



How to include people with dementia in the activities of Alzheimer associations

This factsheet is intended as a guide for staff and volunteers of Alzheimer associations as to how they can work towards being inclusive of people with dementia. It was developed by Alzheimer's Disease International (ADI) in consultation with ADI members and people with dementia.

Why include people with dementia?

Increasing awareness about dementia and the development of treatments has led to earlier diagnosis. As a result, people with dementia are contacting Alzheimer associations asking to be included because there is a better understanding of their needs as expressed directly by them.

It is important to acknowledge that people with dementia have abilities that need maximising so they can remain active participants in life. People with dementia can contribute their direct experiences to the development of programmes and services and help Alzheimer associations develop a greater understanding about the experience of living with dementia. This can help reduce stigma, inequality and discrimination and enable a person with dementia to feel valued and included.

This factsheet will look at how Alzheimer associations can support people with dementia and involve them in their activities.

Some ways of supporting people with dementia

It is essential to ask people with dementia exactly what it is that they want and need before considering setting up any of the following services.

1 Providing Information –

specifically for people with dementia on topics such as:

- What is dementia?
- Treatment
- Support and resources available
- Practical tips for coping
- Planning for the future

Factsheets, booklets, videos and websites may all be useful ways of providing information. Consult and involve people with dementia in the development of information materials for them. Remember that people with dementia are not all the same. Those affected at an early time in their life will have different needs to older people. Also think about how information is presented, such as the font type and size.

2 Support groups – like carers, people with dementia may need someone to turn to for support or just to talk. Other people with dementia are the only people who know first hand what a person with dementia is experiencing. Setting up support groups for people with dementia is an important way of providing support but does require careful planning and groups should be led by supervised, trained facilitators.

3 Link to other resources – other organisations in your country may provide support for people with dementia, such as those concerned with mental health generally or the welfare of older people. There may already be support or advocacy groups available. It is important to find out what support other organisations are providing so that you can refer people with dementia to them.

Dementia Advocacy and Support Network International (DASNI) is a network of people with dementia throughout the world who support each other mainly via online chat rooms and email. For more information visit their website at www.dasniinternational.org Please also see the list of other online resources provided by Alzheimer

associations at the end of this factsheet.

4 Educational programmes – many Alzheimer associations provide educational programmes such as seminars, workshops and courses for carers. Consider organising sessions for people with dementia either on their own or with their carers. Relevant topics may include:

- How a diagnosis is made
- The different causes of dementia and their effect on behaviour
- How to plan for the future – using powers of attorney, making wills, living wills
- Coping with a diagnosis
- How to simplify and organise your home and life
- Support from new technology

Involving people with dementia in Alzheimer associations' activities

If you are working towards being inclusive of people with dementia then you should involve people with dementia throughout your organisation in meaningful positions, not just 'figurehead' ones. This is a complex process and to avoid tokenism, one that must be carefully thought through and supported by your board members and staff. The term 'involvement' describes the whole range of practical ways in which the views and preferences of people with dementia can be sought and their influence brought to bear on your association's activities.

Suggested ways you can involve people with dementia:

- Appoint a person with dementia to the board or executive committee
- Appoint a 'person with dementia advocate' either as a member of staff or volunteer, with the sole responsibility of identifying and addressing the needs of people with dementia
- Hold regular 'people with dementia consultation groups' and surveys on services/programmes provided to determine whether their needs are being met and if not, assess how programmes/services could be improved
- Advocacy – invite people with dementia to share their experiences to help develop policy
- Programme development – consult people with dementia when developing new services and information
- Include the perspective of a person with dementia in your awareness campaigns
- Invite people with dementia to speak at appropriate events and conferences

Some important issues to think about

Encouraging a commitment to involving people with dementia –

Support and encouragement cannot come from one individual on their own. Involve everyone in the planning and in working towards the same goals. You may want to consider organising a workshop for members of your association about involving people with dementia.

Sensitivity and understanding –

People with dementia may need additional support to contribute their perspectives. For example, more time to express themselves at meetings. You may also need to allocate funds to provide private transport to attend meetings.

Supporter – People with dementia may like to invite a friend or supporter to help them in meetings and facilitate their contributions.

Loss of competence – This is probably the most difficult and sensitive aspect of involving people with dementia, that is what happens when the person with dementia is no longer able to perform a role in your association, be it as a member of your board or part of a consultation group. The starting point is to talk about it and work towards reaching a solution together. It is important not to deny that someone is no longer capable of fulfilling their role, as the work they are responsible for will not get done. This may affect the mission and credibility of your association. However, it is important to remember that just because a person is not able to fulfil a particular role, this does not mean that they are no longer able to contribute in other ways.

Perceptions of time – People with dementia only have a limited time to contribute so it is important that everyone understands this. A small delay on an agreed deadline may not matter to people without dementia but may be significant to someone with dementia who may have different priorities. Agreeing realistic time expectations can help.

Ground rules – Ask people with dementia whether there are any ways meetings could be made easier for them e.g. breaks, presentation of written material, lighting, sound levels.

Acknowledging contribution – When a person with dementia is no longer able to perform his or her role, it is important for the rest of the board/group to acknowledge and celebrate the contribution that individual made. However, it is important to recognise the efforts that people have made throughout, not just when they no longer can.

Conclusion

This factsheet is intended as a guide to help you work towards being more inclusive of people with dementia and to highlight some of the issues you need to think about.

The fundamental principle to remember when involving people with dementia is to ask them for their views and listen to what they say. Do not

assume that you can act or speak on their behalf.

It is the right of people with dementia to be involved in the organisation that represents their interests. Involving people with dementia is a new direction for many that with careful planning and support can only help to improve the effectiveness of Alzheimer associations in achieving their fundamental goal of supporting people with dementia and their families.

If you need any further advice or information please contact ADI.

Useful resources

Books/booklets

Alzheimer Society of Canada. (n.d.). First steps: For those recently diagnosed with Alzheimer's disease. 10 pages.

Alzheimer's Society UK. (2001). I'm Told I Have Dementia - What you can do. Who you can turn to. 25 pages.

Yale, R. (1995). Developing Support Groups for Individuals with Early Stage Alzheimer's Disease. Health Professions Press. 230 pages.

Factsheets

Factsheets for people with dementia have been produced by Alzheimer's Australia and can be downloaded from their website, www.alzheimers.org.au

Websites

The following websites include sections for people with dementia

Alzheimer Society of Canada: www.alzheimer.ca

Alzheimer's Association USA: www.alz.org

Alzheimer's Australia: www.alzheimers.org.au

Alzheimer's Disease International: www.alz.co.uk

Alzheimer's Society UK: www.alzheimers.org.uk

DASNI: www.dasniinternational.org



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