

Dementia Awareness Toolkit for Sand Dune Site Managers: Contacting local groups



How to contact a local group and work on a project together

People living with dementia are the only true source of information about what it is like to live with dementia. To know what adaptations we may, or may not need to make, **we need to have meaningful conversations** with them.

But how do you do that?

You may want to work with a local group or set up your own focus group to understand some dementia specific needs. For example, if you are setting up an event or a creative project. Or you may be considering questions at your site around visitor experience, information, or changes to facilities.

Working with a local group supporting people living with dementia

- You may want to connect with an existing group where people with dementia feel safe and supported to share their views.
- It is important to consider that many are fearful of being critical – so better to frame it as a fun and creative experience.
- Be aware that not everybody in a group will be interested in your work – it may be better to invite people to come together from various groups and offer tea and cake as a thank you.

Setting up your own focus group:

- You may be able to set up your own group by using your usual media channels or by targeting your membership. This way you may find that you have people who already know your site who have experience either from living with dementia, or in a carer's support role.
- Some people may have already experienced difficulties. They may care about your site and have come up with solutions.
- Engaging with people who already use your site, may lead to some becoming passionate advocates about what you do.

Starting conversations with a local group

Before contacting a group, it may be helpful to read up on the following DEEP guides:

- [Collecting views of people with dementia](#)
- [Involving people with dementia in advisory groups](#)

These guides have been co-produced with people living with dementia and describe good practice for involving people and hearing their views.

- Contact the group coordinator and explain your idea. It is important to have an open mind and not make assumptions around dementia and disability.
- Seek advice from the group coordinator about the best way to arrange a visit that fits in with the group and their timings. Sometimes coordinators can take on a facilitation role.
- Embrace co-production (working together) for all steps of what you are doing.

- It may be helpful to have a short summary (written in inclusive language and with photos if helpful) to draw on for conversations before and at your meeting. This may cover the reason you are here, or what you would like to do with the group.
- If you are asking people to visit your site, consider what information people might need to think about before going to a place they've never been before.

Visiting a local group on the day:

- Bring visual materials (pictures, leaflets, postcards), and handling materials (natural objects or items linked to the site) to help with conversations.
- Take cake!
- Be guided by what the group is doing. You may be joining in other conversations or activities before it's your turn.
- Wear a name badge so people can easily read your name
- When you are introduced, be friendly and clearly explain why you're here.
- Be brief – the main point is to hear other people's voices
- Speak slowly and don't overwhelm people with information.
- Spend time with people in the group getting to know them and listening to what they say.
- Visual prompts – you might want to use short key questions on card to have on the table
- Consider taking yellow **'I want to speak' cards**. Editable download cards are available [here](#) People with dementia tell us that using these cards helps get attention in a discussion group so that they can say an idea or suggestion before they lose the immediate memory or point in that conversation.
- Consider how you will ask questions; creative questioning can help people join a conversation even if it's not directly about why you are there. For example *'I wonder what.....?'*
- Questions about a place might include: *'What do you like to do? What might you like to do? What do you find tricky? What might help?'*
- Visual prompts – you might want to use short key questions on card to have on the table
- Simple nature boxes containing items to look at and handle can be a good way to start conversations. Consider how people can experience them through the senses e.g. texture, smell, unusual colour or shape.
- Consider bringing a tablet device, (or use a TV smart screen if available) to show short video clips (1-2 mins long) as another way to show or explain things you want to talk about. Short videos of places, specific facilities or showing an example of an experience can be really engaging.
- At the end of the session agree with the group what the follow up and next steps will be.
- If the group is going to make a site visit, work out with the group a plan for that visit and what you hope to achieve.



Site visit with a focus group.

If you have invited people to visit your site, you should have already met with them as a group, spoken to them individually or worked closely with a local group organiser so people know what to expect and what you hope to achieve out of a visit.

You will also need to:

- Complete or draw on your existing risk assessment.
- Provide a clear plan and instructions for the day.
- If you plan to record, take photographs or use quotes then you must get everybody to sign a consent form.
- Be clear about breaks, refreshments, quiet areas and access to toilets and other facilities.

- Make sure that what you plan to do as a group is flexible and considers support needs within the group. The best way to do this is to ask people individually before the visit – ‘What can I do to make the meeting comfortable for you?’
- If other staff or volunteers are attending, it is helpful if they have some dementia awareness or experience. However, the most important thing is for people to be treated respectfully and as equals.
- Ensure that there are enough members of staff and/or volunteers to meet and welcome group members as well as provide support (if needed) during the visit and when people leave.

* For an example of working with a focus group, see the report [Dynamic Dunescapes – Building the voices of people living with dementia into a four-year partnership project \(Dementia Adventure, 2018\)](#) (This example shows how Lincolnshire Wildlife Trust, Dementia Adventure and the Square Hole Club - a young onset dementia carried out a site visit at Gibraltar Point NNR. They worked with Wildlife Trust staff on how to improve visitor experience from experience on arrival, getting to and using the bird hides, and how accessibility information was provided.

After your visit to a local group or site visit

We all like to get feedback when we have been asked for ideas and suggestions. It is an essential part of working together.

After your visit, ask the group or facilitator how they would like to get feedback. This might be by visiting the group again, or producing a clear summary with images.

If you have not acted on what was suggested, it is also important to give feedback about why this did not happen.

A clear bullet point list of ‘**You said.... We did**’ responses can work well.

How do I find local dementia and carers support groups?

Search for your nearest group by asking locally, and searching online including Facebook. Every area is different in terms of how local services are funded and who delivers them.

These organisations provide a search option to find groups and services by entering the nearest town or a postcode:

- Age UK – [Age UK dementia and carer support groups](#)
- DEEP – the UK Network of Dementia Voices – [DEEP groups](#) consists of around 80 groups of people with dementia – groups that want to change things.
- Alzheimer’s Society - [Dementia Connect - local support groups and partner services](#)

You could also do a web search for local authority dementia support services and your local Dementia Action Alliance (DAA) for contacts. Local DAA’s list dementia friendly organisations and businesses in their area as well as news of events and initiatives. It varies by area how active DAA’s are, and how up to date their information, so check carefully.

See also: Dementia Awareness Toolkit – Site Considerations & Auditing, downloadable from <https://dynamicdunescapes.co.uk/get-involved/site-managers/>

This resource was produced by [Dementia Adventure](#) and [Dynamic Dunescapes](#).

