

(LEVEL 2) APPLICATION TO CHALLENGE FUND

Applicants should refer to the associated criteria for accessing the Challenge Fund when completing their application in order to maximise their chances of success.

Name of applicant or lead organisation submitting application	Helen Hay Alzheimer Scotland
Position within organisation	Regional Manager
Address	Stadium House Alderstone Road Livingston EH54 7DN
Telephone number	01506 533 108
Email address	hhay@alzscot.org

<p>Name and summary description of initiative</p> <p><i>(please note- initiative requires to comply with all relevant legislative requirements e.g .Equality Act)</i></p>
<p style="text-align: center;">Dementia Friendly West Lothian</p> <p>Dementia is a significant issue for people in Scotland. While not a direct consequence of ageing, the prevalence of dementia is increasing as people live longer and the proportion of older people in the population has risen. Dementia is a condition which changes the lives of those diagnosed and of those close to them. People with dementia not only face challenges around diagnosis, support and treatment but also face real challenges in their day to day lives – maintaining contact with family and friends, going to the shops, buying goods and services, maintaining hobbies and interests - the sorts of activities which most other people take for granted. These challenges are made more difficult due to a lack of understanding about dementia in our communities.</p> <p>A dementia friendly community is one where people are committed to work together to respect the human rights of people with dementia and to help them to remain a part of their community and not become apart from it. This involves people in all walks of life learning about dementia and doing very simple and practical things that can make an enormous difference. Dementia really is everybody's business.</p> <p>Recent work on dementia-friendly communities has grown out of national and international research and policy development in age-friendly communities. This research shows that people with dementia and their families choose to shop, relax and do business in those places that make them feel welcome and where support and assistance are readily offered.</p>

If people are not welcomed into activities or organisations, the loss is not only felt by the commercial sector. Reduced use of leisure and community activities may hasten the onset of dependency on statutory services, especially if loneliness or depression follows on from a withdrawal from 'normal' life. Therefore, supporting people to live well with their dementia, as active citizens, has benefits for businesses, health and social care as well as for the individuals themselves.

Dementia Friendly West Lothian aims to improve social inclusion for people with dementia by increasing awareness and understanding of dementia within people owning, working or participating in a wide range of shops, businesses, services, organisations and community groups. The initiative will focus on Bathgate in the first instance, with the longer-term aim of rolling out the initiative to other towns and villages in West Lothian.

A dementia-friendly community has been described by people with dementia as one that enables them to:

- find their way around and feel safe
- access the local facilities that they are used to (such as banks, shops, cafés, cinemas and post offices, as well as health and social care services)
- maintain the social networks that make them feel still part of their community.

The success of the initiative will be judged by the extent to which people with dementia feel encouraged and empowered to ask for help and support in everyday situations; and the extent to which people with dementia feel that they are included in their community, more independent and have more choice and control over their lives.

The initiative will be run by a part-time Project Worker and will involve:

Fact finding/scoping

- Market research - analysis of the ways in which people with dementia engage in the community; what helps, and hinders this process; what people have stopped doing since their diagnosis and why; what new things people might like to be doing; and what they think can be done to help. Various methods will be used, including talking to people one-to-one and in group settings such as the Dementia Café, asking people to complete a questionnaire, and by "walking the patch" with people with dementia, to get a feel for how they really experience getting out and about in their communities. This can be a very effective way of finding out more about how people with dementia experience their local environment. It can also help to identify ways in which to support local facilities to become more dementia-friendly. Volunteers will be used to undertake some of this activity under the guidance of the Project Worker. The Project Worker will also analyse the data gathered during the recently held Shared Care Scotland event in Livingston where delegates were asked to map out what being dementia friendly might mean or who it might involve.
- Asset mapping - compiling a database of local shops, businesses, clubs, groups, associations and public organisations, prior to seeking their support and assessing their willingness to take part in the initiative. This stage will also involve compiling a list of local community leaders, influencers and activists who may be persuaded to support the initiative and encourage others to take part. Experience from the Motherwell Dementia Friendly Community project showed that the Fire & Rescue and Police services are both very receptive to becoming involved.

