

Living life with dementia

Local Age UK contributions to quality outcomes
for people living with dementia and their carers



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Document purpose	To support implementation of the National Dementia Strategy and A State of the Nation on dementia report and demonstrate the contribution of the Age UK network in this field.
Title	Living life with dementia Local Age UK contributions to quality outcomes for people living with dementia and their carers
Publication date	January 2011 – version 1 August 2014 – version 2
Target audience	Local government, commissioners, local Age UKs, voluntary sector and strategic partners.
Description	This document: <ul style="list-style-type: none"> • provides commissioners with clear and simple ideas for support and services that contribute to the nine key outcomes listed in the State of the Nation report • presents a range of services for people living with dementia and their carers that local Age UKs provide, often working in partnership with other organisations • quotes older people living with dementia and carers who are using these services, bringing to life the ways in which policy can be translated into positive, practical and life-changing action.
Contact	Copies of this document can be downloaded from www.ageuk.org.uk/dementiafriendly
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Acknowledgements	Many thanks to those local Age UKs and Age Concerns who have shared their service examples to illustrate their contributions. Many thanks to members of the Department of Health Strategic Partners Programme who offered timely and helpful contributions for the the original content and format of this report. Thank you also to colleagues in Age UK who were involved in the refresh of this publication, including Tom Gentry, Policy Adviser, Age UK, Rebecca Barnham, Project Manager, Age UK and David Terrace, Programme Manager – Prevention, Age UK This booklet is funded by the Department of Health as part of the Health and Care Voluntary Sector Strategic Partner Programme.

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Introduction

‘Thank you for treating me like an individual.’

The G8 dementia summit, held in London in December 2013 resulted in a commitment by leading nations to develop a cure or treatment for dementia by 2025.

Most of the coverage of the Summit was focused on the global commitment to dementia research. However, woven through the proceedings of the Summit itself were more personal stories of the impact that dementia can have on the individuals living with a diagnosis.

It is a measure of how far the dementia landscape has changed in the last ten years, that the Summit was opened by Peter Dunlop, a person living with a diagnosis of dementia.

In his address he said:

“I find it difficult to work out what the time is, and that’s particularly useful when I’m fishing ...as for the future, whilst there is no doubt there will be other hurdles, at the moment I am continuing to enjoy my life. I still drive and above all I am still fishing.”

This is powerful for a number of reasons.

Firstly, although it illustrates some of the challenges that dementia can bring, it also reminds us that with the right support, people with dementia can, and are living well with dementia. It reminds us that people with dementia retain skills, aspirations, a sense of humour and a desire to maintain their connection with the activities, places and people that give their lives meaning.

Nevertheless, developing dementia remains one of the great fears of people in later life. The sheer scale and associated narrative surrounding the expanding numbers of people being diagnosed makes it easy to overlook the individual stories of people who develop dementia and the carers, family and friends who support them. Dealing with day-to-day issues, such as paying bills or remembering hospital appointments, and continuing to pursue hobbies and interests can become challenges, sometimes seemingly insurmountable without some practical help and support. Dementia brings people into contact with various health and social care professionals and making your views and opinions known to those in authority does not come easily to everyone. At the same time, every experience of dementia is different, if ever there was a case for personalisation of services and support (and adopting a person-centred approach) it is in the field of dementia.

The decade leading up the Summit has been a time of intense change in the dementia landscape.



Three factors have been particularly significant in driving these changes.

Firstly, **increasing longevity** means that there are more people living with dementia. It is estimated that some 800,000 people have dementia in the UK and this figure looks likely to double in the next thirty years.¹ It is estimated that 21,000,000 people in the UK have a family member or close friend with dementia, so one way or another there will soon be very few people whose lives are not affected.

Secondly, dementia policy has been heavily focused on the need for a **timely diagnosis** of dementia, and there have been some improvements in many parts of the UK in the numbers of people getting a diagnosis at an earlier stage.

Until relatively recently, the majority of people getting a diagnosis of dementia had significant levels of impairment, and often needed high levels of support, simply because they were getting their diagnosis late in the disease process. This is changing quickly, and as Peter reminds us, many people receiving an earlier diagnosis of dementia are likely to have many years where they can remain relatively high-functioning and generally need lower level services.

Thirdly, not only are more people getting a diagnosis, and getting it earlier, but the **expectations** and **aspirations** of people now moving into later life are changing too. People are more likely to want to stay active, to stay connected to their lives and communities, and to have a say in decisions that affect their lives.

These three factors are having a significant impact on services, and the way they are delivered.

We know that services will have to change in order to deliver what people will want and need in the future. Services are commissioned on a case-by-case basis using mechanisms such as personal budgets; creating new challenges and opportunities for services providers.

¹ Dementia 2012: A National Challenge, Alzheimer's Society

Age UK's position

We also know that traditionally Age UK has supported people with dementia both through the provision of specialised dementia services and within mainstream community based services. However, the changes outlined earlier mean that there is a growing focus required on how mainstream services can develop to meet the changing needs of new cohorts of people living with dementia.

There will always be a need for specialist services, both for people with high levels of support needs and for diagnosis and post-diagnostic support. However, people with a timely diagnosis of dementia will be spending most of their time not within health or social care, nor within specialised services, but living in our communities and part of mainstream society.

Age UK is ideally and somewhat uniquely placed to support people with dementia to live good lives and stay connected to the people, places and activities in their communities through its mainstream services, including information and advice and a wide range of wellbeing services.

At Age UK we recognise the challenge of turning policy aspirations into practical reality. The aim of this guide is to shine a light on some of the ways that local Age UKs are making a difference to the lives of people living with dementia and their carers. Several of the services here show how people with dementia and carers are being supported to help themselves and each other.

