



# Supporting and Accommodating People with Dementia at Professional Conferences and Other Events



## INTRODUCTION

Because members of Dementia Alliance International (DAI) have a unique perspective on conferences we decided to assemble responses from post-event informal email surveys of the past four years to see how people with dementia and care partners feel about the access, support, and enablement provided at professional meetings of Alzheimer's Disease International (ADI) and other conferences or events.

In other words, we asked if such events are dementia friendly, accessible, and accommodating for people of all ages and disabilities.

We go to these meetings and sit on boards or other advisory committees to educate people on best practices for supporting us, to dispel myths and stigma surrounding diseases like Alzheimer's and other dementias.

Our attendance and speeches at conferences (on science, medicine, human rights, disabilities, etc.) directly improves our wellbeing and positively impacts our quality of life. In fact, this form of self-advocacy is not only beneficial to our sense of identity, but also contributes to the development of new treatments, methods of rehabilitation, and eventual cures by researchers who listen carefully to what we say. We are the experts of the lived experience of dementia.

We hope this report helps future conference organisers in their efforts to make the conference experiences of people with dementia as meaningful, productive and accessible as they are for all other attendees.

Thank you.



Kate Swaffer  
Chair CEO & Co-founder  
Dementia Alliance International



# CONTENTS

THE HUMANS RIGHTS OF PERSONS WITH DISABILITIES	2
CREATE DEMENTIA- ACCESSIBLE VENUES	4
USE RESPECTFUL LANGUAGE	6
AVOID LABELLING PEOPLE WITH DEMENTIA	7
PROVIDE A DESIGNATED MEETING ROOM FOR PEOPLE WITH DEMENTIA	8
MEDIA GUIDELINES	9
WHEN INVITED KEYNOTE SPEAKERS ARE PERSONS WITH DEMENTIA	10
SPONSORSHIP	11
CLOSING REMARKS	12



Breakfast meeting group ADI 2012 in London

# THE HUMANS RIGHTS OF PERSONS WITH DISABILITIES

The Convention on the Rights of Persons With Disabilities was adopted by the United Nations General Assembly ten years ago, and has been ratified by 167 Member States and the European Union. It promotes the full and equal enjoyment of all human rights and fundamental freedoms by people with disabilities. One of these rights is to be supported to participate fully in the community.

We therefore recommend the following accommodations for people with dementia at conferences and related events:

1. A person with dementia should not be scheduled last or late at night, to avoid cognitive fatigue.
2. Inquire if a person with dementia is travelling alone, and offer to provide an assistant at the event.
3. Provide people with dementia with the contact name and number of a conference staff member.
4. Keep distractions to a minimum while a person with dementia is speaking (e.g. tweets, chats, and messages while the Chair is calling for questions).
5. Ask photographers to avoid crossing between the audience and the speaker; this is distracting from both perspectives.
6. Inquire as to whether relevant communication supports\* are needed, such as picture based communication boards, easy to read information and trained staff, to provide equal access for persons with cognitive disabilities.



\* Refer to Scope Australia's Communication Access guidelines:  
<http://www.scopeaust.org.au/service/communication-access/>



Professor Peter Mittler CBE presents on human rights at ADI 2016 in Budapest

## CREATE DEMENTIA - ACCESSIBLE VENUES

Every country has individuals or organisations of persons with disabilities who can provide an evaluation of the setting (also called a disability audit) to ensure full and equal access at any event. Conference organisers should make use of this expertise and make it possible for people with dementia to share their expertise.

Alzheimer's Australia provides free online tools to help modify venues to become dementia-friendly environments, with appropriate signage, modest effort, and minor expense. ([www.enablingenvironments.com.au/audit-tools--services.html](http://www.enablingenvironments.com.au/audit-tools--services.html))

General guidelines for dementia-friendly settings include the following:

1. Conference staff need to understand Basic English, and interpreters should be available.
2. Paths to restrooms and clear coloured signage indicating separate facilities for men and women must be clearly visible.
3. If lifts are not easily accessible, provide assistance to people with dementia for long walks, or for navigating stairs.
4. Offer appropriate support for people with visual and/or hearing impairments.
5. Disability access to the stage such as steps or a ramp with a handrail, is a requirement for all conferences and is essential for older people with or without dementia.
6. Appropriate disability equipment and assisted technology should be available at all conference venues and public buildings.
7. Support staff to be available for people with disabilities at central access points. Conference staff need basic training in how to assist people with dementia. For example, a Dementia Friends session should be offered.

