



# Guidelines on Inclusive Travel and Meetings for People with Dementia

**These guidelines are targeted at organisers of meetings and travel involving people with dementia and also include some feedback for people with dementia and carers attending such meetings.**

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# Introduction

People with dementia have a right to participate actively in society and to have a say in decisions that affect them and their lives. All reasonable measures must be taken to enable them to exercise that right. Many people living with dementia have described feeling empowered or valued after participating in meetings and discussions (e.g. about research or advocacy activities). Including people with dementia in such activities acknowledges the significance of their life experiences and the value of their perspectives, viewing them as experts in their own right. It is therefore crucial to organise travel and meetings with accessibility in mind and to consider the specific needs and wellbeing of people with dementia. Ensuring inclusivity involves not only physical aspects but also addressing cognitive and emotional issues. It is essential to provide clear information, offer adequate support and create an environment that is suited, as far as possible, to people's requirements.

This document provides some guidance for people and groups who are responsible for organising meetings and travel involving people with dementia<sup>1</sup>. The topic of inclusive travel and meetings for people with dementia was initially addressed by the EWGPWD in 2020 and has been revisited in the course of several consultations with the group's members in 2023. These guidelines are, therefore, based on the perspectives and experience of members of the EWGPWD. Some additional input was also provided in 2023 by the members of the recently formed European Dementia Carers Working Group (EDCWG).

The guidelines specifically focus on the measures that meeting organisers should consider taking when arranging travel for/with people with dementia and organising inclusive meetings (e.g. how to plan and structure meetings, present information, facilitate discussions and ensure understandability, respect and diversity). This can include many different types of meetings, but these guidelines specifically relate to working meetings (e.g. not peer support or informative meetings). There are also different possibilities to consider such as when one or more people with dementia are invited to a meeting alongside professionals, or with meetings in which all the people involved have dementia. Guidelines already exist that were developed with people with dementia on how to make venues, meeting spaces and information accessible/understandable to people with dementia. For this reason, this document does not provide detailed recommendations on these issues. Similarly, as the EWGPWD has already produced guidance on communicating with/about people with dementia and portraying them in an ethical and inclusive manner, this will not be repeated in this document but is very relevant to the topic.

In the first part of this document, we cover eight key issues, each starting with a broad recommendation followed by an explanation on how to fulfill that recommendation. In number eight we specifically address issues related to online meetings. The list is not exhaustive; these are just examples. The second part of this document includes tips for people with dementia and carers/supporters from the members of the EWGPWD and the EDCWG.

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<sup>1</sup> Hereafter referred to as "meeting organisers".

# Guidelines for organisations involving people with dementia in meetings

1. The organisation of meetings and travel should be adapted to the needs and preferences of a broad range of people with dementia, including people from marginalised groups and minority groups.

It is important to ensure that people with dementia have opportunities to travel to and actively participate in meetings, should they wish to do so and to the extent that this is possible through the provision of appropriate support. Such opportunities and support should be available and adapted to people from a broad range of different backgrounds (e.g. people with different types of dementia, different ages groups, living in rural areas, people from minority or marginalised groups).

Consider getting in touch with other organisations (e.g. gatekeepers from minority groups) to help reach out to people from diverse backgrounds and learn about their possible needs and preferences regarding travelling to and attending meetings

2. Organisers should encourage people with dementia to consider whether it may be helpful to be accompanied during travel or at meetings by a supporter<sup>2</sup> of their choice.

Whilst some people with dementia may not need any support for attending meetings, others may need or find it reassuring to have someone who can help them when preparing for the meeting, whilst travelling or during the meeting. This should be a person of their choice, ideally someone they already know and feel comfortable with. It could be a relative (e.g. a spouse/partner, daughter or brother) or a friend, volunteer or staff member from a dementia association.

The supporter might not necessarily be needed all the time. The support whilst travelling may be particularly relevant, for example, in the case of international travel. Having a supporter can be very helpful when things happen unexpectedly, or to provide guidance, reassurance or emotional support during travel, thereby promoting autonomy and respecting self-determination rather than taking over unnecessarily. Organisers should also have a clear policy about their responsibility for the safety and wellbeing of people with dementia travelling to and attending meetings.

