

Including people with dementia – Shaping generic services

April 2014

A project report by Steve Milton, Innovations in Dementia (CIC)

Based on the 2012 programme of work, funded by Department of Health Strategic Partners Programme.

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Innovations in Dementia

Innovations in Dementia is a small but influential not-for-profit company that works nationally 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 and enabling them to live well. Steve Milton, the author of this report, has worked in social care since 1987 as a researcher, writer, trainer and service manager, working mainly in the third sector. He has worked in the field of dementia since 1995 - running the Alzheimer's Helpline before becoming a director of Innovations in Dementia (CIC) in 2007.

Why we have written this report?

In August 2013, the Alzheimer's Society published its report "**Building dementia-friendly communities: A priority for everyone**".

The report explored new evidence from people with dementia about their experience of living in their communities. Its findings suggested that:

- Many people with dementia do not feel part of their communities
- Many people with dementia would like to do more, but need support to help them engage and stay active.
- There is a lot of goodwill within communities toward the idea of being more supportive and more dementia-friendly.
- There is a lot that can be done at community level to support people to live well with dementia and overcome the barriers they face.
- The kind of support people said they needed to live well included more support and services, including 1-1 support through befriending, and the provision of information to help them in their day- to - day lives.

Since the Dementia Strategy was launched in 2009, there have been significant improvements in the diagnosis of dementia, with more and more people getting a diagnosis at a stage when they still have potentially many years of independence ahead of them. The numbers of people in this situation are set to increase, with a target of two thirds of people getting their diagnosis by 2015*

Anyone familiar with the work of the Age UK network will recognise the huge potential that its mainstream services have in providing the kind of support that people with a dementia say they need to live well, especially those in the early stages of dementia.

Since 2012, Age UK has been working with local Age UKs to help them to make their mainstream services more dementia-friendly. We started working with 15 local partners in 2012, and another 45 will join the Dementia Friendly programme by Autumn 2014, through funding provided by Big Lottery Fund. The current cohort will have an additional element of support around the development of well-being services, in part building on the success of the "Fit as a Fiddle" programme. This element of the work is being led by Dementia Adventure CIC.

This report is focused on the work with the first round of 15 local Age UKs from 2012/13.

We wrote this guide to outline the work we are doing, and we hope that it will both inform and inspire other organisations that want to provide mainstream services which are more accessible to people with dementia.

*"the Prime Minister's Challenge on Dementia - Delivering major improvements in dementia care and research by 2015: Annual report of progress" DH May 2013

Innovations in Dementia (IID) was commissioned by Age UK as part of the Department of Health Strategic Partners Programme in August 2012 to work with fifteen local Age UKs to support them in making their mainstream services more accessible to people with dementia. The intended outputs of the project were:

- to involve people with dementia and carers in looking at current services and what could change to make them more accessible
- to develop an action plan for those changes
- to share action plans and other good practice
- to collate findings and produce a report appropriate for the wider Voluntary and Community Sector, including Dementia Action Alliance members

Participating local Age UKs

15 local Age UKs participated in the first round:

• Coventry	• Blackburn with Darwen
• Solihull	• Blackpool
• Doncaster	• Lancashire
• West Cumbria	• Norfolk
• East London	• Calderdale and Kirklees
• Wigan	• North Tyneside
• Gloucestershire	• Wirral
• Isle of Wight	

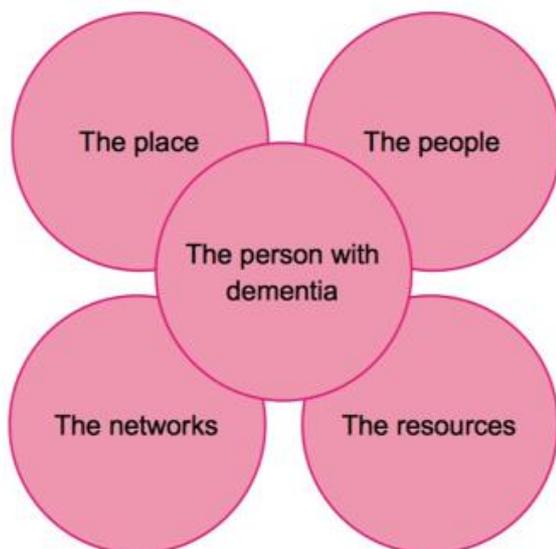
The Project

Initial meetings in London

In September 2012, participating local Age UKs attended meetings in London to meet each other and the consultant, and to share existing practice and ideas for making mainstream services more accessible to people with dementia.

