or changes he observes on his delivery round.
- The staff in the pharmacy have been up-skilled to question if someone with dementia has become suddenly unwell and advise checking to see if there are symptoms of a urinary tract infection.
- The placement of a display of information about dementia.

The pharmacist also worked with the other shops in the parade to raise awareness of dementia. This work is built on the strength of a small community where people know each other.

Areas for more work

- It is important that shop staff, hairdressers, post offices and frontline council staff are given dementia awareness training. This needs to be repeated over regular intervals because of staff turnover.
- There are a number of online resources available to help and support groups to establish local dementia friendly communities, which include: -
 - Alzheimer Scotland's report on the [Motherwell project](#).
 - Alzheimer Scotland's [dementia friendly toolkit](#).
 - The Joseph Rowntree Resource Hub DEMENTIA WITHOUT WALLS. This [Resource Hub](#) has a range of external links for those wanting to learn about and develop Dementia Friendly Communities.
- It would be useful to developing the Barnton pharmacy dementia friendly model to create network of dementia friendly pharmacies across the city. This would help and support a large number of people with dementia. There would also be the benefit of influencing local community shops. This would involve developing the Barnton Pharmacy checklist to make it a comprehensive guide and creating an online list of useful resources. It would also require an environmental audit of each premises.

CORNERSTONE 3 - NETWORKS

Do those who support people with dementia communicate, collaborate and plan together sufficiently well?

There are good examples of people working together to ensure a dementia friendly community. Initiatives include

- Alzheimer Scotland: dementia friendly community and corporate work and also the development of supporting dementia friendly resources
- Dementia friends: Alzheimer Scotland
- Dementia Friendly Edinburgh: bringing together organisations to change perceptions

Below are some examples of people and networks working together.

Alzheimer Scotland

- The Dementia advisors' work provides information and advice to help find the dementia support the person needs. This includes local groups and services. They also help the local community be more dementia-friendly and influence policies and services.
- The Alzheimer Scotland link workers are key workers in providing a year's post diagnostic support.
- Art in the City is an Alzheimer Scotland initiative to allow people with dementia to have a cup of tea and discuss paintings.

Barnton Pharmacy: Examples of networks developed in the pharmacy project

The pharmacist has taken the lead in driving forward the Barnton dementia friendly community. Some of the activities of the community include the following:

- Alzheimer Scotland Dementia Advisor has provided three awareness raising sessions for nearby shopkeepers and the local community
- Open days were also held at the pharmacy where the Dementia Advisor was able to see people in the consulting room.
- Other shopkeepers encouraged to come to the pharmacy if they notice an individual who may be struggling with their dementia.
- The pharmacist has become involved in the local dementia forum and works closely with other health professionals including GPs.
- The Dementia Advisor established the café and remains involved in the Barton Pharmacy initiative
- There is a dementia blog run by the pharmacy
- To encourage other pharmacies to become involved she has developed a pharmacy checklist.

The Barnton pharmacy described close links with the local doctors and community health teams as being an important part of improving the service the pharmacy were able to provide. A Community Psychiatric nurse leads the Pioneer group.

The pharmacist and the dementia advisor said that the wider opportunities and networks for people with dementia within the community have yet to be explored in any depth. For example there is potential for working with schools and intergenerational work with care homes or working with the nearby golf courses.

Views of people with dementia – The Pioneer Group

- We would like to work with other organisations and shops

Corporate organisations

Alzheimer Scotland is working with some large organisations like local authorities and NHS Boards, as well as some big companies who are keen to become dementia friendly – visit the [website](#) for more information. They have developed a second version of their Dementia Friendly Community logo for partner organisations.

Other examples

Individual communities are coming together to create dementia friendly environments. These communities include:

- Dementia friendly Portobello
- Dementia friendly Pentland
- Dementia friendly communities for Juniper Green, Currie and Balerno
- South Queensferry
- Muirhouse and Pilton

These groups are run by committed volunteers, professionals and Third sector organisations and are at different stages of development and involvement of people with dementia. They are evolving in different ways with little in the way of financial resources. However the drive of individuals involved is extraordinary

The Balerno Group has recently secured funding from the Rotary Club to develop leaflets to help with the consultation process it intends to conduct in each of the areas it covers. They were also keen to acknowledge that they are not experts and need help and support.

