

*Expert series*



***Living life  
with dementia***

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

<b>Document purpose</b>	To support implementation of the National Dementia Strategy.
<b>Title</b>	Living life with dementia: Local Age UK and Age Concern contributions to quality outcomes for people living with dementia and their carers.
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<b>Target audience</b>	Local government and NHS commissioners.
<b>Description</b>	<p>This document:</p> <ul style="list-style-type: none"> <li>• provides commissioners with clear and simple ideas for support and services that contribute to the nine key outcomes listed in the revised implementation plan</li> <li>• presents a range of services for people living with dementia and their carers that local Age UKs and Age Concerns provide, often working in partnership with other organisations</li> <li>• 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.</li> </ul>
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## Introduction

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# *‘Thank you for treating me like an individual.’*

(An older person living with dementia using Age Concern Lancashire’s flexible outreach service).

The number of people living with dementia in England is high and set to increase dramatically, in line with our ageing population. There are 750,000 people living with dementia in the UK now, and by 2025 there will be over 1 million.<sup>1</sup> The lives of almost every person will be touched by dementia.

Dementia is predominantly a disorder of later life, with both the incidence and prevalence of the illness increasing exponentially with age. But we know that dementia is neither an inevitable nor a natural consequence of ageing, and that there is significant scope to prevent some types of dementia. Nevertheless, developing dementia remains one of the great fears of people in later life and their families.

The sheer scale of the problem makes it easy to overlook the individual stories of people who develop dementia, their carers, family and friends. 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. 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.

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

<sup>1</sup> National Dementia Declaration, launched October 2010. Age UK is a signatory to the National Dementia Declaration, a sector-wide initiative involving a range of national organisations in the Dementia Action Alliance. This is led by the Alzheimer’s Society and supported by the Department of Health. As part of this initiative we have made a commitment to work in partnership and have published a plan of the action we will take to work towards the key aim of the Alliance – to transform quality of life for the millions of people affected by dementia.

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*The aim of this guide is to show just some of the ways that local Age UKs and Age Concerns are making a difference to the lives of people living with dementia and their carers.*

The National Dementia Strategy has received widespread support but there is variation in its implementation. At Age UK we recognise the challenge of turning policy aspirations into practical reality. The aim of this guide is to show just some of the ways that local Age UKs and Age Concerns 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. In particular, we focus on a wide range of community personal support services offering flexibility, support and enjoyment for older people living with dementia and their carers.

As the Department of Health has highlighted, these services are integral to its priorities of early intervention and prevention of inappropriate admission to hospital, or premature moves into care homes. We also recognise that about one-third of people with dementia do 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.

The service examples and case studies here reflect the key components of a genuine community personal support service. We hope that these services will inspire you to think about 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.



**Heléna Herklots**  
Services Director, Age UK

## **Background to quality outcomes and community personal support services**

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The Department of Health's (DH's) revised implementation plan for the National Dementia Strategy<sup>2</sup> (NDS) has, as a key priority, the improvement of outcomes for people living with dementia and their carers. Working in consultation with partner organisations, the DH has identified key outcomes which people living with dementia and their carers expect from health and social care services. These outcomes are still in development, in partnership with the Alzheimer's Society and people living with dementia and their carers.

Nine quality outcome statements are currently proposed which capture what people living with dementia and their carers have told the DH they aspire to:

*'Thank you for treating me like an individual.'*

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*'I was diagnosed early.'*

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*'I understand, so I make good decisions and provide for future decision-making.'*

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*'I get the treatment and support which are best for my dementia and my life.'*

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*'Those around me and looking after me are well supported.'*

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*'I am treated with dignity and respect.'*

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*'I know what I can do to help myself and who else can help me.'*

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*'I can enjoy life.'*

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*'I feel part of a community and I'm inspired to give something back.'*

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*'I am confident that my end-of-life wishes will be respected. I can expect a good death.'*

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<sup>2</sup> *Quality Outcomes for People with Dementia: Building on the work of the National Dementia Strategy* (2010). DH. 8 September 2010.

The Strategy also states that a comprehensive community personal support service is needed to underpin the key goals and would include:

- home care that is reliable, with staff who have been trained in dementia care
- flexibility to respond to changing needs, not determined by rigid time slots that prevent staff from working alongside people rather than doing things for them
- access to personalised social activity, short breaks and day services
- access to peer support networks
- access to expert patient and carer programmes
- responsiveness to crisis services
- access to supported housing that is inclusive of people with dementia
- respite care/breaks that provide valued and enjoyable experiences for people with dementia as well as their family carers.
- flexible and responsive respite care/breaks that can be provided in a variety of settings, including the home of the person with dementia
- independent advocacy service
- assistive technologies, such as telecare.

