Half the Story

A guide to meaningful consultation with people living with dementia, families and carers.

> “You cannot feel what it is like inside our minds. Without us, you only have **half the story**.”
>
> Person living with dementia

Acknowledgement

Half the Story contains information, tips, and strategies for community groups, service providers, businesses or other organisations that want to consult in a meaningful way with people living with dementia, families and carers.

It will help you:

- set up your consultation process
- refine your approach
- increase participation and engagement.

People living with dementia, families and carers may like to share this guide with their peers, clubs, community groups, fellow committee members, and service providers.

Dementia Australia co-authored this guide with people living with dementia, families and carers. We sincerely thank them for their contribution.

For further information and enquiries please contact:

National Dementia Helpline
1800 100 500

Find us online
dementia.org.au

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Definitions

The terms used in **Half the Story** are based on advice from people living with dementia, families and carers.

Some people may prefer different terms. When working with people living with dementia, families and carers, it is good practice to ask which terms they prefer.

Advocate
An advocate is a person living with dementia, family member, or informal carer who is participating in consultation. Advocates bring more than just a lived experience of dementia. They offer a wealth of skills, expertise and industry understanding of dementia.

In other settings, you may also see the term ‘consumer’ used to describe people in this role. This role is different from a legal or medical advocate. A legal or medical advocate is someone chosen to speak or make decisions on a person’s behalf.

Meaningful consultation
Meaningful consultation describes activities where the primary aim is to seek out, affirm and ratify the voice of people living with dementia, families and carers. You may see this type of activity described as engagement, advocacy, involvement, or participation.

The Public Participation Spectrum, developed by the International Association for Public Participation, is used by many agencies, including the Department of Health, to map the level of consultation required for a project. These levels are: inform, consult, involve, collaborate and empower. Co-design is an increasingly popular form of meaningful consultation which is equivalent to the level ‘collaborate’. We explore these levels of participation on page 17.

Families and carers
Families and carers are people of any age or gender who provide informal support to a person living with dementia. ‘Family’ refers to the intimacy of the relationship, but a person may not necessarily be a relative. When we speak of families and carers, we include current and former carers. Some people prefer the terms ‘care partner’, ‘family carer’ or ‘caregiver’.

Person living with dementia
A person living with dementia is someone living at home or in residential care, who has a diagnosis of dementia. It refers to people diagnosed with dementia of any type, including people with younger onset dementia. It can include people with a provisional diagnosis or mild cognitive impairment.

Project
Project describes stand-alone, ongoing, or time-limited activities that would benefit from meaningful consultation with people living with dementia, families and carers. This includes dementia-friendly communities, service reviews, policy development and resource creation.

Understanding the full story

Introducing meaningful consultation

Meaningful consultation is necessary to understand the full story. Half the Story shows you how to meaningfully consult with people living with dementia, families and carers. It explores:

- the importance of meaningful consultation
- various consultation approaches
- consulting in an accessible way.

Many of the recommendations are based on advice from people living with dementia, families and carers with years of advocacy experience.

> **“People don’t want to ask, so there is a big silence. You need to speak up and fill the gap.”**
> Person living with dementia

When we consult in an accessible way we remove or reduce the barriers that prevent people from participating. These barriers can be physical, environmental, or societal. People living with dementia, in particular, are at risk of negative stereotyping, discrimination, or having their voice or decision-making power taken away. This can also impact families and carers. Before embarking on a consultation project, consider how you might reduce these barriers, rather than feeling overwhelmed by them.

Dementia, as a condition, does not discriminate. It can affect people from all cultural backgrounds, ethnicities, religions, ages, genders, sexualities, professions and economic backgrounds. If you have met one person living with dementia, you have only met one person living with dementia. No two experiences are alike.

We can challenge our own understanding of dementia by:

- becoming a Dementia Friend
- learning about the different types of dementia
- trying different consultation approaches
- talking with people living with dementia, families and carers.

Expect that meaningful consultation will require you to work differently. Most of these changes are simple. Others require time, resources and commitment.

In many ways, meaningful consultation, especially with people living with dementia, is still an emerging methodology. Even experienced facilitators occasionally experience setbacks. However, by building meaningful consultation into your project, you are supporting a global movement towards greater transparency, empowerment and inclusion.