As the Department of Health has highlighted, these services are integral to its priorities of early intervention and prevention of avoidable admission to hospital, or premature moves into care homes. We also recognise that only about one-third of people² with dementia live in care homes, and give examples of work that is being undertaken in partnership with care home staff to improve quality of life there.

We hope that these services and practical case studies highlighted here will inspire you to think about what is possible for people living with dementia and what needs to be put in place in your local community, to help people living with dementia and their carers to live the life they want to, and truly live well with dementia.

Pam Creaven

Services Director, Age UK



² Dementia 2012: A National Challenge, Alzheimer's Society

Background

The policy landscape and quality outcomes

This is by no means an exhaustive account of the various policy streams driving change in the field of dementia. Rather, it attempts to pull together the most relevant aspects of the landscape to indicate the direction of travel of dementia policy as well as highlighting those areas in which Age UK has the most potential to make a real difference to the lives of people living with dementia and their carers.

Living well with dementia – a national dementia strategy was published in February 2009 and focused on raising awareness of dementia, driving improvements in diagnosis, treatment and care.

The strategy was widely supported, though implementation was varied across the UK, and it was clear that more needed to be done.

The first edition of **‘Living Life with Dementia’** was published just over a year after the launch of the national dementia strategy.

The Prime Ministers Challenge was launched in 2012 and laid out ambitious plans to build upon the work of the dementia strategy. It recognised that while there had been progress since the launch of the dementia strategy, notably in the creation of dedicated memory services, reduction in the use of anti-psychotic medication, and the growth of the Dementia Action Alliance; that there remained much work to do. The Challenge itself focuses on three main areas:

- driving improvements in health and care
- creating dementia-friendly communities
- boosting dementia research.

For the purposes of this report, it is the first two of these priorities that are most relevant. It is perhaps the emphasis on the creation of dementia friendly communities that is the most marked change in direction of travel and a recognition that dementia requires a whole-society approach, and can no longer be considered wholly the domain of health and social care.

In May 2013, the Department of Health published **‘the Prime Minister’s Challenge on Dementia – Delivering major improvements in dementia care and research by 2015: Annual report of progress’**.

The report outlined areas where progress has been made, including:

Driving improvements in health and care:

- the aim of ensuring that two thirds of people with dementia have a diagnosis and appropriate post-diagnostic support by 2015
- new incentives for GPs and hospitals to risk-assess and diagnose dementia and provide better support for carers
- a recognition by NHS England of the key role of public health
- the launch of a “dementia care and support compact”
- a commitment by 230 NHS trusts to make their hospitals dementia-friendly.

The creation of dementia-friendly communities:

- the Dementia Friends initiative run by Alzheimer’s Society aims to create 1 million “dementia friends” by 2015
- over 50 communities working towards becoming dementia-friendly
- the creation of more than 20 local Dementia Action Alliances
- dementia education in more than 20 schools.

A few months later, 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.

A few months later, ahead of the G8 summit the Department of Health launched its landmark **‘State of the Nation report on Dementia Care and Support’**. The report highlights existing good practice, as well as areas for improvement in the field of dementia and casts a light on local and regional variations in the way that people with dementia are supported.

Also contained within the report was a revised and restated set of ‘quality outcomes’ for people with dementia, first mooted in The Department of Health’s revised implementation plan for the National Dementia Strategy.

We want a society where people with dementia can honestly say:

- I was diagnosed in a timely way
- I get the treatment and support, best for my dementia, and for my life
- I am treated with dignity and respect
- those around me and looking after me are well supported
- I feel included as part of society
- I know how to participate in research²
- I know what I can do to help myself and who else can help me
- I understand so I am able to make decisions
- I am confident my end of life wishes will be respected, I can expect a good death.

How is Age UK responding?

Age UK has been working on a number of fronts to respond to the challenges and opportunities presented by the new dementia landscape.

Membership of the Dementia Action Alliance

Led by Alzheimer's Society, the DAA has a membership of over 900 organisations from across the spectrum of health, social care, leisure and emergency services, and businesses from banks to pharmacists. All members have signed the National Dementia Declaration – a call to action across a range of domains. Members also lay out an annual action plan.

Age UK's position:

Age UK will work to influence the development of policy and services, nationally and locally, on how best to respond to the anticipated increase in the number of people living with dementia. We will support our partners in developing their services and sharing good practice, and will seek to find practical ways to make our own services more accessible to people with dementia and carers. We will offer training to those working in health and social care to improve their knowledge and skills in working with people with dementia, and we will continue to support high quality research into dementia and cognitive decline.

Supporting local partners to make their services more dementia-friendly

Since 2012, Age UK has been working with local Age UKs to help them to make their mainstream services more dementia-friendly.

This work is being driven largely by a recognition of the increased numbers of people with an earlier diagnosis of dementia who neither need, nor want specialist services.

Over time, it appeared that people in the very early stages dementia were often being incorrectly referred to specialist services, when in fact they were seeking access to mainstream services, with an understanding of dementia. For people in the early stages of dementia, mainstream services have enormous potential in supporting them to stay independent and maintain connections with their interests and community.

In 2012, 15 local Age UKs took part in a Dementia Friendly Communities programme, funded through the Department of Health Strategic Partners programme. The aim of the programme was for local partners to review their services around a number of key themes, and then provide ongoing support to develop action plans for improvement. They focused on:

- the extent to which the voice of people with dementia is heard within the organisation
- the accessibility of the environment in which services were delivered
- the accessibility of written and published information
- the level of dementia-awareness across staff and volunteer groups
- how they worked with local and regional strategic partners
- how they used their internal resources to support people to access mainstream services.