The service examples in this booklet demonstrate how local Age UK and Age Concern services actively contribute towards achieving these quality outcomes, and also illustrate the hallmarks of a genuine community personal support service.

The case study of Mary on the next page illustrates the complexity of one carer and her husband's needs on their journey of living with dementia. It demonstrates the flexibility of services they require to support them best on this journey.



## Dementia Support Service Age Concern Salford

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*Mary, 85, has been caring for her husband, aged 90, for a number of years. He has vascular dementia. Mary has no family in the local area and her situation means that she is not able to get out as much as she would like.*

Mary was isolated and was beginning to feel the strain of her caring role. After she had spent a short stay in hospital, it was felt that Mary could use some support and so a social worker referred her to Age Concern Salford's Dementia Support Services (DSS).

The service was able to provide her with a named support worker who has built up a relationship with her and continues to support her in a number of ways, including providing information and emotional and practical support, as well as referral-making, liaising with other services, and facilitating social support.

Because of the deteriorating condition of Mary's husband, Mary has an ever-changing number of issues and concerns that she talks through with her support worker on a regular basis, either on the phone, when her support worker visits her, or on a trip out. This emotional support boosts her as she is able to discuss all her issues with somebody outside of the family but who knows her situation. Practically, her support worker will sometimes offer to give her a lift to a hospital appointment, take her shopping for essentials, or even just post some important letters if she is unable to leave the house.

Recently it became apparent that Mary would benefit from having regular breaks as she was becoming exhausted and

over-worked. Her support worker gave her information about her options and liaised with social services. Mary's husband was, initially, reluctant to accept going to a day care centre, so Mary's support worker took him to show him around and introduce him to other service users. This lessened his anxiety and he now goes twice a week. Mary's support worker also registered her with Crossroads, a sitting service for her husband, so that she could go to church twice a month and maintain her social contact there.

When Mary's husband was admitted to hospital in an emergency, the support worker liaised with the medical teams involved to ensure that all relevant services (speech therapy, occupational therapy, physiotherapy, continence team, Memory Assessment and Treatment Service, and social services for home care) would be in place when he came home.

Mary was feeling isolated and felt she knew no one in a similar situation when she was first referred to this service. Her support worker encouraged her to go to a number of different events, including carers' days, coffee mornings, the allotment and on trips out. Mary and her husband have been able to meet other couples and either chat socially or share with each other the issues they may have. Mary always feels good after these events and says they really 'bump up her spirits'.

Dementia Support Services continues to support Mary in her situation and encourages her in the excellent job she does, hoping to be able to offer her all the support she needs throughout her caring journey.



# *Service examples addressing quality outcomes*

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This section has divided the nine NDS quality outcomes into five groups. Relevant services offered by local Age UKs and Age Concerns are featured in each grouping.

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**1** *'I was diagnosed early.'*

*'I get the treatment and support which are best for my dementia and my life.'*

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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.

Benefits and outcomes of Age UK/Age Concern 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.
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## ***Dementia Care and Advisory Service***

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### **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 Concern 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.

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# Dementia Advisory Service

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## Age Concern Havering

*'I wish I had someone who really understood what it is like to be caring for a person with dementia. I looked after my husband for several years and found that our friends started to stay away. This service is really excellent and is a way to help a family through a difficult phase of their lives.'* (A carer)

The need for this service was identified by carers and offers information, advice and ongoing support, and signposts services to people living with dementia and their carers. Personalised and tailored support is provided to older people affected by dementia along their whole journey – from initial diagnosis right through to support after their death – and also deals with the impact of carer and family bereavement.

Information and advice – as well as ongoing support – is provided to anyone who has been diagnosed with dementia, as well as their families and their carers and those people who may have dementia but have not yet been diagnosed. Appointments are made via a drop-in centre. Home visits, phone calls and drop-in sessions are offered, and also a library of materials stocking internet sources, videos, books and leaflets. The team attends the Older Persons' Community Mental Health Team Disciplinary meetings and provides information, advice and support at the Memory Service clinics.