Disseminate information about dementia

Basic information leaflets about dementia will be circulated to a wide range of places such as pubs, post offices, supermarkets, shops, schools, GP surgeries, libraries, hairdressers, pharmacies, chiropodists, bowling clubs, churches or faith communities, and social clubs, to start to heighten awareness of dementia as an issue. This will use existing material supplied by Alzheimer Scotland.

Developing publicity and training materials

- Campaign materials, flyers, introduction letters, information packs
- Awareness raising materials to use for shops and businesses (handy tips and hints; posters) See appendix for example of Hints and Tips leaflet.
- Powerpoint and other presentations tailored for particular audiences.

At this stage, the Project Worker will issue letters of invitation to the businesses, groups and organisations identified explaining what the initiative is about as well as the business benefits of being dementia-friendly. The interest shown from the invitation will identify a number of organisations and businesses to try to bring on board as “trail blazers”, working with them to deliver awareness training to their staff, using a cascading “training the trainers” approach in larger organisations or businesses, and develop action plans through which they will commit to becoming dementia friendly. The conversations with people with dementia about how they engage with the community may flag up some key areas to focus on such as transport or leisure facilities or the local supermarket.

The Initiative will then be launched at an event for a wider circle of community leaders, business people and groups, as well as people with dementia and their families. Businesses and organisations which sign up to the scheme can be provided with a sticker, featuring the scheme logo which they can display in their window, as well as digital versions for use online and in other promotional materials. (see appendix for example)

Publicising the initiative as widely as possible will be important at all stages to encourage people with dementia, their partners and families, staff and volunteers from all walks of life to get involved and make a difference. This will include articles in the press, organisational newsletters, websites and online networks, local partnership fora and more formalised events as well as social media.

Delivering training/awareness raising, to include:

- information about dementia – signs and symptoms, progression of the illness
- the impact on everyday life – things people might struggle to do
- how to identify someone who may have dementia
- recognising when things change for customers/people they see regularly
- understanding the emotional support needs of people with dementia and their carers
- how to communicate with people with dementia
- knowing when to ask for help from a more experienced colleague
- what help is available for people with dementia and how to signpost them
- bespoke topics for particular staff groups, for example helping people using transport to make sure they're going in the right direction and have confidence that the bus will drop them where they need to be.

Creating a dementia-friendly community cannot be undertaken all at once. It is therefore important to develop a phased programme.

What evidence is there to support your view that this initiative is required and is considered beneficial?

It is estimated (Alzheimer Scotland, 2014) that there are currently 2184 people with dementia living in West Lothian. In 10 years' time, this figure is projected to increase by 50% to 3286. As well as those individuals with the illness, there are many partners, spouses, sons, daughters and other family members affected in their role as carers and supporters.

However, older people form the fastest growing sector of the population of West Lothian, according to *Achieving Positive Outcomes - West Lothian Community Planning Partnership's Single Outcome (SOA) agreement 2013-2023*. This predicts that, from 2008-2033, the number of 65-74 year olds will increase by 80% in West Lothian, compared to 48% in Scotland and the number of over 75s will increase by 151% in West Lothian compared to 84% in Scotland. This means that the Alzheimer Scotland projections for the numbers of people with dementia may well be an underestimate.

The rationale for this initiative is supported by both national and local policy objectives. Scotland's second National Dementia Strategy 2013-16, launched in June 2013, focuses on providing good quality life at home for longer, supporting the development of dementia-friendly local communities, timely, accurate diagnosis, and better post-diagnostic support. People with dementia and their partners, families and carers have the same human rights as every other citizen. However, it is widely recognised that, in addition to the impact of the illness, they face cultural, social and economic barriers to fulfilling these rights. The Charter of Rights for People with Dementia and their Carers in Scotland (2009) includes:

- the right to live as independently as possible with access to recreational, leisure and cultural life in their community
- the right to help to attain and maintain maximum independence, physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life; and
- the right to access opportunities for community education and lifelong learning.