A report into the early stages of this work can be found at www.ageuk.org.uk/dementiafriendly

In 2013, a second cohort of 15 local Age UKs joined the programme and another 30 will join in Summer 2014. This new programme is funded by the Big Lottery Fund and will also focus upon the creation of new wellbeing services which are accessible to people with dementia; this will build on work from the previous Fit as a Fiddle programme.

Information and Advice guides

Age UK has recently produced two new guides on dementia:

Caring for someone with dementia takes carers through the dementia journey, from getting a diagnosis for the person they care for, to talking to family and friends, joining a carers group, accessing help and more. It looks at the practical things a carer can do – creating a safe and comfortable home, organising finances – as well as the practical and emotional help they can get. The guide touches on caring for someone with later stage dementia who may have challenging behaviour or need to move into a care home. Readers can use whichever sections are relevant to them now, and keep the guide for future reference.

Living with early-stage dementia is aimed at people who have been newly diagnosed with dementia at an early stage, and focuses on how they can live well with their condition. It looks at how to stay active, go on holiday, create a safe and comfortable home, and ways to stay independent. It also takes readers through the practical steps they can put in place now – such as writing a will, setting up a Power of Attorney, organising their finances – and lets them know about the help they can access.

The Disconnected Mind

The Disconnected Mind is a multi-disciplinary research project that aims to discover how our thinking skills change with age, and what we can do to protect our cognitive health in later life. The project is led by Professor Ian Deary at the University of Edinburgh and is funded by Age UK. The research is based on a cohort of people born in 1936 in Lothian, Scotland, who all sat an intelligence test in 1947, at the age of 11. Cohort members, now in their late 70s, undergo comprehensive cognitive and physical testing every three years. Allied to their childhood IQ data, this provides an invaluable and unusual resource for studying cognitive ageing across the life-course as well as during ageing itself. As the project progresses, some members of the cohort will develop dementia. This is, of course, unfortunate, but will provide opportunity to study the changes that lead to this condition.

Gifted Housing Service

Age UKs Gifted Housing Service is a unique service which provides a holistic property and care and support service to older home owners who give their property to the charity in their lifetimes; and then receive practical help and support with maintenance and with their care and support. The service employs care co-ordinators who get to know donors well and provide support from the point of the donation, when usually the donor is quite well, right through to the end of their lives. Gifted Housing uses the Contented Dementia approach to support people with dementia to stay living at home as long as possible. This approach focuses on generating contented feelings of well-being through connecting with pleasant and familiar memories from the past. Through sharing the approach with carers and relatives and friends, as well as other professionals, older people are supported to stay living independently at home much longer than might have been anticipated.

How local Age UK services help people with dementia to say:

- I was diagnosed in a timely way
- I get the treatment and support, best for my dementia, and for my life
- I am treated with dignity and respect
- those around me and looking after me are well supported
- I feel included as part of society
- I know how to participate in research
- I know what I can do to help myself and who else can help me
- I understand so I am able to make decisions
- I am confident my end of life wishes will be respected, I can expect a good death.

The case studies in this booklet demonstrate how local Age UK services and initiatives actively contribute towards achieving these quality outcomes.



1

‘I was diagnosed in a timely way.’
‘I get the treatment and support,
best for my dementia and for
my life.’

Timely information at all stages is key to enabling older people living with dementia to access their rightful benefits, appropriate services and opportunities for life-enhancing activities and support. Raising awareness of dementia across the spectrum of services and integrating them helps to break down the stigma of dementia and reduce the isolation of people living with dementia and their carers.

Mainstream information services have a huge role to play not only in providing post-diagnostic support but also in providing the information that people need to live their lives. Providing training for frontline and information staff and volunteers can help overcome some of the fears and misunderstandings that can lead to inappropriate referrals to specialised services where they are not needed:

‘Finding training that reflects a positive approach to supporting those with dementia and their carers has not been easy. Training can be very mechanical, focusing on the illness, types of dementia and behavioural problems. Age UK Solihull want their staff and volunteers to be inspired, to be positive, not to see a condition that is hopeless and a person that is helpless. We want to support individuals to help themselves, not to be passive but to challenge this illness that strikes fear into so many.’

Lucy Garratt

Head of Services, Age UK Solihull

Benefits and outcomes of local Age UK services include:

- providing information and advice about dementia
- providing information and advice to help in all other areas of life that affect older people, such as housing, benefits, transport and care issues.

1.1

Dementia Care and Advisory Service

Age UK Stafford and District

‘The centre is invaluable. Mum has stimulation and companionship, and I can relax at work knowing she is cared for.’

(A carer)

Age UK Stafford and District provides a dementia care service with day care facilities, an ‘at home’ sitting and personal care service, and a specialist advice and support group for people living with dementia and their carers.

The service operates from Monday to Saturday and has 30 places per day available in purpose-built accommodation. The service is available to anyone over 50 who has been diagnosed with dementia. Baths or showers, hairdressing and therapy are provided, as well as a range of activities including exercise, gardening, Wii sessions, dancing, outings and opportunities for having fun and a good time. The building has a number of areas so that activities and quiet areas, both inside and out, are available.

Contact details

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01785 60 70 60

Age UK Stafford and District
Bradbury House
Weston Road
Stafford ST16 3RS

1.2 Healthwise Age UK Hertfordshire

Healthwise helps to ensure that older people with depression and early dementia can continue to remain independent and to enjoy a healthy and happy life for as long as possible, through an enjoyable 10 week programme of healthy eating, gentle exercise, digital inclusion and social interaction.