Initial service audits - October to November 2012

Innovations in Dementia (IiD) visited each participating local Age UK and met with relevant staff to run through an initial audit of services, focusing on the extent to which they were accessible to people with dementia. We focused on five “domains” which our previous work had identified as being particularly relevant to the dementia-friendliness of organisations.



- The engagement of **people with dementia**, specifically the ways in which people with dementia had a say in the services being provided.
- **The Place** – Focusing on the physical environment in which services were delivered, as well as the accessibility of published materials to people with dementia.
- **The People** - Awareness about dementia among staff, volunteers, and in some cases, existing service users.
- **The Networks** - Local networks and partner organisations that may be able to support local Age UKs locally in making their services more accessible.
- **The Resources** - Internal resources that might be available to support the engagement of people with dementia in mainstream services.

Having discussed these domains, we then identified key areas for action and drew up action plans for each local Age UK.

Progress meetings - December 2012

Participating local Age UKs attended a second set of meetings at which we shared learning from the audits and discussed how the action plans were to be taken forward.

Delivery support - January to February 2013

Innovations in Dementia worked with participating local Age UKs providing additional support to enable them to implement or refine their action plans, including:

- Conducting an environmental audit of Age UK premises.
- Meeting with representatives of the Older People's Reference Group to help them make their meetings and processes more accessible to people with dementia.
- Delivering two-hour awareness sessions for staff and volunteers, including staff who will cascade the sessions to others.
- Meeting with staff to help refine their dementia training strategy
- Meeting with staff to help refine their action plan.
- Meeting with staff to help plan an engagement session with people with dementia.

Development meetings - February 2013

At the final meetings in London, participants shared their action plans, discussed learning from the project, and shared ideas for taking the work forward in the future.

Sharing resources and learning

In support of the project, a range of resources were created to support the rollout of action plans. These included:

- An environmental check-list
- Guidelines for consulting with people with dementia and carers
- A guide to producing dementia-friendly written material for people with dementia
- A help-pack for customer facing staff
- Guidelines for managers using the Social Care Institute for Excellence e-learning for staff and volunteers
- A two-hour awareness session for staff and volunteer induction

These resources can be downloaded at www.ageuk.org.uk/dementiafriendly.

What we learned

In our work with the fifteen local Age UKs we encountered a range of creative and innovative approaches to supporting people with dementia. However, most identified clear areas for improvement in the accessibility of mainstream services. Given the changing demographic, and the fact that people are being diagnosed with dementia at much earlier stages, this resonates very clearly with the potential of Age UK nationally to respond to the need to make our communities and organisations dementia-friendly.

Most people now being diagnosed with dementia will not need or want specialist services at the time they are diagnosed, they want to remain part of their communities, and Age UK is uniquely placed to make this happen.

The voice of people with dementia and their carers

The voices of people with dementia and their carers should be at the start and the heart of the process of creating dementia-friendly services. Finding out what people want and need from our services is vital.

Some Age UKs who participated in the first round set up engagement events and processes to seek the views of people with dementia.

Others worked in collaboration with strategic partners, this can be a good way of pooling resources and effort and of avoiding people feeling “over-consulted” on similar issues by different organisations.

Others worked to strengthen the capacity of other engagement fora for older people to include people with dementia.

Of course, hearing the voice of people with dementia is not just about one-off events. If you have ways in which service users make their feelings known and are included in decision-making then you can think about what you might do to make those processes as accessible as possible.

Consultation methods

There are a variety of ways of seeking the views of people with dementia. Some of them, like face to face interviews, questionnaires or small group work may already be familiar practice within your organisation.

Age UK Coventry conducted “walk the patch” exercises with people with dementia, who were able to offer a good insight into what it is like to navigate their buildings. Age UK Coventry found this process very effective and are now delivering a similar service to Coventry City Council:

For the people with dementia involved there was a real sense that they saw the process as important and valuable and with each person it was clear that their contributions were considered. In one case, a day centre member telephoned the worker from Age UK Coventry on the day following their visit as he had thought of something else he wished to raise and didn't want it to be missed, a clear indication of the significance of the process for the individuals involved.

Nichola Lavin, Age UK Coventry

However, you will need to make sure that whatever process you use is, in itself, as dementia-friendly as possible.

The resources listed below may be useful in deciding your approach, and making sure that it is as accessible as possible.