> **“I have an inquiring mind. Interacting with people in person or speaking to a group—I just love being a part of helping people and making a difference.”**
>
> Person living with dementia

Why meaningful consultation matters

People living with dementia, families and carers have important things to say about life with the condition, their hopes for the future, and areas where better support is needed. Through consultation, you can identify opportunities for improvement and develop solutions together.

Meaningful consultation:

- respects advocates' dignity and human rights
- recognises knowledge and skills
- amplifies advocates' voices
- involves people in decisions that will affect their lives.

Meaningful consultation can dispel myths and misconceptions about dementia. It ensures your project is ethical and meets the needs of people living with dementia, families and carers.

Becoming an advocate and participating in meaningful consultation is empowering for people living with dementia, families and carers. It is an opportunity to become a community champion, create positive change and break down discrimination.

> **“I value the opportunity to share my 15 years of lived experience with people new to the world of dementia. One can learn about driving a truck, but until one has driven one, that knowledge is useless. Practice makes perfect; lived experience makes perfect.”**
>
> Family carer

What makes consultation meaningful

Consultation becomes meaningful when we hear, respect, and act upon the ideas, opinions and experiences (both good and bad) of people living with dementia, families and carers. It is a genuine invitation to shape the outcome of your project.

Sometimes advocates feel that a consultation is not meaningful. This can occur when:

- they are asked to approve a decision which has already been made
- it is too late to make suggestions or changes
- they are there to meet a deliverable, indicator or funding requirement
- it lacks support from managers or senior decision-makers
- they cannot participate to their full capacity
- other participants use jargon, acronyms, or terms they don't understand
- people without dementia talk on behalf of people living with dementia (paternalism).

> **“Work with our strengths, whoever we are.”**
>
> Person living with dementia

> **“Being an advocate creates inclusion and friendships. Having my views valued and considered brings me a great sense of purpose.”**
>
> Person living with dementia

> **It is imperative that the authentic voices of people with dementia and care partners of people with dementia are heard and valued, and that our feedback is acted upon. So far, in my experience, very little has ever been acted upon. And when I dare to have a different opinion, I am no longer invited to the table.**
>
> Person living with dementia

We can avoid these issues with proper planning and a positive approach.

Meaningful consultation thrives when everyone:

- is positive and enthusiastic
- understands the different types of dementia
- is ready to listen with an open mind
- can speak without judgement or consequence
- has genuine capacity to influence the outcome
- respects each other's interests, skills, and abilities.

Benefits of meaningful consultation

> **The reason I do advocacy is to bring about change for the better.**
>
> Person living with dementia

People living with dementia, families and carers become advocates because they want the best possible outcomes for Australians affected by the condition. They offer unique insights and ideas that will add value and conviction to your project.

People living with dementia, families and carers:

- are experts in the lived experience
- can identify shortfalls, gaps or unmet needs
- bring new ideas and perspectives
- can advise on feasibility and efficacy
- can help you reach your target market
- come from a broad range of professional backgrounds.

> **“ It gives meaning to the discussion when people living with dementia validate the project as meaningful and useful. It’s good for researchers and others to meet people with dementia because it makes it real and can influence future projects. ”**
>
> Person living with dementia

> **“ It answers the need for health and aged care policymakers, researchers and non-government organisations to understand the issues that affect the wellbeing of people with dementia and their carers. ”**
>
> Family carer

Benefits of becoming an advocate

People living with dementia, families and carers tell us that being an advocate:

- is enjoyable and rewarding
- is intellectually stimulating and helps maintain cognitive function
- offers fulfilment from helping others
- introduces them to new friends, peers and experts
- gives a sense of belonging
- expands understanding of dementia research, treatments and services
- is validating and gives meaning to their diagnosis
- inspires a sense of purpose.

> “I love the fact that it brings me into contact with others. I love to help plan strategies, give recommendations, listen to other’s opinions and learn about new treatments or improvements. So far, I have been privileged to meet a great group of people.”

Person living with dementia

> “I enjoy putting forward the thoughts and ideas of the people in my support group, as well as my own ideas. It is the lived experience that is needed.”

Person living with dementia

> “When I am consulted, it validates the years I invested into this role of caring. It affirms that my contribution, my role as a carer, is valuable. I am also consulted much more these days about forward-thinking in the areas of health and aged care management. I find these engagements invigorating and enthralling.”