Healthy eating sessions introduce older people to healthy foods that they may not have tried before. Gentle exercise helps strengthen muscles and creates that 'feel good' feeling. Through digital inclusion older people are able to get in touch with friends and family and learn interesting new skills. Social interaction by joining a local group helps prevent that feeling of loneliness and 'it's only happening to me'.

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Case Study

Frank and Joan

Frank contacted Age UK Hertfordshire and explained that his wife Joan had been diagnosed with dementia a year before. Frank explained that while Joan was making a good recovery from cancer surgery, she had become quite depressed, had lost interest in socialising and had become quite isolated. He also mentioned that at times Joan could become verbally aggressive with him and had in the past been violent towards him. Frank was struggling to cope, he was receiving support from local health services and from family but he felt that Joan really needed to socialise.

Frank was given the details of a Healthwise group that was due to start nearby. He was very keen although anxious that Joan would not want to come or participate in the activities. During the first session Frank was very chatty with the other members of the group but Joan remained fairly quiet. The session began with gentle seated exercises. Joan joined in along with the rest of the group, although she appeared quite hesitant.

Frank and Joan came to every session and as the weeks went on Joan became much more relaxed, she joined in with every activity and laughed more with every week that went by. Joan even brought in some paintings that she had done in the past to show the other members. Frank said that Joan looked forward to coming to the Healthwise group and that she would often talk

about the activities to her family. He said that she seemed much happier at home as well.

Frank and Joan have since become involved with other Age UK Hertfordshire Healthwise groups. During this time there has been a huge change in Joan from when she first started attending. She seems much more relaxed, less anxious and generally happier. Joan remembers a lot of what she has done in the sessions and Frank says that the decline in her dementia has slowed down; although she still has her bad days she generally has a lot more good days.



2

‘I am treated with dignity and respect.’

‘Those around me and looking after me are well supported.’

Opportunities for carers and people living with dementia, to network are vital in providing support, information and signposting. Many local Age UKs offer the opportunity to meet, share experiences, have a coffee and pick up useful information. They also provide a gateway to other Age UK services. Most local Age UKs provide information, support and breaks for carers across their dementia services.

Benefits and outcomes of local Age UK services include:

- providing carers with peer support and opportunities for socialising, pleasure and fun
- helping people living with dementia to take ownership (rather than being ‘done to’)
- providing services which are sensitive to a persons individual and cultural needs.

2.1

Dementia Daycare Centres

Age UK Blackburn and Darwen

Age UK Blackburn and Darwen run two day care centres: Spring Bank Court and Apna Ghar that offer daycare for mentally or physically frail older people, from Monday to Friday. Their daycare supports older people to continue living at home independently or with a carer. Transport to and from the centres using wheelchair accessible minibuses with trained escorts can be arranged.

The Spring Bank Court Centre is located within the Spring Bank Court Extra Care Sheltered Housing complex in Mill Hill, Blackburn. A freshly cooked meal is provided at lunchtime with all dietary needs catered for.

Apna Ghar has been designed to cater for specific cultural and religious needs and has a prayer room. Apna Ghar is located within Bangor Street Community Centre. A freshly cooked halal or vegetarian meal is provided at lunchtime made from food stocks purchased from local reputable halal suppliers.

A wide range of therapeutic and stimulating activities are on offer at both centres, including traditional games and handicrafts, armchair exercise, music sessions and entertainment. Trips and activities outside of the centres are also arranged. In addition there are personal care services such as bathing and hairdressing.

Access to the daycare centres is through referral from Blackburn with Darwen Borough Council’s Adult Services Department following an assessment of need, or by private contract.

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2.2

Dementia Support Service

Age UK Lancashire

‘It’s good because it makes him think, it makes him go out, whatever the weather, he’s got something to do and he’s a lot brighter afterwards, not as withdrawn. He has always been an outgoing person and that’s what he’s doing, meeting other people.’

(Wife and carer of an older person with dementia)

‘Can’t believe I managed that walk, I never thought I would’.

(Older person with dementia who used to enjoy walking and hasn’t been for a walk since a fall)

Age UK Lancashire’s Dementia Support Service provides people, who are experiencing the early stages of dementia or memory problems, with support to re-connect with their local communities, thereby increasing their independence and emotional resilience.

Working with partners across the statutory and voluntary sectors, Age UK Lancashire has developed this innovative person centred, step up, step down approach, building circles of support which enable and empower an individual.

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.

The service began by working in partnership with the local CCG and Adult Social Care to support people and their carers on discharge from a specialist local rehabilitation centre, following a stay in hospital.

It has rapidly expanded to include anyone in the community with memory problems, or diagnosed with early stage dementia, living in Lancaster and District.

Following initial assessment, which, if within the rehabilitation unit takes place on admission and is an opt out process; a personal support plan is developed followed by intensive support on a 1-1 basis with trained staff. As confidence increases a planned transfer to a trained volunteer takes place who will then continue to develop the circles of support with the individual, their family and carers, stepping down support following periodic review if required, but also stepping up support if need increases.

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2.3

Younger Dementia Group Workington

Age UK West Cumbria

‘I wish I could do this every day instead of being sat on my own!’

(Older person living with dementia, speaking after the group’s visit to a heavy horse centre)

This is a peer support group for younger people (under 70 years of age) living with dementia, and their carers. This service aims to identify and bring together these people into a peer support and social network group. Through this work Age UK West Cumbria is helping to build the confidence of people living with dementia and their carers, to help them get out into the community and to access information, advice and support. Providing practical tips about living with dementia and signposting other local services to them are an invaluable part of this service.