A quarterly newsletter with information, useful ideas and updates on services is distributed to carers, GPs, health and social services, libraries and other agencies and organisations. The outreach co-ordinator for this service also delivers talks and training on dementia and dementia-related topics to professional and community groups, nursing or residential homes and hospitals. The carer support and information groups meet three times a month to provide an opportunity for carers to meet each other in small groups, to socialise, to hear from informative speakers and to benefit from peer support. Training on dementia and related topics is provided to care homes.

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# 2 *'I am treated with dignity and respect.'*

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

Benefits and outcomes of Age UK/Age Concern 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').
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## Demenshare

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### Age UK Cheshire

A woman caring for her husband and a user of the Demenshare website asked in one of the various discussion groups about a local Men in Sheds project. She was looking for somewhere that her husband could attend (he has early to moderate dementia), while she attended a local carers' training event. Members in the discussion group soon identified a local resource that met her needs and so she was able to attend the event. She has now made new links with another network for the future.

Demenshare.com is an online, peer-support network for people who are living with dementia in Cheshire East. This website resource is aimed at anyone who has been affected by dementia. People with a diagnosis, carers, family and friends, and professionals can access the website 24-hours a day. It is run as a partnership between Age UK Cheshire, Cheshire East Council, Central and Eastern Cheshire PCT and Opportunity Links.

This peer support network enables individuals and agencies to share stories and experiences online, and to build virtual and other types of peer support that reflect personal choices and interests. It also enables people to look for local solutions to their problems. Information and support is readily available for people affected by dementia at the times when they most need support. Age UK Cheshire is finding that users go online quite late in the evening, indicating that this is often the most appropriate time for many carers to research and connect, and often the time in the day when the need for support and networks is most acute. Demenshare's new and innovative approach also helps to reduce stigma by increasing awareness of dementia locally through discussion boards on the website. The service provides low-cost peer support opportunities for people with dementia and their carers, and increasing engagement with public services including GPs. This in turn provides commissioners and decision makers with important customer insight information.

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## Peer Support Networks Stockport

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### Age Concern Stockport

*'The friendships that have been established through this group are getting stronger each week.'* (A staff member)

Age Concern Stockport offers user-led peer support for people living with dementia and their carers, families, and post carers. The Peer Support Networks Stockport project aims to help put people in similar circumstances and with similar interests in touch with each other. The Network can also help set up new social or activity groups for people. Stockport is a Demonstrator Site<sup>3</sup> for the Department of Health's National Dementia Strategy and is running three strands of peer support in the area. Age Concern Stockport is running the strand on user-led peer support in partnership with the Alzheimer's Society, Pennine Care NHS Trust, the community mental health team and Stockport dementia training services, who have provided support staff with training in working with people with dementia. Stockport Metropolitan Borough Council has assisted the project with promotion and publicity of services.

Age Concern Stockport offers support in the form of local group activities which are easy to access and which offer a familiar community environment instead of a clinical setting. For example, the service offers walks in local parks for people with dementia and their carers in areas where there is currently little or no provision of services. Age Concern Stockport also carries out awareness-raising sessions with local Muslim organisations and is helping to establish user-led peer support services within the Muslim community.

A partnership with St Mary's church in Cheadle has enabled Age Concern Stockport to establish a friendship club for people living with dementia and their carers. Church volunteers help at the club and have made use of a newly refurbished room that is available. The club offers activities such as table tennis, indoor bowling, table football, and Nintendo Wii and a variety of table games.

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<sup>3</sup> Living Well with Dementia – A national dementia strategy: demonstrator site programme. Demonstrator sites identify and share the lessons they have learnt with other sites within the programme and with the Department of Health, to enable rapid dissemination to other local authorities, PCTs and third sector organisations within the wider health and social care community. The two service models being tested are Dementia Adviser Services and Peer Support Networks, with pilot funding for these until March 2011.

## Singing Group – Age Concern Stockport

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*From consultation work that we carried out, it was clear that there was little, if any, service offered to people in some areas of the borough. One group activity that was highlighted as lacking but that people wanted to participate in was a singing group.*

We managed to locate a central community environment for the group to meet in, to book a singer/piano player to lead the group, and also trialled the group throughout July for three weeks. The singing group started with seven participants and by the end of the three weeks had grown to ten.