It is important to ensure ahead of the meeting that the person with dementia and the supporter have discussed and agreed on the supporter's role (e.g. whether they are expected to attend the meeting or only assist with travel and/or preparation). Whilst there should be some flexibility, as needs and wishes may change along the way, this helps ensure that the supporter understands their responsibilities and knows what to expect.

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<sup>2</sup> Supporters in these guidelines refers to any person (e.g. spouse, adult child, friend or volunteer) who provides support to a person with dementia whilst travelling to or attending a meeting.

3. Travel arrangements should be discussed in a timely manner and should be adapted, as far as possible, to each person's needs and preferences.

Travelling can be an exciting and positive experience. However, it can also present certain challenges; it can be disorientating, cause anxiety, uncertainty or confusion and, at times, be physically tiring. It is therefore of paramount importance to discuss this with people with dementia and take into consideration their potential cognitive difficulties, as well as specific needs and wishes affecting their physical, emotional and psychological wellbeing. This discussion should cover travel from the person's home to the meeting venue (and back) and accommodation if and when needed. The actual organisation of travel and accommodation can also at times be challenging and overwhelming for people with dementia. Therefore, if possible, organisers should offer to book flights, trains, taxis and hotels etc. in advance.

Travel can be at local, national or international level and may differ in terms of the level of complexity or potential challenges for people with dementia. There is sometimes support available that people with dementia can benefit from (e.g. special assistance at the airport or train station, quiet areas, disability ID holders/badges etc.). When arranging and discussing travel arrangements, it is important to be aware of these possibilities, share this information with the person with dementia and their supporter, make sure they understand how they could benefit from these resources and offer to arrange them if that would be helpful. To ensure that people with dementia are well rested and can meaningfully participate in the meeting, it is important to offer direct flights and minimize unnecessary connections and layovers, avoid very early or late departure times and offer the option to stay overnight or arrive a day before if and when appropriate.

If travel plans include taking more than one flight or train, it is crucial to make sure the person with dementia knows about and is comfortable with the amount of time between the connections. It is also important to ensure that people with dementia have enough to eat and drink whilst travelling (for their comfort and wellbeing but also to avoid dehydration and other physical consequences). Specific needs linked to possible overnight stays should also be considered (e.g. the type of room, preference for a room near the lift or in a quieter part of the hotel, twin/double bed or separate room depending on the relationship to the supporter).

It is essential to keep in mind that unforeseen events like illness, accidents or emergencies can affect travel and meeting plans. This can even include events such as natural disasters or terrorist incidents. A person might need to stay an extra night or reschedule their flight if they fall sick or if their flight or train is cancelled because of weather conditions or strikes. If this occurs, make sure that appropriate and timely measures are taken and that the person is supported accordingly.

People with dementia and supporters should receive clear, written information about the travel logistics and arrangements and a named contact person that they can contact for any questions or unexpected issues during the journey (also outside office hours).

#### 4. Financial issues should not deter people with dementia from participating in meetings.

Travelling to meetings can involve several costs and sometimes it can become quite expensive. To ensure that people with dementia have equal opportunities, it is important that such costs are properly covered and do not hinder their travel to and participation in such meetings.

Expenses should be covered, as far as possible, by the organisers upfront (i.e. in advance especially for foreseen costs such as travel tickets, hotel accommodation and taxis) and/or as a reimbursement afterwards (e.g. for other out-of-pocket expenses such as meals whilst travelling, bus fares or metro tickets).

The person with dementia and their supporter should receive clear and transparent information about which costs will be reimbursed, how to claim expenses and what will be required (e.g. original receipts). The expenses covered should include reasonable costs incurred whilst travelling and attending the meeting for the person with dementia as well as their supporter. Reimbursement should be made in a timely manner and the reimbursement process should be straightforward, clear and accessible.