Regular attendees of the peer support and social network group receive a monthly bulletin with details of social activities, along with information about whether transport for each trip is provided. The bulletin also includes a summary of the last meeting, so that people who were not able to attend can keep up to date. The group, which meets monthly, is run by one Age UK staff member and supported by volunteers. This service receives referrals from the local Community Mental Health Team, Age UK West Cumbria’s other services and the Alzheimer’s Society. People with dementia and carers can also refer themselves to the service.

The service is part of a National Dementia Demonstrator Site Pilot and is funded by the Department of Health.

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3

‘I feel included as part of society.’ ‘I know how to participate in research.’

Many local Age UKs provide a range of daytime opportunities, both in people’s homes and in day centres, which enable people living with dementia and their carers to stay in touch with their local community. An important element of service provision is the opportunity to have fun and to enjoy a dance or an activity purely for its own sake.

People with dementia tell us that they want to stay connected to their lives, their interests and communities. They also tell us that following a diagnosis they often feel that they have little to offer, or lack opportunities to contribute to their communities or have a say in decisions that affect their lives.

In many areas local Age UKs are taking the lead in the creation of dementia-friendly communities, in recognition of the fact dementia needs a whole-community approach. Many have taken what they have learned from looking at the accessibility of their own mainstream services and are now working with local partners to share their experience and understanding of what people with dementia need to live well in their communities.

Benefits and outcomes of local Age UK services include:

- enabling carers to have a break from caring, thereby reducing their isolation
- providing opportunities for people with dementia to spend time doing activities and interests that are important to them
- supporting people with dementia to give something back to their communities and have a say in decisions that affect their lives
- providing leadership to strategic partners in the creation of communities in which it is easier to live well with dementia
- involving people with dementia as active participants in testing new ways of improving the accessibility of mainstream service.

3.1 Involving people with dementia Age UK Coventry

Age UK Coventry have been involving people with dementia, through gathering their views and ideas regarding how dementia friendly their Age UK public offices and shops are. They achieved this by developing a ‘walk the patch’ exercise, which combined a visit to each of their 5 public venues with one to one time with a person with dementia. During these visits people with dementia were asked questions and given prompts to help identify how they felt about each of the areas as they walked around and to highlight how they could be easier to navigate. The clients who took part enjoyed the activity and contributed many useful ideas, as well as highlighting some good practice which they felt made their interactions easier.

The results of the ‘walk the patch’ exercise, along with a dementia friendly audit helped form the basis of a series of actions to make each area more dementia friendly. The changes were often quite simple to implement and mainly focused on signage, lighting and colour.

Following this project, Coventry City Council tasked Age UK Coventry with ensuring people with dementia were fully involved in a local dementia friendly environments project, which aimed to improve the environments of 5 day centres and residential care settings across the city. A small team of staff and volunteers visited each of the venues to engage with the people with dementia who use or live in these settings, to gather their views and ideas about their environment.

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.

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3.2 Mainstream services

Age UK Solihull

‘Focus on the person and their needs, not a diagnosis or a label.’

Age UK Solihull have taken a different approach to how it provides services for all older people their families and carers. Over the past two years, their ethos has shifted to recognise and understand dementia but not let it define the person. Their view is simple: ‘focus on the person and their needs, not a diagnosis or a label’.

All services provided by Age UK Solihull are now regularly assessed to ensure they are accessible to all, irrespective of whether or not the individual has a mental or physical condition. Dementia specific services are not provided, indeed, recently the Carers Support Scheme, which was restricted to carers of those living with dementia, has been opened out to all carers of older people living with a long term condition. The aim is to ensure all services reflect the needs of the older population of Solihull and the illnesses they live with: they are inclusive of all.

They are keen to spread this message across Solihull and have organised a large event entitled: ‘Dementia Does Not Define Me’ in Solihull. Age UK Solihull’s staff and volunteers will be attending, plus 120 people living with and working in dementia. This event brings together some of the country’s most inspiring speakers and their aim is to ensure a lasting legacy for dementia support in Solihull.

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3.3 Creating Dementia Friendly Communities: Mary’s story

Age UK Isle of Wight

Mary has Alzheimer’s disease, and is a member of the Dementia Friendly Communities steering group for the Isle of Wight project being piloted in Ryde, Creating Dementia Friendly Communities.

Mary was a regular passenger on the Island’s Southern Vectis buses and had experienced sudden memory loss on two occasions, unable to recall where she was going. On the first occasion she was treated with respect, patience and understanding from the driver, which allowed her panic to subside, which then helped Mary to start recognising landmarks. Unfortunately on the second occasion she was hurried and when she tried to explain where she was going, she was told there was no such place and was made to feel very stupid. She was left embarrassed, feeling frightened and vulnerable, not knowing what to do next.

Mary would not use the bus after this latter experience. However, as part of the ‘Dementia Friendly Community’ work, Southern Vectis have been a strong partner working with Age UK Isle of Wight. As a direct result of Mary’s experience, they produced a series of ‘Safe Journey Cards’; the cards cover a range of issues including: ‘I am visually impaired’ ‘In case I fall’, ‘I have difficulty walking’, ‘I am hard of hearing’, ‘I have difficulty speaking’ and most pertinent to this project a card which says, ‘I have memory problems’.

Mary was issued one of the ‘Memory problem’ cards at the official launch of the Ryde pilot project.

Mary tried out the card. The driver immediately recognised it and went out of his way to ensure she knew where she was going. She said he couldn’t have done more for her, and as a result of this will continue to use the buses for as long as she is able.

Age UK Isle of Wight are working closely with Southern Vectis to ensure all staff are familiar with these cards and drivers are trained to effectively communicate with people who have dementia.

Until communities understand the problems which people with dementia face on a daily basis, these situations will happen again and the resultant loss of independence and self worth leads all too quickly to loneliness and depression.