At the end of the three weeks we asked the group for their evaluation. Everyone said how much they had enjoyed the group and wanted it to carry on. It was explained that if the group was to continue, it would have to be paid for in order to cover the running costs and would cost £3 a session per person. Everyone in the group was happy to pay.

The group was unable to meet at the venue throughout August because of maintenance work, so I suggested that the group meet at a local pub once over August so we didn't lose touch as a newly established support group. The group suggested that we meet up every week on the same day and same time at a local pub that offered a good meal deal. This arrangement continued throughout August and proved popular and the group increased to 13 people.

In September the singing recommenced at the Parish Rooms and every week we are seeing new people joining the group. The group has now grown to 28 members. The friendships that have been established through this group are getting stronger each week. Several of the couples who have become friends through the group have organised a holiday together and have been away together for a weekend break.

## **Younger Dementia Group Workington**

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### 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 two staff members and supported by one member of staff from the Alzheimer's Society. 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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## ***Pabulum Dementia Café***

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### **Age UK Norfolk**

*‘These events help him to maintain his independence. They also give me a chance to talk to other carers in the same situation. You get little tips on how to cope and what to do in certain circumstances.’ (A carer)*

Pabulum Café provides a space for people with dementia, their carers, family and professionals to come together to share experiences, offer support and learn from each other. Each month there are activities based on different reminiscence-themed subjects, such as fashions of the era, schooldays and washdays. The café is open to the public and has a friendly, welcoming environment, thus helping to reduce the stigma of dementia. The café also offers opportunities for people to form new friendships and find support networks, and offers carers help with organising respite. Information about the medical aspects of dementia and changes in behaviour often associated with dementia is provided by inviting professionals to the café.

There are four café venues in Norfolk, three of which operate monthly and the other twice monthly. Pabulum Café is open for two to three hours each morning and structured to engage people in reminiscence and activity, to encourage as much interaction and memory stimulation as possible. At all sessions carers can choose to stay with the people they care for throughout the session, or to spend time separately with other carers. Referrals are not required. The cafés are staffed with one paid co-ordinator and up to 12 trained volunteers.

#### **Contact details**

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Old Catton  
Norwich  
Norfolk NR6 7BJ

**3** *'I feel part of a community and I'm inspired to give something back.'*

*'I can enjoy life.'*

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Many local Age UKs and Age Concerns 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.

Benefits and outcomes of Age UK/Age Concern 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.
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## **Dementia Support Services (DSS)**

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### Age Concern Salford

*'If it wasn't for my support worker,  
I think I would have given up.'* (A carer)

DSS provides information, advice and support to people who have dementia and their family and carers. This is offered individually through home visits or drop-ins, and through carers' training and peer-support groups. DSS also runs a Buddy Service, which provides social and activity groups for people with early-stage dementia. It is also currently running a National Demonstrator Site project offering peer support and learning groups for people with dementia. This latter project (called Friends For Life with Dementia) is located across the eight neighbourhoods of Salford so that people can easily access groups and, where possible, be linked in with other mainstream activities in their neighbourhood. The service is jointly commissioned by Salford Council and Salford PCT.

These services all provide interventions that delay moves into residential care, help to keep people living with dementia and their carers active, and prevent social isolation and depression. Use of peer support increases the capacity of services and most importantly encourages carers and people living with dementia to shape and contribute to service development.

The services cover the local authority area of Salford. Age Concern Salford can support carers of anyone who has dementia and will accept any referral from someone who has been diagnosed with dementia or from their carer. Age Concern Salford will also provide general advice to someone who has not yet been diagnosed. The service works closely with the local Memory Assessment Treatment Services team, Carers Centre, Integrated Care teams and the local dementia resource centre.

#### **Contact details**

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## **The Withy Trees Day Support**

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### Age Concern Central Lancashire

*'It's nice to get out and (it) gives me something to do.'*

(Older person living with dementia)

The Withy Trees Day Support service provides specialist care and support for older people who have physical or mental frailty and are living in the Preston district. The service has been developed to reflect the needs and capabilities of each older person living with dementia who attends the centre, and also responds to the needs of carers by offering respite, information and advice, and emotional support. An individual care plan is agreed between each person living with dementia and their carer, and support staff member, and takes into account the aspirations, dietary requirements, physical and mental capabilities, hobbies and interests of the person living with dementia.

The service enables carers to access support and help with day-to-day tasks when caring for the person living with dementia and ensures that there is a smooth transition from home to day care for the person living with dementia. Carers can access respite at short notice and family members are encouraged to ask questions of the care worker to help them understand dementia and its impact.