#### 5. People with dementia should receive appropriate and accessible information before the meeting.

Background reading materials should be sent to people with dementia well in advance of meetings (one to two weeks in advance). This should include not only an overview of the topic, the purpose of the meeting, why people with dementia have been asked to participate and who is organising the meeting, but also what is expected from them and what kind of support will be available. Background reading materials should not include jargon or technical terms and should be written in plain language and in an accessible format. If technical terms have to be included, a glossary should be provided. In addition, any pre-meeting materials and support should be appropriate for a broad range of people and should not be culturally biased.

It is important to offer people with dementia the opportunity to ask questions or for certain issues to be explained before the meeting. This can contribute towards a good working relationship with participants and also reassure those who are perhaps not familiar with or confident about participating in such a meeting.

#### 6. Organisers should try to provide the right balance between support, the promotion of wellbeing and empowerment during meetings so as to promote meaningful participation of people with dementia in meetings.

Whether inviting one or a few people with dementia to a meeting with other people who don't have dementia (e.g. researchers or policy makers) or holding a meeting with people who all have dementia, the needs of people with dementia should be carefully considered and prioritised. It should not be just "business as usual". This applies to the way the meeting is structured, the facilitation of the meeting, the layout and facilities of the venue and the materials provided. The Chair or facilitator of the meeting should be aware that people with

dementia are participating in the meeting, have a good understanding of dementia and create the necessary atmosphere and conditions to enable them to express their views and contribute meaningfully to the discussion.

Plain, straightforward language should be used and it should be borne in mind that some people may need more time to understand and express themselves, especially if the main language being used in the meeting is not their mother tongue. It is important to speak slowly and clearly (without exaggerating). Presentations and slides should be clear and not too crowded without exaggerating.

Careful consideration should be paid to how topics will be addressed in the meeting. Questions should be relevant and appropriate (e.g. about the personal experience, views or concerns of people with dementia, rather than about abstract facts and figures). Organisers should bear in mind the possible complexity and sensitivity of certain topics. Sufficient time should be allocated to explaining the topic and allowing for questions. Vignettes can often be helpful when addressing sensitive topics. When addressing sensitive topics (e.g. palliative care, progression of the disease) a plan should be in place to ensure the wellbeing of the people participating in the meeting. If possible, sensitive topics at the end of the meeting should be avoided.

There should be sufficient breaks during meetings and the person with dementia should be encouraged to have a rest during the meeting whenever they feel the need. As meetings and travelling can be tiring, people with dementia may appreciate having some time and a space to unwind and relax before setting off back home.

Meals, snacks and drinks should be provided during and between meetings. When meetings are long or over several days, opportunities to socialise and get some exercise or fresh air should be considered.

It is sometimes helpful to break up into smaller groups. This option should be considered in advance as meeting rooms are not always ideally designed for this (in terms of available space, room layout and acoustics).

Meals, snacks and drinks should be provided during and between meetings. When meetings are long or over several days, opportunities to socialise and get some exercise or fresh air should be considered. Toilets, lifts and stairs should be close to meeting rooms, easily accessible and signposted.

## 7. A mutually respectful and positive atmosphere should be promoted.

Meetings should take place in a safe, open and respectful environment where everyone feels comfortable expressing their views and perspectives, without fear of judgment.

The facilitator or chair of the meeting should ensure everyone has an opportunity to speak, and no one dominates the discussion. It is also important to ensure to equally value everyone's contribution and not to differentiate between experts by experience and experts by learning. There should be time for introduction at the beginning of the meeting, especially if participants are unfamiliar with each other, to help people feel more comfortable. It should



be clear to the participants how their feedback will be used. Providing this information helps ensure transparency and reciprocity. It also assures participants that their input is valued and contributes to the decision-making process or activity in a meaningful way.

Whenever possible participants should find meetings enjoyable and rewarding. Their input should be acknowledged and should be shown for their contribution.

#### 8. Consider the specific needs of people with dementia, and also of their supporters, with regard to participating in online meetings.

Online meetings really took hold during the COVID-19 pandemic. They brought with them challenges (with some people finding them overwhelming, experiencing visual overload, having technical problems and not feeling comfortable speaking etc.). These issues were not limited to people with dementia but having dementia resulted in some additional challenges and their supporters were not necessarily always familiar or at ease with online meetings. Such meetings nevertheless also had some advantages (e.g. people could continue to “meet”, meetings were less costly and people from more remote areas could more easily attend). Some of what has been mentioned so far about meetings applies to the organisation of online meetings and the following points should also be considered.

