Introduction

Alzheimer Scotland is Scotland’s leading dementia voluntary organisation. We work to improve the lives of everyone affected by dementia through our campaigning work nationally and locally and through facilitating the involvement of people living with dementia in getting their views and experiences heard. We provide specialist and personalised services to people living with dementia, their families and carers in over 60 locations and offer information and support through our 24 hour freephone Dementia Helpline, our website (www.alzscot.org) and our wide range of publications. Alzheimer Scotland welcomes the opportunity to contribute to the Equal Opportunities Committee’s Inquiry into Age and Social Isolation.

Alzheimer Scotland’s response has been informed by contributions from the Scottish Dementia Working Group (SDWG) and The National Dementia Carers Action Network (NDCAN).

General Comments

Every aspect of Alzheimer Scotland’s work is designed to ‘make sure that nobody faces dementia alone’. We fully understand that for people with dementia and their carers, social isolation can cause serious harm to their health and wellbeing at a particularly challenging time. The progression of symptoms in dementia can lead to a loss of abilities, which may limit a person’s ability to continue with activities in which they may have partaken for years. This can lead to a loss of confidence, loneliness and depression, all of which can further isolate the person.

For people with dementia and their carers, the process of social isolation will often begin well before the diagnosis of dementia is made owing to the nature of how symptoms typically emerge.

Alzheimer Scotland’s 5 Pillar Model of Post-Diagnostic Support\(^1\), now being implemented across Scotland as part of the Scottish Government’s commitment to 1 year of Post-Diagnostic Support, includes a pillar on ‘supporting community connections’. The pillar aims to build resilience through maintaining and building on a person with dementia’s existing social networks, to enhance their quality of life and maximise the natural support they receive from those around them. These connections should be included in the personal plan created by the person with dementia with the support of their link worker in order to reduce the risk of social isolation and reduce reliance on care services.

Link workers are therefore crucial to the delivery of post-diagnostic support for people with dementia, their families and carers, to enable risk and plan purposeful community activities.

Similarly, our 8 Pillars Model of Community Support\(^2\) sets out that personhood for people with dementia is fundamentally underpinned by an individual’s interpersonal

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\(^1\) [http://www.alzscot.org/campaigning/five_pillars](http://www.alzscot.org/campaigning/five_pillars)

\(^2\) [http://www.alzscot.org/campaigning/eight_pillars_model_of_community_support](http://www.alzscot.org/campaigning/eight_pillars_model_of_community_support)
identity, their established relationships and social connections. We recognise that often, people with dementia and their carers lose social contact and experience feelings of detachment from mainstream community life, increasing their risk of isolation and resulting in a greater reliance on care services.

Pillar 8 of the model is ‘Community Connections’, which sets out the importance of ensuring that people with dementia and their carers are supported to maintain and build on their existing social networks and have opportunities for peer support identified to enhance their quality of life.

Remaining active and connected within the community enables people with dementia to maintain their normal patterns of living and activities for as long as possible. Some people may require help to maintain their community connections and not withdraw from aspects of everyday life, whilst others may have already withdrawn and need support to reconnect. The right support can assist the person and their carer to identify the areas of their life that are most important to their well-being. We have set out examples of our approach in the following paragraphs.

Peer support provides the opportunity for both the person with dementia and the carer to learn from those experiencing similar challenges and can facilitate the development of coping strategies to maximise a person’s independence, self-esteem and wellbeing.

The 8 Pillars Model is currently being tested in five sites across Scotland as part of the Scottish Government’s National Dementia Strategy. This includes work around maintaining community connections for people with dementia and their carers.

How people with dementia experience social isolation

As part of our response to this inquiry, the Scottish Dementia Working Group (SDWG) shared some of their experiences of social isolation and how this has impacted on them.

The group told us that people with dementia can feel isolated and disconnected from their community as many public places, including cafes, supermarkets and road traffic, are too noisy which can be distracting and overwhelming; this results in many people with dementia avoiding such places, leaving them less opportunity to socialise within their communities. Similarly, the group noted that even within a community or when amongst other people, it is possible to feel isolated, as in instances where other people may not be familiar, a person may be less inclined to speak in case they forget their words.

It was also suggested that the relationships between family and friends can change significantly, leading to an individual becoming socially isolated, with the process described as slow and progressive. The group told us that it can start with people not being invited to events as others assume that a diagnosis of dementia will prevent a person from going out or will stop asking if a person declines as a result of challenges with their dementia.

The stigma and inaccurate perceptions around dementia continue to be an issue for people with the condition. Experiencing negative attitudes can discourage a person from social interactions and make them more reticent.

Conversely, the group noted that social isolation can occur as people ‘withdraw’ because family or carers, whilst trying to support the person with dementia, become too involved in the life of the person, often beginning to take over and do everything for the individual, limiting their resilience and autonomy.

However, the group made clear that feeling isolated is subjective in nature, noting the importance of recognising that people who have always preferred their own company should not subsequently be labelled as isolated or withdrawn simply as a result of their diagnosis of dementia.

