



Working to become
**Dementia
Friendly**
2014-2015

DAA

Newbury Dementia
Action Alliance

NEWBURY DEMENTIA FRIENDLY COMMUNITY END OF PROJECT REPORT

Sue Butterworth

September 2014

CONTENTS

Introduction & Background	Page 3
What is a Dementia Friendly Community	Page 4
The National Dementia Declaration	Page 4
Why the Project is important	Page 5
Statistics for West Berkshire	Page 5
The Consultation Process	Page 6
Consultation Feedback	Page 7
The Newbury Dementia Action Alliance	Page 9
Opportunities & Activities	Page 10
Conclusion & Recommendations	Page 13
Acknowledgements	Page 15
Appendix I – Signed Action Plans	
Appendix II – Action Plans in Progress	

Introduction & Background

The Newbury Dementia Friendly Community Project was commissioned by West Berkshire Council using funding successfully secured from the Prime Ministers Challenge on Dementia Fund and was hosted by the Alzheimer's Society. This was a one year fixed term project providing one member of staff working 17.5 hours per week. Similar projects ran simultaneously in Wokingham and Reading. In Newbury the Dementia Action Alliance Co ordinator was Sue Butterworth.

The objectives of the project were :

- to identify ways in which Newbury could become a more dementia friendly place to live and work in line with the National Dementia Declaration. (Appendix i)
- to conduct a consultation with people with dementia and their carers to establish local needs and opportunities
- to obtain 50 action plans for positive change from within the local business, service and public sector community
- to obtain working towards dementia friendly community status for 2014/2015
- to set up a local Dementia Action Alliance
- to host a public launch of the project
- to raise awareness of dementia amongst the local community
- to look at ways to sustain the project going forward

What is a Dementia Friendly Community

A dementia friendly community is a city, town or village where people with dementia are understood, respected and supported and are confident they can contribute to community life

The National Dementia Declaration

I have personal choice and control or influence over decisions about me

I know that services are designed around me and my needs

I have support that helps me live my life

I have the knowledge and know-how to get what I need

I live in an enabling and supportive environment where I feel valued and understood

I have a sense of belonging and of being valued as part of a family, community and civic life

I know there is research going on which delivers a better life for me now and hope for the future

Why this project is important

800,000 people are currently living with dementia in the UK

670,000 family & friends are acting as primary carers

500,000 with dementia are living in the community

One third of people with dementia live alone

77% of people with dementia feel anxious or depressed

67% of people with dementia do not always feel part of their community

44% of people with dementia feel they lost friends after they were diagnosed

The number of people living with dementia in the UK is expected to rise to 1,000,000 by 2021

West Berkshire Statistics

Estimated number of people currently diagnosed as living with dementia : **1267**

Current diagnosis rate for dementia : **48.7%**

Number of Social Service maintained dementia beds in care homes : **134**

Estimated cost of dementia care : **£5m**

(there are new statistics being released by the Alzheimer's Society on 10/9 so we need to decide if we should wait for these as they are likely to show a significant increase in those diagnosed)

Consultation

The objective of the consultation was to ensure that the project maintained people with dementia and their carers at the heart of its work, ensuring that this was a grass roots project that made a tangible difference to the lives of people living with dementia and their carers in Newbury

A variety of methods were used to gather information from people living with dementia, their families and carers in order to establish those things that they would like to see changed within their community.

Data Collection included :

- Discussions with users at Alzheimer's Society Service Groups
- One to one informal interviews with people with dementia and their carers
- Display stand and personal interaction with over 100 members of the public on World Mental Health Day at Newbury Hospital
- Presentations and discussions at the Carers Courses run by the Memory Clinic
- Participation at Carers Rights Day at Newbury Town Hall
- Discussion with the YPWD Empowerment Group
- Walks around Newbury Town Centre, The Memory Clinic, West Berkshire Community Hospital and the Corn Exchange with a person with dementia to give feedback on accessibility, facilities and environment
- Discussions and presentations with businesses to establish how they could contribute to a dementia friendly community

Feedback

Below is a summary of the feedbacks that were received.

- Road Safety

Uneven pavements are hazardous
Hard to see the kerbs
Not enough crossings

- Public Transport

Dementia awareness training for bus drivers,
More rural bus routes & frequent
Route maps at each bus stop

- Outside Environment

Colour coded street signs
Plenty of “you are here maps”
Public Toilet signs
More seating available for rest stops or waiting for people
Parking and pedestrian only access causing a problem for those with mobility and dementia
Dementia awareness training for parking attendant staff
Free blue badge parking available when you have to park in a non disabled space with your blue badge as all others are occupied.
Eye level signage of blue badge parking spaces