An outreach service is also available from Monday to Friday between 8.00am and 8.00pm, which provides additional support in the cared-for person's home.

#### **Contact details**

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## Outreach Worker Scheme

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### Age Concern Kensington and Chelsea

*'Enjoyed it very much. Would like to come again!'*

(An older person living with dementia)

Age Concern Kensington and Chelsea employs a small team of trained outreach workers to visit people living with dementia in their own homes and to support them to take part in stimulating activities, either at home or out in the community. They also arrange group activities and signpost other appropriate services to individuals and their families or carers.

The Outreach Workers Scheme is funded by the Royal Borough of Kensington and Chelsea Social Services and the Primary Care Trust. It offers an alternative for older people who are living with dementia in the borough, who may not be helped by group activities but who would get more out of taking up a hobby or activity that they used to enjoy. The focus of the service is on the person living with dementia, but there are also plus points for their families and partners, who might benefit from respite, from having other services signposted to them, or from just seeing the person they care for in a happier mood.

Age Concern Kensington and Chelsea receives regular referrals from social workers, Admiral nurses and other health professionals and self referrals. The service reaches approximately 60 people a year and is for older people with, or without, a formal diagnosis of dementia, but who may have problems with their memory, social functioning and their family or other carers.

#### **Contact details**

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## **Flexible Outreach Service**

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### Age Concern 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 Concern Lancashire's Flexible Outreach Service provides people who are experiencing the early stages of dementia with the 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 seven months to visit a country café.

The Flexible Outreach Service has a services co-ordinator and eight part-time support workers, plus a small number of volunteers who also provide one-to-one support. Anyone living in Chorley and West Lancashire with any form of suspected or diagnosed early-stage dementia, including younger people with early onset dementia, can access this service. Age Concern 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 imaginative, effective and person-centred service.

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## **Dementia Day Centres**

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### Age Concern Sheffield

*'A welcome light to help my husband and myself to have some time away from each other.'* (A carer)

Two of Age Concern Sheffield's centres cater specifically for older people who live with mild to moderate dementia. Activities at these centres are designed to provide mental and physical stimulation and to slow down the rate of cognitive decline through reminiscence, quizzes and daily living skills such as setting the table and washing up. Other activities include yoga, singing, cooking, birthday celebrations, gentle exercise and trips out. Staff have a good understanding of individual older people's preferences, needs and wishes. The centres provide social contact and stimulation for people living with dementia, offer low-level support for older people at risk, and help to maintain and promote independence. For example, advice on safety at home, aids and adaptations is provided. The service also enables the care and monitoring of very frail and vulnerable older people.

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## Dementia Day Centre – Age Concern Sheffield

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### Case study A

*Bill is 87 and has dementia. Three years ago he was referred to an Age Concern Sheffield dementia day centre to give his wife a break, after an attempt at respite care away from home left him extremely disorientated and upset.*

Initially Bill attended for just one day a week, but last year when his wife's own ill-health was further exacerbated by shingles, this was increased to three days. He has settled well into the centre, particularly enjoying art and craft activities, and his wife reports that he is more alert, less confused and less verbally aggressive.

The day centre has made it possible for Bill and his wife to remain together at home, for the time being at least, which is what both of them wanted.<sup>3</sup>

### Case study B

*Mr A has Parkinson's disease and has been diagnosed with dementia. His wife is his carer.*

Prior to his illness, Mr A and his wife had enjoyed an active social life, but the strain of caring for her husband and the impact that this had on their ability to socialise was causing stress for both of them. A referral was made to Age Concern Sheffield for a day care place at a dementia day centre.

Mr A enjoyed his time at the day centre and it provided respite for Mrs A from her caring role. Mr and Mrs A approached Age Concern again to request a further day at the day centre so that Mrs A could take part in a valued social activity.

Mrs A recently commented that the day care has been 'a welcome light to help my husband and myself to have some time away from each other'. Mr A 'enjoys the different environments and the company of both staff and fellow visitors'.





## Time Out Service

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### Age Concern Enfield

*'The ladies that come here give her a lovely time. That's what I need to know – that she is well cared for and happy.'* (A carer)

This service provides home-based respite for carers of people living with dementia. Trained care staff look after the older person and provide interesting and stimulating activities, while the carer takes a break. Every effort is made to ensure that staff work with the same person so that routine and stability for that person living with dementia is ensured. The service provides a gateway to use of the day centre facility.