The following are examples of the types of basic training currently available:

- 1) Dementia Friends UK sessions  
<https://www.dementiafriends.org.uk/WEBArticle?page=what-is-a-friend#.WAMMLzsugRI>
- 2) Dementia Alliance International  
<http://www.dementiaallianceinternational.org/events/master-classes/>
- 3) Alzheimer's Society UK, Understanding and supporting a person with dementia  
[https://www.alzheimers.org.uk/site/scripts/documents\\_index.php](https://www.alzheimers.org.uk/site/scripts/documents_index.php)
- 4) The Alzheimer's Australia video series, Is it dementia?  
<http://isitdementia.com.au>
- 5) The Alzheimer's Australia Talk to Me brochure  
<https://www.fightdementia.org.au/research-and-publications/papers-and-evaluations/talk-to-me>
- 6) Murray Alzheimer Research and Education Program, By Us For Us series of guides  
<https://uwaterloo.ca/murray-alzheimer-research-and-education-program/education-and-knowledge-translation/products-education-tools/by-us-for-us-guides>



DAI members at ADI 2016 in Budapest: (L-R) Dennis Frost, Helga Rohra, Agnes Houston MBE, Hilary Doxford, Mary Radnofsky, Kate Swaffer, Peter Mittler CBE, Chris Roberts

## USE RESPECTFUL LANGUAGE

We ask that all conference and event organisers and delegates use Dementia Language Guidelines, and that they ask they are used in all forms of media surrounding their events.

Currently, the Dementia Language Guidelines from Alzheimer's Australia are the most comprehensive, and the Deep Engagement and Empowerment Project (DEEP) language guidelines, Words Matter, support these well.

Using respectful language allows people to recognise that dementia is not the defining aspect of someone with a diagnosis, and does not necessarily reflect his or her capacity, or level of understanding, or their experience of living with it.

The appropriate way to refer to people with Alzheimer's, Lewy Body Disease, or any of the more than one hundred other forms of dementia is to say they are "living with or diagnosed with dementia," not "suffering" from it, as we so often hear in the formulaic media usage.

To be labelled publicly as a "sufferer," or as "demented" today is as disrespectful as being called "retarded" (a term considered insulting and demeaning by many with other disabilities). While we acknowledge that for some, the experience of living with dementia maybe one of suffering, it is important not to refer to all of us in that way as it is not the sum of everyone's experience, and can also cause suffering.

It is vital to use language at conferences that reduces stigma and focuses on the abilities not deficits of people with dementia, to help everyone to maintain self-esteem.

Our survey responses consistently mentioned clarity and accuracy as topics of importance. For example, we still hear experts mistakenly contrast "Alzheimer's or dementia," then accurately refer to Alzheimer's as one of almost 130 causes of dementia. These mixed messages continue to confuse people and keep myths alive.

### Respectful Language Links

Alzheimer's Australia (2016) Dementia Language Guidelines,

<https://www.fightdementia.org.au/files/NATIONAL/documents/language-guidelines-full.pdf>

Deep Engagement and Empowerment Project (2016) Dementia words matter: Guidelines on language about dementia,

<http://dementivoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>



## AVOID LABELLING PEOPLE WITH DEMENTIA

Delegates at conferences are usually identified by badges, and differentiated with words, ribbons, or colours to indicate their role (e.g. Speaker, Board Member, Staff, Sponsor, Guest, Representative, Press, etc.).

A diagnosis of dementia does not define a person's standing or responsibilities at such an event. It is therefore inappropriate to visibly brand or label any individual as a "Person with Dementia." No other delegates are labelled by disease or disability, nor should they be. Even at a number of 2016 conferences, some speakers have been indicated only as "Person with Dementia" and not by name on the final program. This is simply unacceptable. Members of Dementia Alliance International have requested that we be identified by name, role, sponsoring organisation and country (if everyone is so identified).

The consensus on our survey was that people with dementia have the choice as to whether and how much they tell others about their condition.

For practical purposes, our members also suggested that extra cards be added into the lanyard packet of receipts and meal tickets, to include, for example:

1. A card with a brief text such as: "I have a cognitive disability, - and may need assistance. My care partner is [insert name] and may be reached by [insert phone number] or in [insert room number]."
2. For care partners, a card with a brief text such as "My partner [insert name] has cognitive disabilities, and may require assistance."
3. An additional card allowing people with dementia access to the "Richard Taylor Room," previously known as the Quiet Room (discussed in the next section).
4. We also recommend a card is included that gives contact details of a staff member or conference organiser, in the case of an emergency or the need for additional support.

It will be helpful for potential delegates of conference and event organisers to indicate in the promotional material leading up to an event that the program will include people with dementia and family care partners and that it is expected that dementia-respectful language is used in presentations (e.g. no reference to 'sufferers').

## PROVIDE A DESIGNATED MEETING ROOM FOR PEOPLE WITH DEMENTIA

Because people with dementia often need a haven from the noisy environment of a hotel or convention centre, it is essential to designate a meeting room close to other conference events for the sole use of people with dementia. It must be off-limits to other delegates or guests, and the press.

If the room does not already have a name, we request if it is ADI event, that it be called 'The Richard Taylor Room' in honour of one of DAI's founder members. Other event organisers may prefer to choose their own name for this room. The important point is that it is NOT labelled the 'Quiet Room' or 'People with Dementia Room' (which potentially further stigmatises a person going through its doors).

This room should be listed and mapped in the conference program and must be easily accessible and comfortable. It should be located close to the conference main meeting rooms to allow easy access. If there is a DAI stand, it would be helpful if this was nearby, which should also be located close to the main conference meeting room or auditorium.



