



**Alzheimer's Disease
International**

How to successfully involve people with dementia in speaking roles for organisations

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This factsheet is intended as a guide for staff and volunteers of Alzheimer associations as to how they can successfully involve people with dementia in speaking roles and supports the document *How to include people with dementia in activities of Alzheimer's organisations* published by ADI in 2003 (www.alz.co.uk/adi/pdf/involving_pwd). Richard Taylor, PhD provided the viewpoint of the person with dementia and Nicole Batsch provided the organisational perspective for this article. A five-page document by no means is inclusive of every situation and consideration to be made for a person with dementia; however, we hope this article will provide guidance to supporting people with dementia in this role.

Speaking roles and opportunities

People with dementia are being included more often in the activities of associations by speaking about their condition at **public policy**, **educational**, and **fundraising** events. In addition, interviews with the **media in print, radio and television** are becoming commonplace. Each of these roles requires sets of skills and abilities for any person; and for someone with dementia, extra care should be taken to maximise his or her success. Always involve the person with dementia and his or her care partner in considering what events are a good fit.

Questions to think about and discuss with the person with dementia and his or her care partner:

1. **What is the goal of the event?** Depending on the interests of the individual with dementia, he or she may prefer public policy type events compared to speaking at fundraisers. Have a discussion about the person's personal interests in helping the cause of the organisation. Also consider whether the person prefers (and has abilities and confidence) to speak on stage to twenty people or hundreds or thousands of people or prefers one-on-one media interviews.
2. **How long would you like the person with dementia to speak?** The person should know ahead of time if they will be speaking for 3 minutes or 30 minutes and what general topics you would like included, such as what his or her diagnostic experience was like, or how he or she benefits from services of the organisation, etc.
3. **Would you like his or her care partner to speak as well?** Think about similar issues and expectations for the care partner about timing and

preferences. Also be careful that the care partner does not speak for (or over) the person with dementia.

4. **What kind of support do you plan to provide?** This can include anything from helping write a speech, to arranging and paying for transportation or accommodation for the event. Practice and training time to help the person with dementia prepare, for example, through several rehearsals and recordings, is also recommended. Discuss the possible questions with the person with dementia ahead of time and ask for the person's input on framing the questions specific to their personal story and communication abilities. People with dementia may also benefit from having a quiet space where they can gather their thoughts or relax before and after the event.
5. **What time of day is the event?** Ask the person with dementia and care partner about the best time of day for this particular person with dementia. Some people can be alert and refreshed after a good night's sleep and some find mornings very difficult. If mornings are difficult, think about strategies for involving the person later in the programme or providing accommodation nearby so the stress of travel does not interfere with the stress of speaking.

Abilities of Persons with Dementia

Every person with dementia is unique and has unique abilities and skills. You may consider a person with limited language abilities to not be appropriate; however the person may want to participate. In such cases, it can be helpful to arrange the event to maximise their abilities. Let's take the following real-life example:

An experienced facilitator moderated a panel of people with dementia with varying abilities to an audience of about 50 healthcare professionals. One person had very mild dementia and when asked open-ended questions, was able to answer with ease. A second person with dementia had been a dynamic speaker in previous years, but was beginning to lose her language skills. It was obvious she was keen to participate and understood broad concepts, but was only able to answer in short phrases. The third individual had virtually no ability to speak in sentences, but understood questions and could answer with yes or no responses.

The seating of the panel was important. The person with the greatest abilities was seated next to the moderator and was asked open-ended questions and the person with dementia provided open-ended answers. This allowed the person with the next level of abilities more time to process the question and formulate her answers by modeling the first person. For the second person, the question was rephrased and based on a previous conversation with the panelist, the moderator gave some leading comments to get the person started. The last person was asked the same question in a way that required only a yes/no answer. Once the person answered, his care partner was seated next to him and was asked to explain his answer,

allowing participation at his level of ability, but not requiring too much that might add additional stress to his disabilities.

This particular event was a success. The audience provided positive feedback about the session and the panelists seemed to feel good about their participation. However, not every organisation will have the staff or volunteer support to make the above example successful. This example illustrates many possibilities and challenges for involving people with dementia in speaking engagements.