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3.4 Living well with dementia

Age UK Norfolk

‘If we give a better service to people with dementia, then we give a better service to everyone.’

(David Disney, Chair, Wymondham Business Group)

Age UK Norfolk launched the first Dementia Friendly Community initiative in Norfolk in Wymondham, in partnership with the town’s Dementia Support Group in September 2013.

For a Dementia Friendly Community to be successful and sustainable it is vital that it develops through a consultative process that listens to the opinions of people with dementia and their carers, considers the needs and capacity of the community and encourages the community to take ownership of the initiative.

Local shops and business are important to the whole community, but especially to people with dementia and their carers. Loss of access to local shops and services has a significant impact on someone with dementia and can make it impossible for them to remain living at home.

Age UK Norfolk has developed an innovative dementia training package consisting of training workshops, a self-assessment audit tool for businesses and a Dementia-Friendly Community Toolkit that offers ongoing practical information and advice after the training.

Over 80 businesses, organisations and local people came together to support the launch of Wymondham’s Dementia Friendly Community initiative, hosted by the Town Mayor.

To date, Age UK Norfolk has delivered the training package to over 70 people including solicitors, café owners, day centre care workers, W.I. members, local independent retailers,

church groups, dementia support group volunteers and staff from the local bank.

The project continues to receive a lot of support from the community. Staff and volunteers from Wymondham Library also attended the training and the library created a booklist and set up a special collection of books concerning dementia to support families, friends, neighbours and other carers. ‘Reminiscence kits’ and ‘Pictures to Share’ books are also available to borrow free of charge.

The dementia support group have also made numerous changes to the physical surroundings of their meeting venue, for example, arranging new signage for the toilet facilities and new table coverings. The group has also reviewed the activities that they do.

Age UK Norfolk has gone on to work with Swaffham Town to develop the Dementia Friendly Community initiative there, which launched in December 2013 and is currently consulting with two other towns in Norfolk.

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3.5 Dementia Community Links

Age UK Lancashire

‘Thank you for treating me like an individual.’

(An older person living with dementia)

‘He really looks forward to these visits.’

(A carer)

Age UK Lancashire’s Dementia Community Links service provides people who are living with early/moderate stage dementia with support to continue to pursue their interests, maintain their independence and retain and develop their social contacts. The aim of the service is to enhance their quality of life and well-being, which can quickly become compromised if they are spending their time worrying about memory loss.

Examples of people’s experiences, as a result of accessing the service, include being able to continue to do gardening and grow vegetables, pursue golf and jogging, compile a life history to be shared and enjoyed with members of the family, and to leave the house for the first time in several months to visit a country café.

Dementia Community Links comprises of a Services Co-ordinator, Support Workers and an increasing number of volunteers.

Anyone living in the areas of Chorley and West Lancashire, with any form of suspected or diagnosed early/moderate stage dementia, including younger people with early onset dementia, can access this service.

Age UK Lancashire works closely with partners in the statutory and third sectors, including the Memory Assessment Service, local authority social workers and Alzheimer’s Society Dementia Advisers to deliver an innovative, effective and person-centred service.

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3.6 Dementia Day Centre Age UK Sheffield

Age UK Sheffield's Memory Lane service is open to older people living with memory loss, including those with a formal diagnosis of dementia.

It offers a friendly place for people to meet each other, chat and join in a variety of activities, entertainment and outings. These activities can help to slow down the rate of memory loss. Memory Lane is a safe environment giving peace of mind for both the older person and their carer.

It is an opportunity for companionship in a safe and supported environment.

Contact details

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Case Study

Gladys

Gladys's family were finding it increasingly difficult to cope with the symptoms of her dementia. Her husband, whose own mobility was becoming worse, found it easier to carry out most household chores himself rather than allow Gladys to help. As she has always been an independent person this reliance on other people was becoming increasingly frustrating for her and affecting her confidence, this added to the problems of caring for her.

After her family discussed these problems with the staff at Age UK Sheffield's day centre she attends, Gladys was encouraged to help support workers and volunteers with some of the day-to-day tasks around the centre.

As a result, Gladys began to feel she was able to contribute again and not just be looked after. Her confidence began to return as she felt she was helping to support the other members of the day centre. As a result, some of the home pressures lifted and her family felt more able to cope.



Martin

Until 3 years ago Martin was working as a Solicitor with his own business. He began having memory problems and was diagnosed with Alzheimer's. Over the last 12 months Martin's memory deteriorated significantly and his wife was struggling to cope on a day to day basis. Martin was offered a place at the day centre. He was reluctant to attend at first but with encouragement from his family and support from the staff has begun to enjoy his time spent at the day centre.

Staff discovered Martin used to enjoy photography and are supporting him to take photos in and around the day centre. Martin's attendance at the day centre ensures he is getting stimulation whilst his wife is getting the respite she needs to enable her to cope.



3.7 Parker Day Centre Age UK Enfield

The Parker Day Centre is for people with dementia and it operates in partnership with the Age UK Dementia Homecare Service. It is specifically for people aged 50+ with early memory problems through to advanced dementia and allows their carers time out for a break. The aims of the service are to: 'enable people with dementia to maintain their independence and continue living in the community with support and allow carers of people with dementia a choice of flexible breaks'

While at the Parker Centre clients can participate in a range of activities in a safe and stimulating friendly environment. The Parker Centre runs two groups, one has clients with early stages of dementia, and the second caters for a more mixed ability of clients with dementia. The Parker Centre is open Monday to Friday 8.30am to 6.00pm and Saturdays 9.00am to 3.00pm.

A cooked meal is prepared on the premises and is served at 12.45pm. Clients are welcome to tea and coffee at any time of the day. An evening meal is also provided for the client if needed.