- Inside Environment

Shop aisles too narrow and cluttered
Education and awareness of dementia for retail and service staff
Hard to negotiate door ways
Too noisy
Coloured toilet seats and no mirrors on the back of toilet doors
Shiny floors can look like slippery ice or water
Black door mats can look like holes
Have “personal” help especially in the larger shops – someone to help them find things
Access to ground floor disabled toilets
A “slow” lane, trained & named staff
Bigger and more frequent signage (use pictures as well as words, make signs unambiguous (eg. 2 for 1)
DFC logo above till points serviced by a Dementia Friend
Priority seating and coloured crockery in small coffee shops

- GPs

To be better trained in dementia and hospitals to have more appointments available

Continuity of care by seeing the same GP / Practice Nurse for each visit

Offer a quiet waiting space / room away from the main reception area

Not to be rushed

The offer of double appointments

Diagnosis to be explained fully, slowly and respectfully

To be called by name, in person by the practitioner for appointments (automated announcements and flashing name alerts are either missed or cause concern and anxiety about where to go next

An acknowledgement that awareness and understanding are not the same thing

An understanding that everyone is an individual and their experience of dementia will be different

Not to be spoken down to / be patronised, especially by receptionists

Clear signage to toilets

Signposting to relevant Community Services and Charities

Receiving the same colour and shape of medication from the pharmacy in repeat prescriptions

- Awareness

Volunteers in the town to help

A local number to ring if you are worried about someone

Need for understanding, tolerance, patience and respect when in the town.

- Activities

Somewhere to go, something to do – drop-in dementia café in the town centre

Somewhere to meet other carers for peer support

Apprehension around walking to local shops 'Did I come this way?'. Solution is to memorise distinctive landmarks such as shop signs, large trees etc

Bank cards with no pin numbers to remember would be welcomed

Meeting up with friends for mutual support was considered very powerful

Newbury Dementia Action Alliance

The Newbury DAA was established in January 2014 and held its' first Steering Group Meeting on 17th January 2014. The group meets monthly and consists of the following members:

John Flynn – YPWD

Vicky Pocock – Carer for PWD and Parkinsons

Rachel Craggs – Crime Reduction Officer – Safer Communities Team

Rachel Johnson - West Berkshire Public Health and Wellbeing

Alison Love – West Berkshire Adult Social Care

Ian Taylor – RBFRS

Carol Brindley – Adult Mental Health Team WBFHT

Nettie Griffin – BID Group Street Ranger

Dominic Bartlett – BID Group Street Ranger

Mary Lesley Downey – Solicitor

Susan Gillespie – PCOS Thames Valley Police

Sue Butterworth – DAA Co ordinator

Working towards being a Dementia Friendly Community status was formally received on 11th March 2014.

Activities and Opportunities

The Dementia Action Alliance Co ordinator has carried out the following presentations and meetings to ensure delivery of the consultation feedback, raise dementia awareness and encourage participation in the dementia friendly community project.

- Newbury Town Council
- Newbury & District CCG
- St Georges Church Community
- Newbury Shop Safe
- The BID Group
- Public Forum Meeting
- The Pharmacy Group
- The Safer Communities Team – Newbury Police
- Thames Valley Public Health England
- Thames Valley Health Knowledge Team
- West Berkshire Volunteer Centre
- Empowering West Berkshire
- West Berkshire Disability Alliance
- Richard Benyon MP

In addition the DAA Co ordinator was invited to and participated in :

Trading Standards SCAM discussion forum

Social Care Public Account

Carers Rights Day

The West Berkshire Pop Up Shop

Thames Valley Health Knowledge Team – Public Forum on Dementia in West Berks

Opportunities that arose from the project

Participation in the Libraries Post Card Project

Participation at the West Berkshire Pop Up Shop initiative

Readibus offer of transport within Newbury – now working with YPWD in Newbury

RBFRS - process for awareness raising of free fire home safety checks

Liaison with DWP visiting officer

Coin recognition chart and tips on dementia being distributed by Memory Clinic

Gardening Club invited to participate in Make a Difference Day – Holy brook

Participation in the Pensioners Fair 12/9 organised by Richard Benyon

Judge a memory box competition on National Care Home Day

Kennet Radio – half hour live interview

BBC Radio Berkshire – Drive time live interview & follow up pre recorded interview

Breeze radio – pre recorded interview

Multiple press releases in the Newbury Weekly News

Two media releases and call to action from MP Richard Benyon

Articles in the BID, Shopsafe, Disability Alliance & Street Pastors Newsletters

Dementia Presentation & Q&A session at the Thames Valley Knowledge Dementia Event

Village Agents signposting to services and updating village noticeboards with dementia information

Production of “Communications tips for dementia” card – funded by West Berks Public Health & Wellbeing

New Memory Café facility at Corn Exchange

Arts for the Elderly at the Corn Exchange

Reminiscence Group at the Newbury Museum

Possible “Men’s Group” joint initiative between YPWD/Beechcroft Memory Clinic/Alzheimer’s Society