- It is important to offer people with dementia and their supporters the opportunity to familiarise themselves with the online platform that will be used for the meeting (e.g. a step-by-step guide, a video tutorial or an online practice session).
- Meeting organisers should clearly communicate the details of the meeting in advance, including the date, local time, a simple agenda, the link and details on how to join the meeting. A reminder should be sent (e.g. one week and one day before the meeting), together with the meeting link.
- Technical support should be offered to people with dementia who may encounter difficulties accessing and during the online meeting. Ideally, there should be someone who is responsible for dealing with technical issues who can help the person to sort out any problems that they may be experiencing, thereby reducing frustration for the person experiencing the technical issues and avoiding disruption of the meeting for the other participants. Additionally, consider asking people with dementia and supporters to provide a telephone number so that the technical issue can be discussed offline during the meeting.
- In particular, it can be useful to discuss with participants the length of the meetings and the number of people present at meetings which is suitable for them. In general, shorter meetings are preferred, however, they should be long enough to make sure there is time for discussing in a meaningful manner and no need to rush over things. In longer meetings (e.g. longer than 1.5h), it is usually recommended to schedule a break of at least 10-15 minutes.
- Meetings should include some social time for participants. This can for instance include time for a chat or icebreaker at the start or end of the meeting.



- As the online environment may be more challenging for some people with dementia, consider organising smaller group meetings or using breakout rooms during the meeting. If the latter, make sure that it is easy for people to move to the breakout rooms.
- Consider whether and how to use visual support during online meetings. On the one hand, this may help people with dementia to follow the presentation, but it may make it more difficult to see the other people at the meeting and make discussions less engaging.
- Meetings should maintain a clear and structured format based on the information sent in advance. It is important to avoid rapid transitions between topics and for speakers to provide clear cues when moving from one agenda item to the next, allowing participants to stay focused.
- Meeting organisers and facilitators should carefully monitor signs that people wish to speak. Sometimes, they might not be able to find the “raise hand” or “unmute” functions, or to react fast enough to contribute to the discussion in that way. This is very common in online meetings but may result in people with dementia forgetting what they wanted to say or losing track of the discussion. For this reason, it can be helpful to have more than one facilitator.

## Tips for people with dementia and supporters travelling to and participating in meetings

### Tips for people with dementia:

1. When travelling to a meeting, don't be afraid to ask for help or information.

“Don't be too proud to ask for help, because generally people are lovely, and they will help you! Take a deep breath and ask”.

“There is no such thing as a stupid question”.

2. If you can, travel with a supporter and plan and discuss travel arrangements with them in advance.

“I have different supporters I travel with. And in my situation, I travel a lot and so I think every time I can do anything... and then sometimes I don't understand something, and it is really important to have a supporter with me, so they have the same view as me in the moment. It is the feeling that I can do it, if I receive instructions, and the supporter receives some too”.

3. Consider wearing a badge or other visible sign that shows you have a disability or dementia and need additional support (e.g. a sunflower lanyard or an EU disability card).

“I have a badge that says ‘I have Alzheimer’s, please be patient’. I accept it advertises my vulnerability, but people are so helpful. So, something like that can help”.

“A lanyard is important. It is so much smoother going in the quick lane. I didn’t get it coming over – and my shoes had to come off and I got a full body search, so it’s really important to have it”.

4. Carry a pouch containing information about your needs, medical condition(s) and other important details that would help should anything happen to you when travelling.

“I wear a pouch every time I travel. It shows your name, that you have dementia and where you’re from. It also can carry your passport and boarding card. If I want help, I need them to know”.

5. Use travel assistance if needed and do not be ashamed about doing so.

“First tip is to know your own limitations and don’t be afraid to ask for help...use the assistance services! Don’t be ashamed!”

### **When attending meetings:**

6. Ask if there is something you do not understand during a meeting/discussion.

“It is important for people with dementia to feel like they can ask the following questions: ‘Can you explain that to me again? Can you repeat that?’”.