There are a number of **independent dementia day care** providers who also make important links in the community to support people with dementia and their families **Community councils** are also making a contribution. The Cramond and Barnton Community Council are showing an active interest in supporting the needs of people with dementia living in their community.

Areas for more work

It would be useful to:

- Extend the pockets of good practice to other areas of Edinburgh, this will require coordination, support and resources (see Cornerstone 4).
- Work with corporate organisations to ensure their workforce is dementia aware. It might be useful for the Council to include dementia awareness sessions for their own front line staff including councillors and those involved in planning, roads, transport, and housing departments both to improve customer care and also to influence planning and transport policy.

CORNERSTONE 4 - Resources

Are there sufficient services and facilities for people with dementia and are these appropriate to their needs and supportive of their capabilities? How well can people use the ordinary resources of the community?

People with dementia and their carers have the right to live as independently as possible with access to recreational, leisure and culture in their community.

Charter of Rights for people with dementia and their families in Scotland

Resources might be specifically for people with dementia or for everyone, but accessible because they take into account the needs of people with dementia.

Specialist support

Evidence from the Murrayfield group suggests that people do not necessarily want to go to dementia clubs. There were seven people in the Murrayfield group. They all had a diagnosis of the early stages of dementia and were over 80 years old. They were coping with bereavement, living alone and other day-to-day challenges. They were struggling with frailty, poor mobility and comorbidities and many felt this was more important to them than their memory problems.

It is unclear if it was because of lack of insight into the illness, denial, fear or stigma but it was impossible to discuss the impact of dementia with the majority of the group. They were even reluctant to admit they knew anyone with dementia and became very defensive at any mention of the word dementia. Consequently it was impossible to be open with them about their diagnosis. There was only one lady in the group who volunteered she had dementia and was able to describe how distressed it made her feel and how much help she now needed. Once again it was help with practical daily living.

The staff refer to the group as 'the club' as people do not want to come if they know it is a dementia group. The staff state that home support care plans seldom mention a diagnosis of dementia and usually refer to cognitive impairment

This finding is backed up by the dementia advisor who described how difficult it was to establish dementia cafes. Despite widely publicising two groups they had failed to become established. A third group which meets in Cramond church hall once a month also proved difficult to develop. However the Consultant Older Age Psychiatrist was supportive and agreed to see some of his patients during the session. This was pivotal as it created a reason for people to attend the group and allowed for the breakdown of inhibitions and the development of relationships. Unfortunately this no longer happens and attracting new members is once again proving difficult. This is essential for a healthy group to continue.

Views of people with dementia from the Portobello group

- It is good to have a designated area at a specific time
- Having a meeting in a local café (not a dementia specific café) allows people with dementia to meet on a regular basis to talk to, and support each other.

Whilst some people enjoy dementia cafés, making them 'more normal' might appeal to a wider range of people. This ensures people are not defined by their diagnosis of dementia. Other areas in different parts of the country have set up successful lunch/coffee clubs, which meet in pubs and hotels.

The divergence of attitudes towards a diagnosis of dementia highlights the importance of stigma campaigns. They are important not only for the general public but to ensure support and understanding is given to people with dementia and their families to come to terms with the diagnosis of dementia and take up available services and opportunities.

The one-year of post diagnostic support should help with this but the lack of insight, fear and stigma remains a challenge to ensuring people with dementia access the help and support they need.⁶ Groups designing services should be aware of these challenges.

Assets for everyone: but dementia friendly

Edinburgh is rich in local resources, this includes

- cultural organisations (museums, galleries, cinema, theatres and visitor centres)
- churches and other faith groups
- shopping centres
- sports centres and clubs (eg golf or bowling)
- cafes and activity clubs eg bingo, rotary

To ensure these are accessible for people with dementia means working through the other 3 cornerstones around improving the physical environment, improving skills

and attitudes of people and improving networks to help people to plan and work together better.⁷

Research carried out over a three year period by Age UK discovered that most people living with a partner or family member 'wanted to be able to do things together and have fun, and that there were too few opportunities for this to happen'. As a result of this a film club was established and one of the carers commented, "it was something normal we were doing together. I really enjoyed the whole thing. It's lovely meeting people who are not afraid to talk to us."⁸

The importance for families to do things together should be acknowledged when planning activities.