The West Lothian SOA document also sets out local priorities relevant to this initiative:

Priority	Outcomes
Older people	Older people are able to live independently in the community with an improved quality of life
Health Life expectancy & Physical & Mental Wellbeing	We live longer, healthier lives and have reduced health inequalities.
Building Strong Communities	We live in resilient, cohesive and safe communities
Protecting People at risk	People most at risk are protected and supported to achieve improved life chances

In addition, tackling inequality has been identified as the core theme for the West Lothian Community Planning Partnership. The partnership recognises that for real improvements to

be made to communities and individuals there is a need to reduce the inequalities gap and tackle the causes of inequality. Understanding the inequalities that communities, groups and individuals within communities face is key to achieving this.

It is widely recognised that many people become isolated following a diagnosis of dementia, and there is a strong tendency for people to withdraw into the relative safety and comfort of their own homes. There is also strong evidence that people with dementia who become isolated from their communities experience faster rates of cognitive decline.

Previous work on developing dementia-friendly communities (eg Innovations in Dementia, 2011 and Joseph Rowntree Foundation, 2012) suggests that high on the list of difficulties that people with dementia report is trying to do the everyday things in the community that others take for granted, such as withdrawing money at the bank, paying bills, shopping and using public transport. Trying to carry on daily life as before becomes more difficult and problematic for people. As a result, they start to feel disconnected from their old groups, friends, activities and places. With very few exceptions, people with dementia say that they have stopped doing things in their community because of their dementia, and because they are wary of the attitude and reaction of others.

Just a snapshot of the problems experienced is given in the quotes below:

“I asked a member of staff at the bus station to write down the time of my bus for me and he refused – pointing at a timetable which of course I don’t understand – who does though?”

“It is so important to give us time, and not make us feel bad if we are taking time to find our money or pack our bags – it makes all the difference.”

“We are having trouble finding activities which are appropriate for someone with early Alzheimer’s. We are lucky to have good friends who help, and I organise and pay for people to exercise with him, take him to museums etc. As Alzheimer’s Disease is being diagnosed earlier it is important for the community to provide (not all for free) activities which are stimulating and keep the person with dementia as well as possible.”

“I’m not always able to remember how to get home.”

Many people with dementia and carers report that family and friends “drift away”. Long established social networks can break down quite quickly and people with dementia and carers can find themselves having to negotiate a new set of relationships.

“I don’t take my husband out much myself as people don’t understand the illness.”

Although the environment and clear, accessible information and signposting are all important, for most people with dementia what they say determines the dementia-

friendliness of local facilities is the attitude of the people with whom they come into contact. People make communities friendly – those people with whom a person with dementia might interact in the course of everyday life – shop assistants, bus drivers, train conductors, the postman, the dustbin man, the library assistant, the gym instructor. These are not people providing care, but people who provide services to all of us.

A case study from Hampshire illustrates this point. “While we were walking around, three different members of staff said “hello” to Jane, and I got the impression that she was a familiar face. I asked Jane if she ever worried about not being able to find things. She told me no, because if she did, she could ask a member of staff for help. I asked if she was confident that staff would help – “Oh yes” she replied. “They are very very helpful.”

The Joseph Rowntree Foundation also indicates that people often don’t like to admit they have dementia, or to ask for help, either because they want to be independent or because they fear the other person’s reaction. They may need to be helped to find a way of telling people they have dementia and, because of it, they need extra time or to be given some specific support. To strangers, they may come across as defensive, withdrawn, or ‘odd’ and the response from others can be variable in consequence.

In addition, it is not easy for people to know how to help their customers or people they meet in the community who may or may not have dementia, or to always get their approaches right. For example, how would an untrained shop worker know if a customer has dementia? There is a skill in being able to ask about dementia or enabling the person with dementia to feel comfortable, safe and included. While staff may be willing to help, lack of confidence or awareness of dementia may cause them to be impatient or dismissive

Have you discussed your application and obtained support from any other person(s) or organisation(s)? If yes, please provide details of others who are supportive.