Resources

Innovations in Dementia (IiD) have produced a guide “finding out what a dementia friendly service means to people with dementia and carers” This can be found at:
www.ageuk.org.uk/dementiafriendly

The DEEP (Dementia Empowerment and Engagement Project) has produced a series of guides for organisations that want to improve their engagement with people with dementia. Of particular interest might be “Collecting the views of people with dementia” These can be found at: <http://dementiavoices.org.uk/resources/deep-guides/>

The Place

The physical aspects of a service from the environment to the written information, plays a key role in determining how accessible those services are to people with dementia.

In our research, people have told us that a physical environment which they can find their way around, in which they know where they are, and which makes them feel safe is a huge advantage.

We have found that relatively small changes can make a significant difference to people with dementia, often at no cost, or very little cost.

One local Age UK conducted an audit of four of their premises, using the checklist below, and has identified some significant improvements that can be made at very little cost.

Even where barriers exist which would be too costly to change, making staff and volunteers aware of the issue can be a big help. If they see a person who appears to be struggling as a result of the physical environment, they will be more understanding and better able to offer help.

Age UK West Cumbria offers a service to support people with dementia to make their own homes more dementia-friendly. This is delivered through its Dementia Assessors.

Resources

liD has produced a guide “Checklist for Dementia Friendly Environments”, and Age UK Coventry have compiled an audit report. Both resources can be downloaded from www.ageuk.org.uk/dementiafriendly

The Social Care Institute for Excellence has produced a comprehensive resource about dementia-friendly environments. This can be found at: <http://www.scie.org.uk/publications/dementia/dementia-friendly-environments/environment/index.asp>

Information

We also know that information which is poorly written or presented can be a major hurdle to people with dementia.

Many local Age UKs have used the guidelines below to audit and adapt their published information.

Resources

The DEEP (Dementia Empowerment and Engagement Project) has produced a series of guides for organisations that want to improve their engagement with people with dementia. Of particular interest might be “Writing dementia-friendly information” and “creating websites”

You can find these at <http://dementivoices.org.uk/resources/deep-guides/>

The People

Most Age UKs identified that resources could best be used to raise the level of dementia - awareness of their staff and volunteers. This chimed with earlier work with people with dementia who identified “the people” as the most important factor in determining whether a community, or organisation was dementia-friendly.

We learned that awareness-raising need not be resource-heavy but does need to be targeted at the right people. We worked with local Age UKs to produce matrices matching specific roles with existing training resources, so that the right people were targeted for training relevant to their role, making the training more effective.

“Give staff the confidence that they can support people with dementia”

Participating Age UK

People with dementia tell us that the most important feature of a dementia-friendly environment is the people with whom they came in to contact.

People make communities and organisations friendly.

It was clear from our early work with local Age UKs that it was not unusual for frontline staff to refer anyone with dementia to a specialist service or “dementia expert” as soon as they are told, or suspect the person has memory problems. This is not always appropriate as they might need a mainstream service like information and advice, and then have to be referred back by the specialist service. This situation is often frustrating for all concerned and it might result in that person never coming back to the service.

People always want to help, but the fear and stigma around dementia can mean that they are unsure of what to do or how to support them. There is a misconception that anyone with dementia will have very high levels of support needs and possibly challenging behaviour, and therefore needs “special” services.

“what was evident was that every call that came in from someone with dementia, it was always someone else’s job, and that wasn’t right. Everybody should be able to deal with whatever call comes in, it’s everybody’s job”

Age UK Blackpool

This is why awareness-raising for both volunteers and staff is so important; both to help people to understand how dementia affects people and what to do to help, and to dispel the commonly held myths and fears around dementia.

“there was a view in some people’s minds that working with people with dementia is a scary thing and the (training) film has helped them to realise that doesn't need to be the case. There is a lot that can and should be done to welcome people to use our mainstream services”

Age UK Blackpool

Perhaps unsurprisingly, most of the local Age UKs identified awareness-raising as a key priority.

However, it is important to note that training must be relevant to the particular role that staff and volunteers have in the organisation. A lot of existing training packages are designed for care staff and not only do these courses have a lot of information that mainstream staff don't need, they can be costly in both time and money and often focus on the needs of people at later stages of dementia. This can have the effect of actually reinforcing the view that all people with dementia have high levels of support needs.

liD identified an E-Learning course from the Social Care Institute of Excellence (SCIE) called **Open Dementia** as being a valuable and flexible resource as a starting-point for training and awareness-raising. It has seven modules, each of which can be completed in about half an hour. It is free-of charge, very high quality, and is values-based.