Edie Mayhew, Anne Tudor, Agnes Houston, Glenys Petrie and John Quinn at ADI 2016 in Budapest

## MEDIA GUIDELINES

We acknowledge that the Press has rarely, if ever, interviewed professionals with dementia (at least knowingly), and that journalists would like to better understand and convey the reality of our daily lives, especially those of us with younger-onset disease. That is also our goal.

However, our experience at previous conferences has shown that the Press did not know about (or did not respect) the privacy of the Richard Taylor Room; they entered and pressured people for interviews and filmed them without their permission.

To keep this from happening, we request that conference organizers work with us, so we can recommend members of DAI who wish to speak to the Press, be photographed, filmed and/or interviewed (some may request prior notice). We ask that the Press be reminded that the Richard Taylor Room is strictly off-limits.

For specific language use, please refer the media to the language guidelines on page 3 as well as to the article, "I am not a victim: Tips for reporting on dementia" <https://www.journalism.co.uk/news/iam-not-a-victim-tips-for-reporting-on-dementia-/s2/a566136/>



## WHEN INVITED KEYNOTE SPEAKERS ARE PERSONS WITH DEMENTIA

When people with dementia are scheduled for keynote addresses, they should be invited at the same time as other speakers (or even earlier). If a person with dementia is unconfirmed by the time of program publication, then write, for example, “Speaker to be announced.” This is preferable to the “Person with Dementia” label.

When DAI members or other people with dementia are invited as keynote speakers, they should be given at least one additional hotel night to allow for jet lag or fatigue; and their care partner’s travel expenses should also be covered.

We also request that ground transportation be arranged and/or that the cost of taxis be covered (since many people with dementia no longer drive or work).

Other dementia-friendly accommodations include clear and distinctive signage and the name and phone number of a conference contact who is available to assist people with dementia.



Agnes Houston and Trevor Jarvis celebrate the 10th anniversary of The Scottish Dementia Working Group at ADI 2012 in London

## SPONSORSHIP

To create an inclusive environment for equal participation at professional meetings, conference organisers need to find sponsors to fund people with dementia and their care partners.

Most are no longer employed, and many cannot afford travel expenses. It is therefore imperative to waive registration fees, sponsor travel, and subsidize hotel and food costs.



International Memory Walk at ADI 2013 in Taiwan

## CLOSING REMARKS

The recommendations in this report are meant to convey examples of the accommodations and disability supports required to enable equal attendance at conferences or other events. Where people with dementia are included to attend events, they must therefore also be supported to ensure inclusion is on an equal basis to all others. We appreciate your willingness to create a fully inclusive and accessible environment that will allow all our voices to be heard.

We strongly encourage new conference organisers to add the voices of people with dementia, even at purely scientific meetings, to ensure that our unique experiences are fully understood in context.

An inclusive conference should include the perspectives of family care partners, parents or children of people with younger onset dementia, representatives from Culturally and Linguistically Diverse (CALD) communities, Indigenous Peoples, Lesbian Gay Bisexual Transgender and Intersex (LGBTI) communities, homeless and other more marginalised individuals whose lives are directly affected by dementia.

Finally, we maintain that people with dementia should speak at professional meetings unless a practical accommodation or interpreter (e.g. Sign Language) is needed. In this way, the public learns to listen to our voices, even if we are not the loudest or most eloquent.

We are all people with names, a unique personal identity, experience, and an acquired wisdom that may surprise you. We can still contribute significantly to the conversation about what is happening to us, - and about our place in society.

**“NOTHING ABOUT US,  
WITHOUT ALL OF US”**







This report was prepared for Dementia Alliance International by Kate Swaffer and Mary Radnofsky PhD, with support from Professor Peter Mittler, and is based on the informal feedback received from many people living with dementia and their care partners who have attended conferences and other events over the last four years.

These guidelines have been prepared with the very best of intentions, and we always welcome additional feedback from people with dementia, those supporting a person with dementia, other speakers or conference organisers with any relevant feedback for our next version of these guidelines.

For additional copies, to provide feedback for the next edition of this report, or if you have any questions, please contact us at [mail: info@infodai.org](mailto:info@infodai.org) or go to the DAI Publications page. <http://www.dementiaallianceinternational.org/resources/publications/>

Dementia Alliance International (DAI) is a 501(c) (3) non-profit organization founded in 2014 and registered in the United States of America, with more than 2,500 members in over 38 countries. We are an advocacy and support group, of, by and for all people with dementia. We advocate for the human rights of 47.5 million people currently diagnosed with dementia worldwide.



We wish to thank Alzheimer's Disease International for supporting people with dementia to attend conferences and meetings, and for their sponsorship of DAI to support this. Our close collaboration is mutually beneficial to people with dementia, our families, and to the ADI members.

email: [info@infodai.org](mailto:info@infodai.org)

web: [www.infodai.org](http://www.infodai.org)

join DAI: [www.joindai.org](http://www.joindai.org)



[www.facebook.com/DementiaAllianceInternational](https://www.facebook.com/DementiaAllianceInternational)



@DementiaAllianc