Activities/Courses for People with Dementia during college holidays from Newbury College

4 Dementia Champions Trained – 5 more investigating dates to train

Over 100 known new dementia friends with in excess of that number again in future planned sessions excluding Veilola who plan to make all 200 collection operatives
Dementia Friends

Conclusion & Recommendations

This has been an exciting year for the project resulting in a greatly increased awareness and understanding of dementia in the local community along with lots of positive outcomes in the goal of making Newbury a more dementia friendly place to live and work. At the onset of the project it was acknowledged that the objectives were very ambitious considering that this was an entirely new initiative which was only commissioned to run for 12 months on a part time basis. This timeframe also had to include the induction and training of the Dementia Action Alliance Co ordinator

The work that has been done in West Berkshire over the past year has evolved from the initial scope of the project due to demand from the wider community and the opportunities that have subsequently arisen. There have been positive changes to the way in which individuals and organisations network together in Newbury, sharing ideas, best practice and awareness raising opportunities for the good of the larger community. As with any new initiative it takes considerable time to new build effective working relationships within a community. This is especially the case when introducing a completely new concept that had not previously been considered by many of those approached to participate. Moving forward it would seem very important that the relationships that have been established are not only maintained but enhanced.

The project has highlighted that there is a need and benefit for having a dedicated Dementia Ambassador for West Berkshire. Having someone in this role on an ongoing rather than project limited basis would allow the community to ensure the continuation of the work that has been achieved by the initial project and also take forward the ideas and opportunities that it is identifying. It has taken time to build momentum for this initiative and the Newbury DAA Co ordinator is now being approached about new ideas and offers of support for a Dementia Friendly Community.

The establishment of a memory café by the Corn Exchange and a reminiscence group by the Museum are two examples of great tangible outcomes of the project that will directly benefit those living with dementia and their carers in their community. By supporting these establishments in their dementia awareness and development of action plans, the Newbury DAA has shown that our community is willing to work to deliver support and services that are not going to have a cost to the Public or Charity sectors. There are also a number of exciting initiatives identified on signed action plans that need to be followed up and developed further. It is very important that a way is identified of capitalising on the goodwill and commitment of local businesses and services and that those who are looking to develop services and make changes to their environments are encouraged and feel supported and receive the tools that they need in terms of training and understanding of dementia.

It would be useful to consider the formation of a working forum of interested parties from organisations in Newbury that in some way support people with dementia and carers. The project has highlighted that there are a good number of organisations and individuals in the area who are working on initiatives that in a variety of ways support those living with dementia and also their carers. At present these groups do not appear to meet to exchange ideas and plans and there would seem to be areas where initiatives overlap. In these situations the sharing of ideas and resources could not only reduce costs and relieve time and manpower pressures but would also allow for growth of new ideas and projects.

The restrictive time limitations of the DAA role has meant that at the end of the project period there are still action plans in progress that will require continued input and support to ensure that they are signed and become members of the Newbury DAA. In addition, as the DAA Co ordinator leaves it is important to consider the issues of Public Liability Insurance, email address and telephone number for public access and the role of Chairperson for the Steering Group. The Steering Group is currently discussing ways in which the good work of the project could continue. In the absence of further funding for the project the Steering Group would be required to continue in an entirely voluntary capacity. Whilst the project is very important to the members and they very much want it to continue, there will undoubtedly be limits on their time and resources that will impact the momentum of the work.

The project remit was to confine the work to Newbury and for time and resource reasons it has not been possible to extend the work further afield. However there have been requests from the community and there is a considerable need to include Thatcham, Lambourn and Hungerford in the dementia friendly community work going forward. The number of people living with dementia in West Berkshire is ever increasing and the demographic of its population indicates that the support of people living with the condition in their community is going to be a growing challenge. The work of this project has been positive and effective but has really only touched the tip of the iceberg in terms of opportunities, potential and need.

It will be important for West Berkshire Council as commissioners of the project to be aware that the status of working towards being a dementia friendly community is reviewed and awarded annually. The review for Newbury will take place in March 2015 and it will need to show ongoing work and commitment to the initiative to maintain its status.

Acknowledgments

The success of this project has been made possible by the enthusiasm and commitment of the Newbury DAA team which has been generously supported by local businesses and services who support a common goal. Special thanks should be extended to the following businesses and organisations who have worked to support the Newbury DAA over the past 12 months :

The Corn Exchange
Newbury Museum
Newbury Library
Newbury College
McDonalds
Starbucks
YPWD
Rainbows Arts & Crafts
The Hands on Company
Newbury Singing for the Brain group
The Berkshire Healthcare NHS Foundation Trust & Beechcroft Memory Clinic
West Berkshire Public Health & Wellbeing
West Berkshire Adult Social Care
The Alzheimer's Society
The Safer Communities Partnership
The BID Street Rangers