**Impacts of social isolation for Carers**

We welcome the committee’s recognition of the distinct experience that carers face during the course of their caregiving role and the increased risk of social isolation that this creates. As part of our response to this inquiry, the National Dementia Carers Action Network (NDCAN) shared some of the challenges of caring and how this impacts upon them.

This is especially true for carers providing care and support to people with dementia, owing to the progressive nature of the condition. This can result in increasing responsibilities and pressure on the carer over a period of time, progressively leaving them with less time, money and energy to engage in other activities. As a result, the risk to carers of risk of social isolation is significantly increased as their capacity to engage and partake in day-to-day social activities is diminished.

From our experience, carers may find themselves restricted to contact with the person for whom they are providing care and support, with some limited contact with external support services. We are further aware that carers will have reduced contact with other family members, often missing out on significant moments; this is particularly true for older carers whose children have left home. Furthermore, carers have told us that in addition to missing out on this normal contact with their families, when there is the opportunity to have contact, it is severely limited by the need to return to their caring role.

Carers have also told us that they can become isolated because of their geographic location which can make keeping in contact with friends, other than by phone, particularly challenging. Owing to the aforementioned pressures, carers often have difficulty and limited opportunities to make new friends. In addition, carers have also indicated that a stigma exists around people with caring responsibilities, telling us that they have experienced people ‘drawing away’ from contact and being unsure how to interact with carers.

Another contributory factor that leaves many carers socially isolated is the difficulty in maintaining employment and the contact and social interaction which comes from participation in the workplace. Carers often find it particularly difficult to continue to balance work and caregiving responsibilities, with challenges around employers being able to accommodate the unpredictable nature of caring arrangements and the
need for carers to be continuously ‘on-call’. In addition, we have heard carers report that the income limit on carers’ allowance can discourage and/or preclude some from combining employment with a caring role.

From this, we can establish an understanding that the caregiving role impacts upon every aspect of normal social interaction and activity in which a carer may partake.

**Best practice and ideas that could be shared across Scotland, including examples of targeted support or initiatives**

Alzheimer Scotland provides a range of services for people with dementia, their families and carers across the country. These include, but are not limited to: day care; reminiscence groups; dementia cafés; forget me not groups; choir/singing groups; and one to one support for people with dementia, their families and carers.

As part of these services, peer support is considered to be an integral part of combating social isolation, particularly for people with dementia. Many feel isolated by their diagnosis and are able to build their confidence through interaction with those in a similar situation who can encourage participation in social activities and groups. This is equally true of people caring for people with dementia who, by attending these services, are able to relieve some of the pressure they experience as a result of their caring responsibilities, as well as meeting and sharing experiences of caring, including approaches that may assist in their role.

Below is a brief description of some of the groups’ practice examples which aim to ensure that people with dementia, their families and carers are less at risk of social isolation, with further details on how the services reduce social isolation and encourage participation.

**Day Care/Home Support/ One to One Support**

Alzheimer Scotland day centres and day opportunities services provide specialist therapeutic interventions which support people with dementia to maintain their skills so that they can stay independent for as long as possible. The services provide stimulation, peer support and social interaction through a range of activities, including life story work, exercise to music, painting and craft work, musical activities, gardening, baking and discussions. In addition, outings are organised based on people’s interests – for example theatre, bowling, garden centres or places of interest.

Furthermore, as well as the benefits for the person with dementia, carers feed back that they benefit from the opportunity for respite from their caring responsibilities, knowing that their loved one is benefitting from specialised support.

In many areas of Scotland Alzheimer Scotland provides personalised support services (sometimes called home support), offering specialist one-to-one support for people with dementia who are at any stage of the illness. The support will be based on the choices, interests and needs of the person with dementia to assist them to live well with dementia and achieve the outcomes they want. In doing so, people are supported to:
- Maintain their confidence, skills and independence.
- Stay involved in their community.
- Keep doing things they enjoy doing.
- Manage everyday activities, including help with personal care tasks.

As part of this, we support people to develop memory assistive techniques, plan structures to their day and maintain their social networks, supporting people to carry out activities themselves - ‘doing with’ rather than ‘doing for’ – underpinning our approach.

Community Connections Project

Many people with dementia ‘fall through the net’ as they have not reached the point of requiring formal care services, yet live alone with no family within the locality, meaning that they may often experience prolonged periods of social isolation.

In Renfrewshire, Alzheimer Scotland provided innovative group and one to one support to help people with dementia reconnect with communities, hobbies, interests and peer groups, as well as promoting active citizenship through contributing to the local community. Through this project:

- Two members have become mentors for social work students.
- The music group run by the service now performs at large scale events.
- Two members delivered presentations at the Care Accolades in 2014.
- A number of the members now socialise independently with some going on holiday together.

Dementia Cafés/Dining Clubs

Alzheimer Scotland runs local dementia cafés across the country where people with dementia can meet other people with dementia for to make friends, socialise and peer support and learning. Attendees can also speak with staff to ask questions and get further information on services and support available in a relaxed environment free from.