✿ **Examples of good practice: cultural activities**

- The Portrait Gallery and the museums have sessions to help people with dementia enjoy visiting exhibitions
- There are plans for a dementia sensory garden at Lauriston Lodge. This project has the support of Edinburgh City Council and is a partnership project with NHS Lothian and Alzheimer Scotland.
- There are independent, very popular singing groups run by volunteers

✿ **Examples of good practice churches**

- Balerno Parish church is a key partner in the dementia friendly Pentland initiative and runs the Palm café
- Murrayfield Churches together, runs the dementia club and is funded by Edinburgh City Council.
- The Church of Scotland has an active dementia training programme for church members.
- Also The 'Heart for Art' project funded by the Life Changes Trust and created by the social care arm of the Church of Scotland. The Edinburgh group uses artists supported by specially trained Cross Reach staff to lead creative arts groups for people living with dementia and their carers

Faith in Older People (FIOP) has for many years worked with churches to help sustain the spiritual lives of all older people including people with dementia. Currently they are developing materials to support churches and their congregations and parishes to become dementia friendly

Views of people with dementia from the Murrayfield group

One member's face lit up when she talked about the church groups she attended

There are a number of excellent resources produced by The Dementia Engagement & Empowerment Project (DEEP) including a number of guides to help support people with dementia when involving them in working groups. <http://dementiavoices.org.uk>

Areas for more work

- Intergenerational support is key to helping people living in care homes to have links to the outside community and the interaction with children has been shown to enrich their lives. There are examples of good practice where specific schools are linked to care homes.
- Close links being developed with different types of clubs such as bingo, bowling, golf etc. These are low cost interventions but important ways to ensure people with dementia remain involved with their communities and sustain their interests for as long as possible.

Recommendations for action

1. Development of a toolkit

To provide consistency and sustainability for future projects a toolkit could be developed to help guide and support the people who are trying to create dementia friendly communities, this could consist of three key tools

A. Overarching principles

It is recommended that overarching principles be adopted by the City these might be adapted from the quality of life indicators (QoLIs) used in the Promoting Excellence Framework. These principles have been developed with people with dementia and focus on a good quality of life.⁹

Hearing the voices of people with dementia in creating dementia friendly communities: an example of overarching principles: -

Overarching Principles for a Dementia Friendly Edinburgh City

1. People with dementia feel empowered and enabled to exercise right and choice, maintain their identity and be treated with dignity and equity in their community
2. People with dementia live in communities where they are able to maintain their best level of physical, mental, social and emotional wellbeing
3. People with dementia live in communities where they feel safe and secure and are able to be as independent as possible
4. People with dementia live in communities where they are able to maintain valued relationships and networks
5. People with dementia have access to quality services and can continue to participate in community life and valued activities
6. People with dementia and their families, friends and carers have access to education and support in their communities that enhances wellbeing of the person with dementia and those that support them
7. People with dementia have access to individuals, groups and organisations in their communities that can support their spiritual or personal beliefs and reflect their cultural wishes.

B. Standardised audit tools - using appreciative Inquiry model

A number of audits have been suggested in this report and further work assist with these is required. A starting point would be using an appreciative enquiry approach