Clients may attend between one and six days a week depending on their needs and circumstances. There is a dedicated transport service which is wheelchair accessible. All employees are highly trained and very experienced.

Clients are referred to the manager, who will assess their needs and complete a care plan. Referrals come from a variety of pathways, including:

- Adult Social Care/Older Peoples Mental Health Services
- Community Psychiatric Nurses and Community Mental Health Teams
- the Alzheimer's Society, via family referrals
- direct referral.

Flexible services can be tailored to meet individual needs through a combination of the Parker Centre and the Dementia Homecare Service.

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4

‘I know what I can do to help myself and who else can help me.’

‘I understand, so I am able to make decisions.’

Independent advocacy services are key to enabling people living with dementia, like any other older people, to have control over decisions affecting their day-to-day lives, and to be supported with decisions they choose to make.

Benefits and outcomes of local Age UK services include:

- supporting the person living with dementia and their carer to obtain their full rights and entitlements
- enabling people living with dementia and their carers to speak up for themselves and take action for themselves.

4.1

Dementia Support Service

Age UK Kensington & Chelsea

Age UK Kensington & Chelsea supports people living with dementia or memory difficulties, their friends and family. The service includes a one-to-one dementia support service, dementia volunteer befrienders, group support, outings and a Dementia Adviser who guides people through the process of diagnosis and helps them navigate the complex systems that people learning to live with dementia, and their carers, often face.

Their education and awareness raising work includes running sessions in the community, being an active part of the local Dementia Action Alliance and producing a Guide to Living with Dementia, giving an overview of services and support available locally.

The dementia support service helps more than 60 individuals each year through one-to-one support which can include visits to galleries, helping people to try new things as well as creative activities like playing music or dancing. The service is as individual as the clients themselves and its flexibility allows this to succeed. The dementia volunteer befrienders programme, matches volunteers with people with dementia for tasks which include: befriending and sorting out paperwork. They also deliver a part of the local Memory Service. The Dementia Adviser is a continuous point of contact for people with dementia and their carers from diagnosis until death.

Their group services include dementia cafés, outings, Exercise for the Mind, a young onset group, a men’s group and creative sessions. The group work combines support from specialist staff with support from volunteers. Groups encourage people to remain connected, focusing on the importance of social involvement for people living with dementia, not only because this can help maintain life skills, but also because it lets people see others coping and often encourages them to support their peers. They also run a regular carers support group, with sessions specifically around supporting someone with dementia.

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4.2 Dementia Adviser Service

Age UK Camden

Age UK Camden's Adviser Service is for older people diagnosed with dementia, or who are experiencing memory problems, living in the London Borough of Camden and family and friends who care for them.

The service aims to provide a single point of contact for information, advice, support and help with access to local services. Clients are visited at home by the Service Coordinator who helps them identify their needs and concerns, and advise on practical solutions. The Service Coordinator then prepares and agrees with clients an "Information Plan". This contains details of clients' needs along with practical solutions. Clients are referred or signposted to relevant local services about which information will be provided.

If required, the Service Coordinator matches clients with a Volunteer Adviser, who helps clients to understand the information they have been given, resolve any outstanding issues and access services they have been referred to. The Service Coordinator and Advisers liaise with professionals where necessary. Reviews are carried out periodically, when clients are contacted and given appropriate further information, advice and support.

The service can support people with memory problems and their carers, at many stages, including during the process of seeking a diagnosis; obtaining information about different types of dementia, what to expect and planning for the future. Also to provide support to cope with memory problems and other symptoms connected to dementia and to access services they may be unaware of.

The service also encourages clients to become more socially active through introducing them to local activity groups, improving their wellbeing and reducing their isolation. The aim is that clients become more confident through empowering them to choose what they need and make decisions about their lives.

The Volunteer Advisers who assist clients have been specifically selected and trained to work with people with dementia, and are supported in their role by the Service Coordinator. All the Age UK Camden Volunteer Adviser staff and volunteers are subject to an enhanced Criminal Records Bureau Check.

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Case Study

Mr A

'I feel my befriender is more honest with me than other people are where I live. I enjoy talking with him, we have interesting conversations.'

Mr A was extremely isolated, his remaining family had returned to Barbados. Mr A had problems with his memory, speech and communication. He had little contact with family and often grew upset during telephone conversations with his sister through frustration with communication.

The only regular contact Mr A had was with staff of the extra sheltered housing whose main job is to carry out practical and personal tasks. He had moved several times – into hospital, to nursing home, to extra sheltered housing and felt unsettled. His interests were in music, books, films and current affairs but had little opportunity to discuss these with others. His career was an IT technician and he has a laptop but now struggles to use it.



Befriending activities and positive outcomes

- Supporting Mr A to use his laptop to write letters to his sister in Barbados (at Mr A's request) – enabling Mr A to communicate with family, helping him to feel settled and connected to those who are special to him. Supporting Mr A to communicate via a means that he feels most comfortable and able.
- Supporting Mr A to feel empowered to suggest and initiate ideas for befriending activities. Supporting Mr A to connect to his profession in IT which enforces his identity and makes use of his skills.
- Supporting Mr A to talk about his challenges of moving home and with communication – assuring him that his voice is being heard and understood and that his opinions have meaning (this is especially poignant as Mr A had told volunteer that he does not feel listened to by his GP).
- Learning about Mr A's life history, interests, hobbies and skills – he had a document which recorded his life history and interests. He initiated the action of sharing this with the befriender and demonstrated pride in expressing his identity and views.
- Mr A and the befriender often listen to music during visits and engage in other meaningful social and stimulating activities such as going for walks or using the computer.
- Mr A also gave the befriender lessons on how to play the keyboard and his guitar which allowed Mr A to display his skills and knowledge and provided a teaching role.