Our Dementia Advisors, Service Managers and Support Workers tell us that people with dementia who attend the cafés often grow in confidence which subsequently encourages participation in other events, with many making other arrangements for socialising outside of the café. Our colleagues report that this creates important peer support networks and broadens their opportunities for social activities, creating informal but strong social supports for each other. Furthermore, carers and family members feedback to us that their loved ones experience improvements in their mood and functional capacity as a result of attending these services.

Similarly, dining clubs have proved to be particularly successful for people with dementia who no longer had the confidence to go to pub or restaurants but who were not in the position of requiring formal services. The restaurants are also open to carers and family members and have enabled natural friendships to form between
peer groups. Alzheimer Scotland’s service in Renfrewshire hosts a monthly ‘World Restaurant Evening’ which reached the final of the Scottish Social Service Council’s Care Accolades in 2014.

**Scottish Dementia Working Group (SDWG)**

Alzheimer Scotland has supported the development and continuing work of the SDWG, which allows group members to actively and meaningfully engage with local and national policy makers and professionals. The group was centrally involved in the development of Scotland’s national dementia strategies and continues to be involved in work to deliver change for people with dementia. While the group is a working group, rather than being social in nature, it has proved a positive outlet for members, challenging stigma and societal perceptions on the limitations of people with dementia. Furthermore, group members have enjoyed personal development through activities carried out on behalf of the group.

**National Dementia Carers Action Network (NDCAN)**

Alzheimer Scotland’s National Dementia Carers Action Network is a national campaigning and awareness raising group for carers of people with dementia, which exists to make the voices of carers heard and raise awareness of the issues impacting on carers.

As with the SDWG, the group is primarily a working group rather than a social group, however, for many members it has proved a positive outlet for members, helping to shape policy and ensure stronger inclusion of carers across health and social care settings. NDCAN members have developed through their activities carried out on behalf of the group and many keep in touch outwith the meetings of the group.

**Effective awareness-raising within communities**

The key to effective awareness raising and reducing social isolation is to utilise existing community settings and improve what is there instead of creating something completely new. People with dementia must be supported to continue to live well in their community, whilst continuing to have normal, everyday experiences and interactions with peers; this is central to the personhood and wellbeing of the person with dementia. As part of this, some of the groups established for people with dementia (for example musical memory groups) will often be held in community settings such as local hotels, church halls or other venues which may already be familiar to the person with dementia, their families and carers. This encourages people to take part in their local community in an environment they know will be supportive and understanding, increasing opportunities for social interaction and activity.

Alzheimer Scotland has been involved in a number of projects around the creation of ‘dementia friendly communities’, a phrase used to describe a community (including shop assistants, public service workers, faith groups, businesses, police, fire and ambulance staff, and a range of others) which is committed to working together and helping people with dementia to remain a part of their community. This involves learning a little about dementia and taking small, practical steps things that can make an enormous difference to people living with the condition.
Alzheimer Scotland is working in partnership with many communities across Scotland who are aspiring to become dementia friendly. We have developed a logo\(^4\) which we hope will start to be seen across the country in business premises, leisure centres, places of workshop, schools, clubs – indeed, anywhere likely to be visited by or supporting people with dementia. The logo does not indicate adherence to a particular set of standards or criteria, but is an indication that, where it is displayed, people are working towards creating a dementia friendly community.

The scheme has been successfully trialled by Alzheimer Scotland in partnership with North Lanarkshire and NHS Lanarkshire, which resulted in Motherwell becoming Scotland’s first dementia friendly town in 2012. In addition to this, the project was recognised for its achievement and won an award at the European Foundations’ Initiative on Dementia (EFID) awards in Brussels in April 2014\(^5\). The EFID awards are noted as “a mark of recognition” for “exemplary practices”.

The final report on the scheme, ‘Dementia: Everyone’s Business’, has been published and details some of the steps taken as part of the scheme\(^6\). In addition, a dementia friendly community ‘toolkit’ has been developed, expanding on the resources created for the Motherwell scheme.

Alzheimer Scotland has also had success in raising awareness of how people with dementia can be supported within their communities through the launch of Dementia Friends Scotland\(^7\). Launched in May 2014, the programme – which encourages people to be aware of people with dementia in their communities and asks them to consider how small things they can do can help people with the condition – has attracted more than 7000 people who have signed up to become dementia friends.

**Conclusion**

It is evident that people with dementia and their carers are at a high risk of becoming socially isolated and that this has the potential to impact negatively on their quality of life as well as their physical and mental health and wellbeing. However, the good practice examples in this submission provide evidence that this is an issue that can be addressed. This requires explicit recognition of the dangers of social isolation, the range of formal and informal ways in which it can be addressed and the value to an individual of continued social interaction in their communities.

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\(^4\) [http://www.alzscot.org/dementia_friendly_communities](http://www.alzscot.org/dementia_friendly_communities)  
\(^6\) [http://www.alzscot.org/assets/0001/4677/Dementia_Everyone_27s_Business.pdf](http://www.alzscot.org/assets/0001/4677/Dementia_Everyone_27s_Business.pdf)  
\(^7\) [http://www.dementiafriendsscotland.org/](http://www.dementiafriendsscotland.org/)