Challenges for the individual

Place yourself in the shoes of the person with dementia. Think about the cognitive difficulties and limitations and what may be helpful for the person to overcome these to be successful. Now think about the emotional impact of what sharing his or her diagnosis may be like. In a moment of inspiration for the audience, this person is about to share their greatest weaknesses and fears. The person may worry about their own ability to perform which places additional stress on the situation. This internal conflict for the person with dementia is not something the event organiser can help overcome. Speaker and media training can help build confidence and provide skills to people who are inexperienced, but people without dementia will not know what it is like to have a cognitive impairment and be asked to speak in public. Be mindful about the complexity and impact of the situation on the person. In addition, discuss potential pitfalls in advance, such as what the person with dementia prefers you (or the care partner) to do if they have trouble finding words or lose their place in their speech. Remind the person that the audience is a sympathetic audience. Although this cannot be guaranteed, most audiences are present for a reason – whether to change voting habits, donate money to the cause or become more educated about dementia.

Care partner considerations

From an organisational perspective, you must balance the needs of the person with dementia and the needs of their care partner. As enthusiastic as the person with dementia can be as a speaker at one of your events, the care partner has additional information, feelings and abilities that are important to consider. Can they adequately support the person with dementia in this role while meeting their own needs? Have the circumstances changed since the last time they participated or since you requested their help? What unforeseen burden may be placed on the care partner by the organisation's desire to provide an opportunity to the person with dementia?

Cultural differences

This article is mostly based from an English-speaking perspective. In Australia, Canada, United Kingdom and United States, people with dementia may face less stigma about speaking in public than in other countries. Discuss the cultural implications with people with dementia and care partners within your culture to

determine the best strategy for speaking engagements. The benefits of helping to overcome stigma is valuable, but not at the expense of someone being emotionally or physically harmed for speaking out.

Ethical issues

Recruiting from within your client base. The National Association of Social Workers (US) Code of Ethics indicates the possibility of “undue influence” on clients from a worker within an organisation. The client, in this case the person with dementia and/or the care partner, is vulnerable and trusts that the person in charge of programmes designed to meet their needs is protecting their best interests. This is an important consideration and people with dementia should voluntarily offer to participate in speaking engagements. Organisations can creatively invite a call for speakers through their newsletters and partnerships with memory clinics.

Matching people with dementia with the right activities. Even with early diagnosis, the dementia field is not yet inundated with hundreds of people with dementia who desire to speak or have the ability to speak in public. When you consider your local area, it may mean a person with dementia from another geographic region needs to come from far away to attend your event. Matching the limited number of people with dementia you have available with the correct activities based on the guidelines in this article will be helpful. A person with dementia may do very well in a one-on-one interview with the media, but not prefer to speak behind a microphone. Even consideration to an intimate media interview requires thoughtfulness about whether ‘in person’ or ‘by phone’ is the best method for the person with dementia to be interviewed.

How many events are too many? Consideration needs to be made to the number of requests of the person with dementia and his or her care partner. World Alzheimer’s Day and Month activities are filled with media requests, educational programmes and fundraisers to promote the cause. Each individual has different abilities and desires. It is important to discuss the many opportunities and requests with the person with dementia and his or her care partner and help identify the best scenarios together.

Designate an organisational advocate. This individual can assist the person with dementia and liaise with appropriate staff within the organisation. Other staff may be unaware of the multiple requests for a specific person with dementia and the person’s abilities may have changed since his or her last event.

What if the person is unsuccessful? The definition of successful is dependent on the individual’s viewpoint, the care partner’s viewpoint and perhaps the organisation’s as well. Although this possibility can be addressed during a pre-speaker training or conversation with the person with dementia and care partner, the impact after it occurs will not be easy. People with dementia have good and bad days and perhaps the day of the event something is amiss or logistically something

goes wrong, for example the person's microphone does not work. There is no "one size fits all" response to this question. However, you must be aware of the likelihood and think about some ways to support the person with dementia after it occurs.

When the concerns of the care partner outweigh the desire of the person with dementia to participate. At some point, you may receive a call from the care partner about the person with dementia's declining abilities or the care partner's inability to support the person in this role. Consider what a transition from this role looks like, discuss this possibility with the person with dementia from the beginning and create a ritual to honour the person with dementia's time and dedication to your organisation.

Establish trust. Trust is built over time between a number of stakeholders such as between the person with dementia, care partner, organisation, the organisation's designated representative, the media, etc. It is important to allow trust to develop naturally and not to take advantage of this trust for the benefit of the organisation. People with dementia are experiencing a part of life where their feelings and relationships are more important than reasoning and information; therefore it is so important that building the relationship and maintaining that trust with the person with dementia is your priority.

The primary barrier for the person with dementia comes not from managing the logistics or external stresses of speaking publicly, but from within the person. These are not things you can help the person with dementia manage. Building trust is the key to establishing an environment where the person feels more secure. It takes more than just a phone call, or a meeting or two to build this trust.