The Appreciative Inquiry Cycle¹⁰

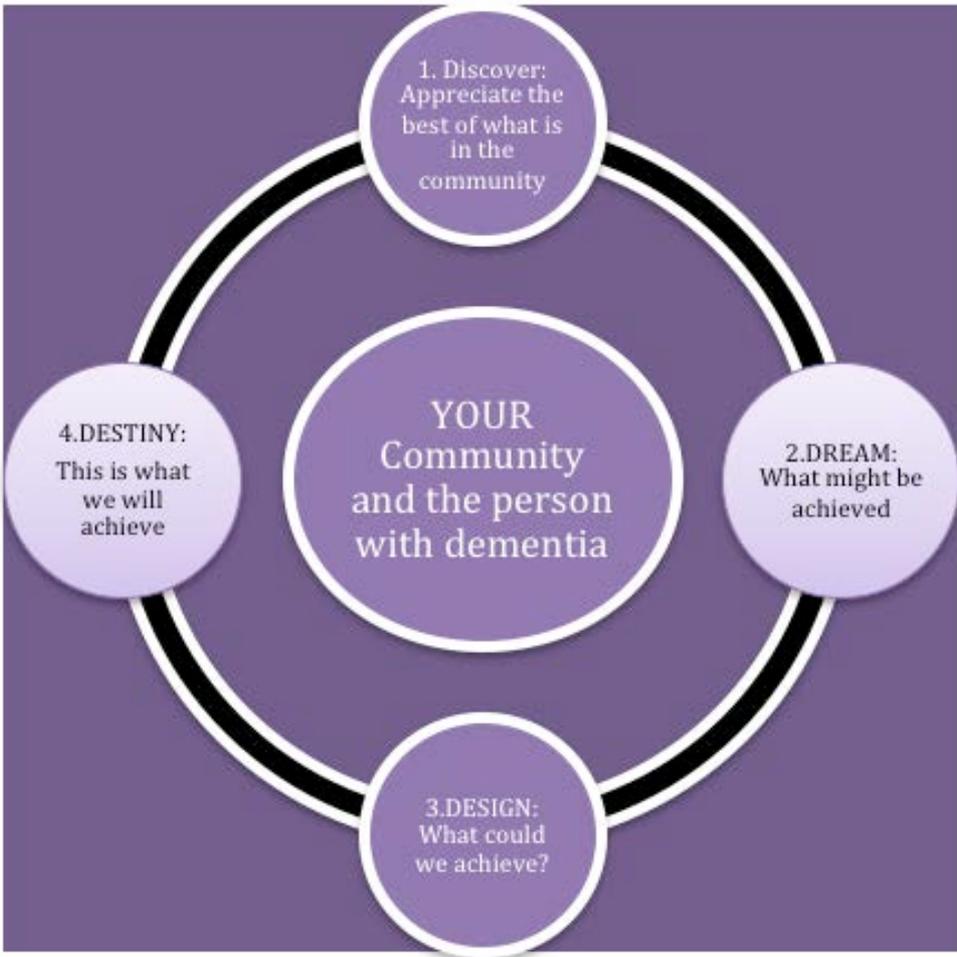
Provides a framework for auditing and evaluating your community and the environment.

Discover (circle 1) by identifying what already works well and it the starting point of the evaluation

Dream (circle 2) what would you like to do to create a dementia friendly community?

Design (circle 3) how are you going to create it? Planning and prioritising - what would work well?

Destiny (circle 4) Delivery and implementation and then back to Dream!



C. The 4 Cornerstone Matrix (Place, People, Networks and Resources) used in this report and outlined in the York City work could provide a useful framework to developing and evaluating projects.

2. Coordination

An Edinburgh City Dementia Friendly Communities Coordinator should be appointed

To ensure dementia friendly communities are sustained, developed and equably distributed across the city there is need for some central coordination. This will supplement the excellent work already being undertaken by local volunteers, health and social care professionals and the Third sector.

If this was to occur the extra work generated would create far more awareness raising than can currently be supported there would therefore need to be further part time appointments to deliver awareness training.

3. Quality control

1. A Charter mark could be developed to recognize and ensure the quality of initiatives.

This would, of course, have resource implications and Alzheimer Scotland has an existing dementia friendly toolkit, which could be a different way of providing a dementia friendly mark.

2. Other more technologically innovative solutions should also be explored – for example there is potential for a service like ‘TripAdvisor’ to allow people with dementia, their carers and families to directly rate services.

If properly implemented these solutions would allow progress to be measured and future initiatives targeted where there is most need.

4. Financial support

There should be a specific fund that individual projects could apply for financial support

This would also help to ensure the projects are good quality and thoughtful in their approach, and that the individuals currently working alone to make a difference will be supported. Let a hundred flowers bloom: This maxim has so far been very successful but it has been starved of one of the necessary nutrients necessary to make the best flowers bloom! Financial support.

Appendix A

About dementia

Dementia includes a range of brain diseases that are typically of a chronic and progressive nature. The term dementia is also used to describe a range of disease symptoms relating to deterioration in cognitive function, behavioural changes and functional limitations. It is caused by diseases and injuries that primarily or secondarily affect the brain.

Although dementia predominantly affects people of an older age, it is an abnormal condition and not a natural part of aging. The experience of dementia is subjective and unique to each individual; it is determined by a number of factors including neurological damage and thoughts, feelings and behaviour of the individual, within their social context.