While this has not been discussed outwith Alzheimer Scotland our previous work on developing dementia friendly communities in Motherwell has been recognised as an excellent model and is being cited in similar developments in other parts of Scotland, the UK and Europe. This initiative also builds on our current work with communities across West Lothian in developing 9 Dementia Cafes which also go towards supporting communities to build community capacity, adapt and deliver support that is tailored to the local area.

Our current charity of the year partnership with the Lloyds Banking Group (LBG) under the banner *Live Well* has led us to develop and roll out dementia-friendly materials in collaboration with the Bank of Scotland (part of LBG). In this initiative we developed dementia awareness training resources which were rolled out across all Bank of Scotland branches in Scotland on the same day in October 2013. This was followed up by providing all branches with posters and leaflets giving key “Hints and tips” for dementia-friendly banking as a refresher and reminder of key points in the training resources. As part of the training, each member of staff was asked to make a personal commitment to do something to make their branch more dementia friendly. See Appendix for sample of leaflet. This is an approach which could easily be adapted for other businesses and organisations in the community and, another high street bank has expressed an interest in us developing a similar initiative, following publicity from LBG.

The Scottish Dementia Working Group, the independent voice of people with dementia within Alzheimer Scotland, and the National Dementia Carers Action Network are both strongly supportive of dementia friendly community initiatives:

“I like to go for the papers every day – if I forget what papers I want, the local shopkeeper shows me the ones he knows I usually get”. *Brian, member of Scottish Dementia Working*

Group

“Today I’m surrounded by like-minded people who understand the importance of social inclusion, who understand that my husband does not wish to participate in activities designed only for people with dementia, but rather be accepted for who he is and just get on with living in the community like everyone else.” *Ann, member of National Dementia Carers Action Network.*

Outline organisation(s) arrangements for supporting / managing initiative

We would appoint an 18 hour per week Project Worker to focus on this initiative. He/she would be based at our regional office in Livingston and be line managed by our locally based Practice Team Leader. Ultimate responsibility would lie with the Service Manager for Edinburgh & West Lothian Services. The Regional Manager for South East & Central is also based in West Lothian and has overall responsibility for all initiatives across a region which covers Edinburgh and the Lothians, Scottish Borders, Fife, Stirling, Clackmannanshire and Falkirk.

The initiative would also be supported by our national Communications & Marketing Team who would assist the Project Worker with developing printed resources and publicising the project (in conjunction with counterparts in West Lothian Council) in print and social media and on Alzheimer Scotland’s website.

The Project Worker will be expected to recruit local volunteers to assist with asset mapping, contributing to focus groups, and acting as “mystery shoppers” at various stages of the project. Many of these volunteers will come from existing initiatives such as the dementia café in Bathgate and, potentially, staff from the Lloyds Banking Group who have a remit to undertake community work as teams or individuals.

The Project Worker will also receive guidance and advice from colleagues in Alzheimer Scotland who have undertaken similar work in their own communities.

How will this initiative impact on or complement existing provision?

Alzheimer Scotland and West Lothian Council share the goal of achieving the best possible outcomes for people with dementia and their families and carers within the resources available. We have a joint vision that supports and services need to change in order to offer improved outcomes and options to people with dementia and their families. Alzheimer Scotland welcomes the opportunity to work with statutory and other partners to innovate and offer an alternative approach to supporting people with dementia and their families and this initiative sets out how we might do this.

This initiative will complement Alzheimer Scotland’s existing activity in West Lothian such as the Dementia Cafes, particularly the Bathgate Memory Café, which provides a meeting place in the heart of the community that gives people with dementia and their carers a chance to meet others in a similar situation. Our Dementia Advisor and Post Diagnostic Link Worker also play a key role in providing information and signposting people with dementia and their families to appropriate activities and sources of support, as well as helping people maintain their community connections and/or develop new ones. However, this initiative will extend this support by encouraging and enabling non-dementia specific groups to become more inclusive and consider how people with dementia could be helped to participate.