The service is open from 9.00am to 6.00pm to help working carers. Staff visit people's homes for between two and four hours during the day or night, providing the flexibility to meet individual needs. They also have a group that is self-directed, which facilitates people with early-stage dementia. People who have greater needs and who are living with later stages of dementia usually meet separately to the early-stage dementia group. People using the Parker Centre enjoy a freshly cooked meal and evening tea, as well as activities throughout the day, including singing, crafts, quizzes, painting and gardening.

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

*‘I understand, so I make good decisions and provide for future decision-making.’*

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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 Age UK/Age Concern 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.
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# Dementia Advocacy Services

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## Age Concern Wirral

*'The service we received was really great and the advocate was very patient with the difficult task of dealing with our issue. He succeeded where I had failed after six months of trying to sort it out.'* (A carer)

This advocacy service is mainly for people with early onset dementia and their families. The service offers advocacy across a range of issues and situations, depending on the nature of the problem, and seeks agreement about the best course of action to take. The service enables people living with dementia and their carers to take control over making key decisions that affect daily life, such as finance, housing and care issues. When supporting people living with dementia who are unable to give consent, the advocate will ensure that any actions are taken with full consideration for the older person's preferences and values, and ensure that the person's rights are respected at all times.

A drop-in service is offered to see a dementia or family advocate. Age Concern Wirral runs clinics twice a week. After an initial meeting, the person living with dementia is able to choose which setting suits them best for further meetings. Dementia advocates support carers in making telephone calls, writing letters, providing support at meetings or appointments, and helping them to complete forms. Advocates also support self-advocacy in the earlier stages of dementia, which facilitates a good relationship in the later stages of dementia. During the course of an advocacy relationship, advocates will undertake all actions needed to achieve the required outcome, including negotiation and representation at all levels.

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## Camden Dementia Advocacy Service

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### Age Concern Camden

*'You gave me a voice.'* (A carer)

Older people living with dementia using Age Concern Camden's Dementia Advocacy Service have reported many positive changes in their lives as a result of being able to have a say in decisions affecting them. For example, an older woman living with Alzheimer's wanted to complain about her care package but was unable to do so because of her condition. The project co-ordinator spent time with her, and over several sessions was able to gather information on the issues and support her to complain to the local council about her care package. Twelve issues were upheld by the local commissioning manager and swift action was put in place to resolve the issues, enabling the older woman to feel more comfortable with her carers, and to have a better quality of life because of this.

The service is available to people aged 60+ with dementia, memory or cognitive impairments, who live in their own homes or in care homes and need an advocate. Awareness-raising sessions are held with members of local Latin American, Somali, Congolese and Asian communities to tackle stigma and discrimination. An Age Concern Camden volunteer, who received the dementia-awareness training as part of his volunteer training, said: 'I found the induction generally very informative and interesting. I feel more knowledgeable and confident in trying to communicate with future clients.'

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## Dementia Advocacy Project – Age Concern Camden

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*The Dementia Advocacy Project has influenced statutory services by making them consider alternatives, in order to meet clients' needs where possible.*

For example, a client with Alzheimer's disease had a sudden deterioration in her condition and had to be admitted to hospital. It was agreed that she could probably no longer manage at home and would need residential care. She was unable to express her wishes and had no family, but a good friend came forward who provided information on what her friend would have liked (for example, a room with a view of a garden and in a particular location in the borough).

The social worker wanted to place the client in the next available home, which was on the other side of the borough and meant her friend would not be able to visit. The Dementia Advocacy Project supported the friend to help the client get the best outcome. The friend was given information on local homes and the kinds of terms to use when speaking to the social worker. The social worker took note and the client was placed in a home in the area requested with a room of her liking. She is now happily settled and her friend continues to visit. The friend called the project worker to say thank you, and said: 'You gave me a voice.'

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

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

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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/Age Concerns 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 Age UK/Age Concern 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.
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## **Enriched Opportunities Project**

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### Age Concern Carlisle and Eden

*'Every time you come in, my heart feels happy.'*

(Older person with dementia)

Enriched Opportunities is based on person-centred planning, and aims to improve the nutritional, physical and mental well-being of older people living in residential-care settings. The project is run in partnership with the Target Well-being programme, which also extends to older people receiving over ten hours of care per week.