Many local Age UKs have supported staff and volunteers to take the Open Dementia course and feedback has been very positive.

There will of course be staff who might benefit from some additional training but the SCIE course provides a firm foundation of knowledge that should be suitable for most staff and volunteers working within mainstream services.

Resources:

The SCIE Open Dementia Programme can be found at <http://www.scie.org.uk/publications/elearning/dementia/index.asp>

We have also produced a guide for managers supporting learners through the SCIE course which can be downloaded from www.ageuk.org.uk/dementiafriendly

Alzheimer's Society has produced a basic “How to Help People with Dementia - a guide for Customer Facing Staff” - which can be downloaded from http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2497

Dementia Friends, this Alzheimer's Society initiative which aims to produce a million people with improved awareness of dementia by 2015. Information sessions are delivered by “Dementia Champions” who will in turn have been trained by Alzheimer's Society.

For more information about Dementia Friends, visit: <http://www.dementiafriends.org.uk>

Networks

“Most importantly - share your learning”

Participating Age UK

Many organisations recognise there is a need to become more dementia-friendly, including many voluntary sector organisations. By working with and supporting each other, you could be making a valuable contribution to helping the wider community become more dementia friendly as well as getting support and learning to apply to your own services.

Examples from this project of good networking, with the potential to result in better mainstream services and communities for people with dementia, include:

- Age UK Wigan worked with the Alzheimer’s Society on a joint engagement process aimed at finding out what people in the area need to live well with dementia. (and therefore what they can do in response).
- Age UK Blackburn are working with their local acute trust to provide volunteers to support people with dementia in mainstream hospital settings.
- Age UK East London and Age UK Wirral are working with local forums for older people, supporting them to make their processes and meetings more accessible to people with dementia.

Age UK is a member of the national Dementia Action Alliance, a partnership of commercial, statutory and voluntary organisations working together to improve services for people with dementia. In many areas, there are local Dementia Action Alliances which can be a valuable resource for networking, partnership working and sharing good practice.

Many Age UKs have been very active in their local Dementia Action Alliance, with some taking the lead role. One of the main areas of activity for local Dementia Action Alliances has been around the process of building dementia-friendly communities.

Resources

The National Dementia Action Alliance website has links to the local alliances :
http://www.dementiaaction.org.uk/local_alliances

A guide to creating a local alliance:

http://www.dementiaaction.org.uk/assets/0000/3986/Getting_Started.pdf

Making use of internal resources

“The bottom line is how to change people’s thinking across the organisation , the message is simple: if we are for all older people then we must be dementia- friendly”.

Participating Age UK

In this project, it became clear that many existing staff and volunteers already had experience of working people with dementia, either from personal or professional experience. Others had a strong interest in dementia and were keen to adapt to new approaches of working:

- Age UK North Tyneside screened all people with dementia currently using specialist services to identify if there were any mainstream services which might be suitable for them.
- Age UK West Cumbria are utilising specialist staff expertise and involving them in training mainstream staff and volunteers.
- Age UK Kirklees and Calderdale are training and supporting “dementia champions” to work with colleagues in each department and to speak up for the need to support people with dementia within mainstream services.

The importance of getting support from Trustees and senior management has been described by many Age UKs.

“This work needs buy-in from the organisation at a strategic level and corresponding authority”

Participating Age UK

“As a CEO, lead change like any other change management process, from the top, with monitoring, and keeping it going. Get the trustees on board”

Participating Age UK

Examples of ongoing work

“For Age UK Norfolk, this has been an amazing 12 months and we are working in a completely different way with people with dementia as well as with a range of new partners in the area. Looking at how we worked with people with dementia has given us the confidence, and the credibility to move ahead with our local partners.”

It’s been a huge learning curve, but thanks to this work, starting with meeting the other Age UKs and then working with the consultant, it gave us the boost we needed. It has gone really well”

Age UK Norfolk

Local Age UKs have taken a range of actions to make their mainstream services more accessible and responsive to people with dementia and to support them to maintain their connections with their interests and communities.

Most participating Age UKs started by rolling out training to staff and volunteers, and many audited their premises and written information. However, a lot of the work that has happened since has focused on building networks with local partners.

Age UK Blackburn with Darwen

Provided support to enable partner organisations to become more dementia-friendly through running training course in dementia. They have also developed their work using “dementia buddies” to open up access to both mainstream services and those of partner organisations, including walking groups. People with dementia told them that ‘one to one support’ is important in helping them to stay connected to their interests and communities.