Statistics

There are approximately 90,000 people in Scotland with dementia. In Edinburgh City the figures for people with dementia are: - ¹¹

Under 65	Over 65	Total
287	7536	7823

Projected growth in the number of people with dementia

By 2031 it is projected that there will be approximately 102,000 to 114,000 people with dementia in Scotland, a 75% increase.¹²

The cost of dementia in Scotland in 2007 is between £1.5 and £1.7 billion. Dementia has a major impact on our economy. These figures include the cost of accommodation (41% of total), informal care (i.e. the costs to family of caring) (36%), social work services (15%) and NHS care (8%). The estimated average cost per annum of a person with dementia is £25,472. The cost of dementia in 2031 is projected to rise to £2.6 - £2.9 billion (at today's prices).¹³

Appendix B

Policy drivers

- **The Charter of Rights** for people with dementia reflects the views of over 500 people (including people with dementia their carers, and professionals) who took part in widespread consultation carried out on behalf of the Cross-Party Group by Alzheimer Scotland between May- July 2009. These rights must be central to all care for people with dementia and their families and are central to understanding the rights of people with dementia in relation to dementia friendly communities.
- **Scotland's National Dementia Strategy 2010 – 2016:** the aim of this is to provide a strategy for delivery of world-class dementia care and treatment in Scotland, ensuring that people with dementia and their families are supported in the best way possible to live well with dementia. Living well with dementia requires the support of the whole community. The Strategy is underpinned by Quality of Life indicators (QoL).
- **Promoting Excellence Framework:** this supports delivery of the aspirations and change actions outlined in the strategy NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) developed Promoting Excellence: A framework for health and social services staff working with people with dementia, their families and carers to support outlined in the strategy.
- **Alzheimer Scotland's Five pillars model** is a framework which describes support for people with dementia adopted by the Scottish Government to deliver one year's post diagnostic support including the importance of maintaining networks and community support.
- **Alzheimer Scotland's eight pillars model** is a framework for people with dementia in the middle stages of the illness. This also focuses on the importance of networks and community involvement.¹⁴

References

- ¹ Power point slide: City of Edinburgh Council Dementia Friendly Communities: It's everyone's business Edinburgh Business Day 2011
- ² Evaluation Support Scotland. *A Stitch in Time*. 2015. Available at <http://www.evaluationsupportscotland.org.uk/how-can-we-help/shared-learning-programmes/stitch-time/> [Accessed June 2015]
- ³ Scottish Government. *Scotland National Dementia Strategy 2010- 2016*. Available at <http://www.gov.scot/Topics/Health/Services/Mental-Health/Dementia>. [Accessed June 2015]
- ⁴ Department of Health. *Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015*. London 2012. Available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf [accessed June 2015]
- ⁵ Crampton J, Dean J, Eley R. *Creating a Dementia Friendly York*. Joseph Roundtree Foundation. 2011. Available at <http://www.jrf.org.uk/sites/files/jrf/dementia-communities-york-summary.pdf> [accessed June 2015]
- ⁶ Alzheimer Scotland. *Delivering Integrated Dementia Care: The 5 Pillars Model of Community support*. 2012. Available at [ww.alzscot.org/campaigning/five pillars](http://www.alzscot.org/campaigning/five-pillars) Accessed [June 2015]
- ⁷ Scottish Government. *Charter of Rights for people with dementia and their carers in Scotland*. 2009. Available at http://www.alzscot.org/assets/0000/2678/Charter_of_Rights.pdf [Accessed June 2015]
- ⁸ Hudson G. *Lancaster-film-project-proves-hit-dementia-patients*. 2014. Available at <http://www.thegoodcaregroup.com/news> [Accessed June 2015]
- ⁹ NES/ SSSC. *Promoting Excellence Framework: A framework for all health and social care workers with people with dementia, their families and carers*. 2011. Available at <http://www.gov.scot/Publications/2011/05/31085332/0> Accessed [June 2015]
- ¹⁰ Copperider D.L, Whitney D, Stravos J. *Appreciative Inquiry Handbook, for Leaders of Change*. 2nd Edition, Ohio: Crown Custom publishing. 2008
- ¹¹ Alzheimer Scotland. *Statistics*. 2015 Available at <http://www.alzscot.org/campaigning/statistics> [Accessed June 2015]
- ¹² Alzheimer Scotland. *Dementia epidemic 2007* Available at http://www.alzscot.org/campaigning/policy_reports/2134_dementia_epidemic [Accessed June 2015]
- ¹³ Alzheimer Scotland. *Delivering integrated dementia care: The 8 pillar model of community support*. 2012. Available at [http://www.alzscot.org/campaigning/eight pillars model of community support](http://www.alzscot.org/campaigning/eight-pillars-model-of-community-support). [Accessed June 2015]