Age Concern staff work with staff in Cumbria's care homes to improve the quality of life of older people living with dementia. They do this by introducing a variety of activities and new opportunities which bring about a change in the culture of the homes and in the care of people living with dementia. The project encourages care staff to become involved in activities and to engage with the local community, businesses, schools and youth organisations.

Care staff have found that the project has made their work more rewarding, while older people living with dementia have reported finding activities stimulating and enjoyable. There is greater involvement from the local community and a volunteer resource ensures sustainability.

Activities and innovations include sensory gardens, baking, fruit tasting, food quizzes, trips out, arts and crafts, reminiscence, reading groups, flower arranging, watching films using Wii and music and dancing. Working alongside Sterling University, the care homes have introduced some simple but successful ways of re-engaging with people living with dementia – and these have been incorporated into staff training. These include using blue crockery to help people living with dementia to better identify food on the plate, introducing picture menus for improved nutrition, using coloured toilet seats instead of white seats, and installing better lighting in corridors to reduce falls. Age Concern Carlisle and Eden is taking these models of good practice into the community and into other care settings.

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## ***Life Story Project and Home not Away***

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### **Age Concern Oldham**

*'I didn't know I was so important!'*

(Older person living with dementia doing Life Story Project)

*'This is the beginning of a new life for me.*

*I feel back in the swing of things.'* (Care home resident)

*'Staff are enjoying their jobs more. They can see*

*the difference the service has made.'* (Care home manager)

Age Concern Oldham has two projects that offer support to older people living with dementia in care homes, and to staff and volunteers.

Life Story Project works on an individual basis with older people in residential care. Up to eight weeks are spent visiting clients with dementia and building a relationship through friendly, informal chats. Volunteers work with older people living with dementia to record information about their lives, using photographs donated by family to help stimulate memories. A life story book is produced to aid memory and to help care home staff and social workers to understand more fully the people they are caring for.

The process of producing the book gives the older person living with dementia a sense of their identity and self-worth, and provides a tool for reminiscence work and ideas for activities relating to the older person's hobbies and interests. The existence of the book helps carers and professionals to see the person living with dementia as the person they have always been – not just defined by their illness. The service is offered to any care home in the Oldham Borough. Age Concern Oldham provides computers, resource material, stationery and equipment to help put together the life story books.

Home not Away is specifically designed to build skills in care home staff to help them develop and deliver therapeutic social and physical activities. By looking at the history, hobbies, preferences and aspirations of the older person living with dementia, staff and volunteers can devise meaningful activities in the care setting and the wider community. These activities match the older person's interests, abilities and hobbies best, and are offered in the most appropriate setting for that person – either one-to-one, or in a small group.



This project is funded by Big Lottery fit as a fiddle and its national partners include the Blood Pressure Association, NAPA (National Association of Providers for Physical Activity), British Heart Foundation, Men's Health Forum and The Keep Fit Association, which all provide a range of written literature and leaflets to complement training materials.

Care homes receive two sessions a week over an eight-week period with a team of trained co-ordinators from Age Concern Oldham and the Alzheimer's Society. These sessions deliver activities and support and mentor care home staff. Training materials and written guidance is provided to staff, as well as ongoing support to ensure that activities become integral to the daily routines of people living with dementia.

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## **Dancing with Dementia**

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### Age UK West Sussex

*'This is great fun. I have not laughed so much for ages and it helps me build up my appetite.'* (Older person with dementia)

*'As the weeks progressed, the numbers of residents involved increased, especially as laughter could be heard all around the home during the sessions.'* (Staff member)

Age UK West Sussex leads eight free Dancing with Dementia sessions with support from care staff at Lindfield Care Home. The project is managed through Age UK's fit as a fiddle project, which is funded by the Big Lottery. The project encourages residents to become involved in other types of physical activity and provides sensory stimulation through equipment and music that people used to listen to when they were younger.

A day workshop is arranged for ten staff and support workers from Lindfield Care Home. The workshop trains and enables the support workers to continue the movement to music sessions once the eight sessions have concluded. Staff lead the movement sessions, incorporating various pieces of equipment that work different areas of the body. Each technique and the corresponding benefits of the movements are described to participants, which enhance their confidence and makes them feel part of the group.

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## Expert series

The Age UK expert series is for people influencing, designing, commissioning and delivering services for later life. The reports present evidence, lessons from experience and practical solutions.

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