7. Recognise your value and expertise as someone with lived experience and know you deserve a place at the table.

“In some meetings, some people, such as researchers or policy makers, may seem a bit arrogant or say something that you do not agree with or find disrespectful. In such cases, you should say what you think”.

8. Do not leave a meeting feeling upset. Make sure you ask for support or share how you feel if you are given the opportunity to do so, and give feedback on what didn’t work so well.

“Do not leave a meeting feeling upset because of certain words that were used”.

“I felt a bit unwell and sensitive about a discussion at some point during a meeting but when I shared this, everyone provided emotional support. It was a special moment for me. And it was also like, I feel like I felt safe”.

9. If you don’t have a lot of experience in using technology for online meetings, be open-minded as online meetings can be a next-best alternative to in-person meetings and have certain advantages (e.g. no need to travel).

“Online meetings are a good second-best option”.

“Nowadays, digital meetings are a great way to involve people who do not live in the same country... The online meetings of our group help create a sense of family and community”.

10. Ask for support with technology if you need it when you join/are in an online meeting (e.g. to your supporter or meeting organisers).

“There are sometimes some technical issues but my husband is my ‘technical manager’ and he is able to deal with such issues”.

### **Some specific tips for supporters:**

11. Familiarise yourself with all the relevant information in a timely manner.

Make sure you have all the relevant information about the travel, accommodation and meeting (e.g. address, time of the meeting, relevant telephone numbers). It is important to discuss this ahead of time with the person with dementia to understand how you can best support them.

12. Discuss and plan ahead for items to bring.

Discuss with the person with dementia all the different things that will be needed for the meeting and travel and, if necessary, provide support to the person to ensure this has been packed. This can include relevant documents (e.g. European health insurance card, passport), medication, and other items that the person may need or may find useful whilst traveling (e.g. book, iPad, disability lanyard or card if available).

13. Understand what is expected of you.

It is important to understand your role as a supporter of someone with dementia, and what is expected of you to support the person while travelling and/or attending a meeting. This may be particularly relevant if you have never travelled before with the person or are not sure of what the person may need or value.

If you are regularly supporting a person with dementia, be mindful that as the disease progresses, the level of support that they need may change as well.

Keep in mind that emotional support for people with dementia may be required in addition to organisational/ practical support.

14. Prepare in advance and know that unexpected events may occur.

Keep in mind that you may also face unexpected situations when travelling and attending meetings. Make sure to enquire about any assistance available at the meeting that can help you support the person with dementia (e.g. a quiet room for them and a meeting organiser who can also provide support at).

15. Make sure to also take care of your wellbeing.

Attending meetings and travelling as a supporter can also be stressful for you so it is important to take steps to take care of your own mental wellbeing.

# Authors

This report was developed by the current members of the EWGPWD in collaboration with Alzheimer Europe (Dianne Gove, Ana Diaz, Soraya Moradi-Bachiller and Daphné Lamirel) building on earlier work carried out by members of the EWGPWD in 2020. Special thanks to the supporters and carers of members of the EWGPWD and to the members of the EDCWG.

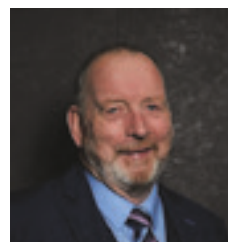
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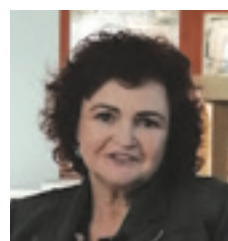
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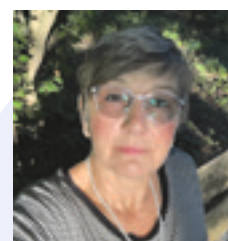
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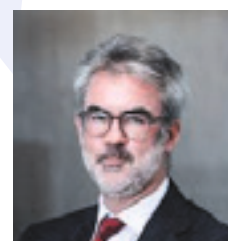
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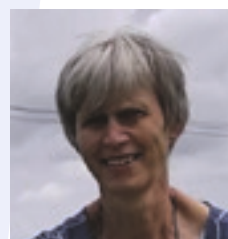
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