5

‘I am confident my end-of-life wishes will be respected. I can expect a good death.’

Good-quality care provided by motivated and well-trained staff can transform day-to-day life for people living with dementia in care homes. Many local Age UKs work in partnership with the Alzheimer’s Society and other organisations to enrich the lives of people living with dementia in care homes, and to increase staff and volunteers’ skills and motivation.

Benefits and outcomes of local Age UK services include:

- supporting care home staff and volunteers to deliver personalised good-quality care that responds to individual needs, and to improve staff and volunteers’ motivation
- helping older people living with dementia in care homes to feel more sociable, optimistic and included.



5.1

Statutory Annual Residential Care Home Review Service

Age UK Oldham

Age UK Oldham is involved in a programme of work, commissioned by Oldham Social Services, which provides the annual monitoring and review process for those people living in residential care in the borough of Oldham. The work involves carrying out scheduled annual statutory reviews of care for individuals and supports the Local Authority Adult Services Safeguarding Team with unscheduled reviews which arise following public alerts or concerns raised regarding individual residents or care home practices.

Whilst carrying out individual care reviews, the team works closely with the resident, their families, care home staff, other agencies or professionals who may be involved in the resident's care e.g. district nursing team, community psychiatric nurses, GPs etc. which enables the review process to be more holistic, person centred and to provide the best possible outcomes for residents in care.

The review process continues to be a statutory requirement to protect and underpin the individual quality of care for individuals living in residential settings and Age UK Oldham follow the national regulatory framework for this process and continue to work alongside the local authority in line with policies and procedures associated with care practice.

The vast majority of the people living in care are suffering from a dementia type illness as a primary reason for needing 24 hour care and the remainder have a physical primary requirement and dementia as a secondary factor. The team have had extensive experience working with vulnerable people, particularly people with dementia. As Age UK Oldham are

an independent organisation, they have received very positive feedback that their contributions have led to improvements in the care review process, not just for residents themselves but their families and / or carers. Giving clients the opportunity to actively feed into the process and being involved in contributing to the outcomes and required actions and changes to the care plan reassures them that their voice is being heard. This joint approach helps to promote personal independence, individuality and encourages the development of new initiatives, which sometimes may feel outside the box, to enhance the well-being and daily life for residents.

Care providers have been responsive to the changes in the review system and have welcomed the Age UK independent status and support. Age UK Oldham have built good working partnerships with the providers over the years with other projects which include Choosing the Right Care, Advocacy Services, Home Not Away, Social Inclusion for People with Dementia and Life Story Work. They hope to maintain this with the development of the independent review and monitoring service whilst providing a safe and competent service for vulnerable people.

Age UK Oldham have been funded to carry out this work from April 2012, upto March 2015 and have a target to carry out around 500 scheduled residential reviews which includes completion of the NHS Continuing Health Care Checklist and 60 unscheduled safeguarding reviews per year. In addition to this, attendance and input into individual case conferences and taking part in specific safeguarding enquiries is often required. The team have regular management meetings and updates with the local authority statutory care management leads within the Adult Services Team and the Clinical Commissioning Group and have access to statutory training initiatives on offer for social care staff.

The service is stringently evaluated by senior management at Age UK Oldham and the local authority Procurement Department at quarterly intervals.

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5.2 The Redwood Respite Service Age UK West Sussex

The Redwood Respite Service is aimed at those living with dementia, who will be looked after by trained staff within a friendly and safe environment. The service is also set up to support relatives or friends caring for someone with dementia.

Once contact has been made with Age UK, clients will be invited to the Centre to meet the team and other members for an assessment and to see what activities are available. There is no time limit to this service; clients can attend as often or as little as their circumstances require and it could be for either a full or half day.

A range of activities are provided throughout the day, including bowls, gentle walking, outings, discussion groups or board/card games. Or there are also opportunities to just sit and relax. A two-course meal is provided and tea/coffee is served throughout the day. Door to door transport is also provided. There is an annual membership fee to attend this service.

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Case Study

Mrs Williams

Mrs Williams joined the Saturday Respite group following a referral from the Alzheimer's Society and Dr Begg, Consultant. Mrs Williams was diagnosed with Alzheimer's a few years ago and her condition has deteriorated considerably over this time.

Mr Williams, her husband, visited the Centre to enquire about the service as his wife was becoming increasingly hard to manage and she needs constant attention and interaction.

Mrs Williams came to the group along with her husband initially to have a cup of tea, have a look around and see how the service would suit her needs. Mrs Williams, a very soft natured caring lady, was adamant she was not staying, as she felt her husband would not return for her.

Mrs Williams stayed for a few hours on the first day while her husband went to the shops. In the meantime she was kept active and joined in our activities, but she constantly asked for her husband.

At the second session, Mrs Williams stayed for lunch, but then went home after as she was very agitated; Mr Williams was growing worried that she would not like the group at all.



Mrs Williams has since attended eight sessions between 10am and 5pm and Mr Williams is able to have his time on a Saturday for the activities he would like to continue with. Mr Williams, on his arrival at the end of the session is always rather shocked that his wife indeed has had a lovely day and has not asked after him. His relief is evident and constantly congratulates the staff on keeping his wife happy, entertained and more so, safe from harm.

Mrs Williams has begun to assist with table clearing, talking to other members, and has a lot in common with one of the other members. Mrs Williams is a Dr of Sciences and also a Director's Assistant of the Shakespeare Company. With this in mind, the staff are able to offer Mrs Williams time to talk, ask her questions and keep her memory of the past still fruitful in her mind.