The initiative will also build on the work of West Lothian Council such as the Ageing Well Initiative, to ensure that as many activities as possible are accessible to people with dementia. There is already a good example of this quoted in the Council’s Winter 2013

edition of Bulletin:

"Jack Malcolm from Craigshill in Livingston, has been taking part in the Tea Dances for two years after he was diagnosed with Alzheimer's disease. He said: "My doctor recommended that I keep as active as possible, and the Tea Dances are perfect for me. "I've been dancing since I was 14 years old and I love it. "The classes keep my mind and body active and I meet people each week for a chat and a catch up. "The Tea Dances are very sociable and everyone has a good time. The music is first class and I'd thoroughly recommend it to anyone."

Please give a description of the outcomes being sought from this initiative.

The success of the initiative will be judged by the extent to which people with dementia feel encouraged and empowered to ask for help and support in everyday situations; and the extent to which people with dementia feel that they are included in their community, more independent and have more choice and control over their lives.

Staying as well as possible and getting meaning and fulfilment out of life are critical outcomes for people with dementia. We know that people living with dementia value the maintenance of a sense of self which is based on social competence, good communication skills, an internal locus of control, good self-esteem and self-worth, maintenance of mobility and levels of physical activity, and connections to their personal, and wider social, community that the establishment of Bathgate as a dementia friendly community will support.

Staff in the participating shops and businesses and members of other organisations involved in the initiative will complete questionnaires before and after each training and awareness session to assess changes in attitudes, knowledge and understanding about dementia and its impact on the individual and his/her family.

The Project Worker will also record outputs from the initiative such as:

- the numbers and range of participating shops, businesses, groups and organisations and any growth achieved
- the number of people included in awareness raising activities/training
- the numbers of Hints and tips leaflets distributed
- the number of participating shops, businesses, groups and organisations achieving what they set out to do in their action plans.

Please explain how you propose to measure if the outcomes you have identified are achieved?

To evaluate the success of the initiative we will use mechanisms previously created to look at the outcomes and experiences for the other areas where we have been rolling out dementia friendly communities activities, particularly North Lanarkshire.

The data gathered from one-to-one and group sessions and questionnaires completed by people with dementia will provide a baseline against which to measure the extent to which they feel more included in the community with more and better access to services and facilities. Similar 'market research' will be conducted after one year to assess any change.

We also propose recruiting "Mystery Shoppers" to visit shops, businesses and services before and after the delivery of awareness training and the development of each participant organisation's action plan to see if there has been any difference. We will also hold evaluation events, using methods such as emotional touchpoints, to gain as full a picture as

possible of the experience and outcomes of those utilising the services/facilities of the project
Breakdown of all associated costs and funding being requested? Please note funding is normally provided in the form of a one off grant for the year in question – if your initiative exceeds the normal one year period this should be highlighted with an indication being given as to the timescale in which the funding will be spent.
See attached budget. We are requesting funding for a 2 year project. The total cost for the 2 year project is £49,938
Please outline any other sources of funding which are to be made available to support this initiative – e.g. grant of contribution from organisation applying or others (this may be in kind)
The post holder would be based at Stadium House, Livingston and benefit from the shared resources at our Regional Office. Economies of scale would also ensure that purchasing of goods, supplies and equipment would be maximised. As a number of other dementia friendly initiatives are being developed in other parts of Scotland, Alzheimer Scotland as the applying organisation will be contributing the time of our Communications and Marketing Team to the project.
What arrangements have been made to sustain the project after the initial investment from the Challenge Fund?
Ideally we would hope that at the end of the 2 year project communities and businesses would have become more dementia aware and a cascade of learning and understanding would be happening. However, we recognise that demystifying and reducing stigma can take time. As dementia friendly communities is a relatively new approach we will need to learn from this pilot project and work with partners to see what is required to embed this approach across West Lothian. The learning gained from this initiative will provide Alzheimer Scotland with additional evidence to support the development of a national toolkit which will be made freely available to other groups and organisations wishing to undertake similar initiatives.

Completed applications may be forwarded electronically to:

seniorpeoplesforum@westlothian.gov.uk

Alternatively they can be printed and sent to:

**Chair
Senior People's Forum
West Lothian Civic Centre
Howden South Road
Livingston
EH54 6FF**