Age UK Blackpool

Made a film with a service user with dementia, to use in training staff and volunteers. “David’s Story” was made with an existing service user and is focused on him going about his day, and only gradually revealing that he is doing so with a diagnosis of dementia. The response from staff and volunteers was very positive.

“What was evident was that every call that came in from someone with dementia, it was always someone else’s job and that wasn’t right. Everybody should be able to deal with whatever call comes in. There was a view in some people’s minds that working with people with dementia is a scary thing and the film has helped them to realise that doesn’t need to be the case. There is a lot we can and should do to welcome people to use our mainstream services. Why do we need to distinguish between people with dementia and everybody else,

it's an older person living with a condition so why don't we just treat them like everybody else and give them support relevant to their needs?"

Age UK Coventry

Began by conducting an audit of premises and written materials with the consultant. They ran "walk the patch" exercises with people with dementia who have been able to offer a good insight into what it is like to navigate their buildings. Age UK Coventry found this process so effective that they have been delivering a similar service to Coventry City Council.

Age UK Doncaster

Now raising awareness of dementia by offering Dementia Friends information sessions to local partners.

Age UK East London

Conducted a major review of all premises and written materials, and "handypersons" have been given new dementia-friendly uniforms with name badges.

Age UK Gloucestershire

Reviewed all buildings and published materials

Age UK Isle of Wight

Initially focused on making their Good Neighbour scheme dementia-friendly. In the last year Age UK Isle of Wight has also taken a lead on dementia-friendly communities, and have been working with a wide variety of partners, including the bus company, schools, churches, shops, libraries and GP surgeries.

Age UK Calderdale and Kirklees

Supporting dementia "champions" in each service and supported service users with dementia to speak out at local engagement events. Day Centre provision is now more accessible to people with early stage dementia, and dementia is now seen as less of a specialist area within the organisation. Involvement with the local Dementia Action Alliance has also raised the profile of Age UK as a provider of support through mainstream services in the area.

“At one time it was seen as very much a fringe activity, and that is changing. The work with Age UK added credibility and visibility to the need to be more inclusive within mainstream services”

Age UK Lancashire

Developed “circles of support” for people with dementia, as a way of supporting networks around the person to enable them to stay connected and build new connections with their communities.

“To date old friendships have been renewed, interests and hobbies restarted, new activities begun and friendships developed, both via peer support groups and through accessing other groups and activities. In addition, support is given to access local services, from shops to banks and the local pub and to ensure access to wider support services”

Age UK Norfolk

Began by producing a comprehensive training package for all staff and volunteers. Age UK Norfolk have been keen to share their learning with local partners and has taken the lead on building dementia-friendly communities. Not only does this have the potential to make local communities more accessible to people with dementia, but also provides Age UK with increased points of contact with older people:

“Age UK Norfolk sees local shops, businesses and organisations as a key route to developing Dementia Friendly Communities. Not only do local businesses and organisations deliver services on a daily basis throughout the community, they are also regularly-visited places that offer key information points where local people meet up and word spreads.”

Age UK Solihull

Began by making training mandatory for all new staff and volunteers. It has experienced a significant shift of focus on terms of its provision for people with dementia:

“Every one of our clients has an assessment whether they have dementia or not and it is about responding to that assessment and responding to what that person needs For example if someone comes to one of our clubs in a wheelchair and they can’t get in its because we haven’t made it accessible and the same applies to dementia.

We don’t want services just for people with dementia and we don’t want services that exclude people with dementia, we just have services. We put extra measures in place for

whatever is needed, like we do for all our people, so if someone likes to walk around we make sure we have a volunteer on hand who will go with them.

There is still a lot to do but as an organisation we are doing much better”

Age UK West Cumbria

Worked with people with dementia on a consultation event with the aim to make Cockermouth the first dementia-friendly town in the area.

Age UK Wigan

The consultant delivered three awareness-raising sessions for key staff and volunteers, who will then cascade the sessions to others in the organisation. They have also teamed up with the Alzheimer’s Society for engagement work with people with dementia.

Age UK Wirral

Has put in a large scale bid to completely remodel their communal areas, and is writing a “statement of rights for service users” to ensure that people with dementia are treated with dignity and respect.

We intend to continue to share and develop the best practice which is already taking place in local Age UKs, and to begin to incorporate and embed the work in Age UK nationally.

For more information about Age UK’s work on dementia please visit www.ageuk.org.uk/dementiafriendly