Family carer

Planning a meaningful consultation

Which projects need meaningful consultation?

People living with dementia, families and carers should be a part of any decision-making process that will impact the lives of people affected by the condition. This can range from daily care and treatment decisions, to national or international policy and service design.

Projects that need meaningful consultation include:

- scoping, feasibility or needs analyses
- developing new services or programs
- reviewing existing services or programs
- setting strategic goals, aims or plans
- applying for funding or grants
- end user or accessibility testing
- creating resources about dementia
- wanting to understand the lived experience
- community developments like a dementia-friendly community.

> **“Nothing can replace the value of the personal story, the personal experience.”**
>
> Family carer

When is the right time to consult?

It is always best to consult as early as feasible, ideally in the planning stages of your project. You should also conduct regular consultation throughout your project. This will ensure you continue to reflect the needs and preferences of people living with dementia, families and carers. It also reduces the risk of getting negative feedback during the user-testing, implementation, or evaluation stages.

> **“Without consultation from the start, you miss out on fundamental points and cannot achieve meaningful results.”**
>
> Person living with dementia

Ethical considerations

When working with advocates who are living with dementia you are likely to encounter some unique ethical considerations. Your consultation plan should include ways you will address the following issues.

Consent

Have an accessible process for obtaining consent, preferably in writing, and provide advocates with a copy. If your project is ongoing, check in routinely regarding consent, particularly if the project changes or you wish to share information outside the consultation (such as images, quotes, or names).

Privacy

Respect advocates’ right to privacy. Never publish or share identifying information without each advocate’s informed consent.

Safety
Advocates must be safe to express themselves without actual – or feared – judgement or reprisal.

Wellbeing
Advocates' physical and psychological wellbeing is the highest priority. Have a respectful exit plan for advocates who no longer want (or are able) to participate. On page 41 you can learn more about overcoming common challenges and looking after advocates' wellbeing.

Honorariums and sitting fees

Respect and appreciation for advocates' contribution and expertise is essential to meaningful consultation. Honorariums and sitting fees are ways of acknowledging their time and expertise.

Asking advocates to participate without payment can unintentionally reinforce an unequal power dynamic and make them feel secondary to the decision-making process.

For face-to-face consultations (such as committees or focus groups), an hourly or daily sitting fee is appropriate. When hosting a large group consultation, or when a sitting fee might affect an advocate's support payment, an honorarium of a gift card, voucher, or other acknowledgement might be preferable.

Video conferences or document reviews also warrant an honorarium or sitting fee.

Not all advocates feel comfortable accepting money for consultation. If the advocate declines, donating the sitting fee to charity or research is an alternative.

The Victorian State Government offers guidance on remuneration rates for advisory-type committees (Type C meetings[1]). Other governments and peak bodies refer to the recommendations of the Remuneration Tribunal for offices not-specified[2].

Sitting fees should be paid on top of reimbursements for travel and other expenses.

> **“The input of an advocate can be invaluable to any organisation. It is a courtesy to make a gesture, even a tiny one, to indicate that the organisation recognises a valuable contribution. This is respectful, and when you consider how much the organisation will receive, it’s a miniscule gesture in terms of their finances.”**
>
> Family carer

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[1] Safer Care Victoria, A guide to consumer remuneration: **https://hic.org.au/wp-content/uploads/2019/11/HIC-SCV-A-guide-to-consumer-remuneration.pdf**

[2] **http://www.remtribunal.gov.au/offices/part-time-offices**

Choosing a consultation method

Identifying your consultation goal

Before you decide on a consultation method it is helpful to identify your consultation goal. Your consultation goal is what you hope to achieve from working with people living with dementia, families and carers. There are three general consultation goals:

1. **Inform:** your goal is to educate or raise awareness
2. **Ask**: your goal is to gather ideas, opinions, experiences, or feedback
3. **Collaborate:** your goal is to work together to achieve an outcome.

You might find it helpful to refer to the Public Participation Spectrum, developed by the International Association for Public Participation. There are five levels in the spectrum:

1. **Inform** – you provide advocates with information that will help them understand the problem and opportunities. Communication is one-way.
2. **Consult** – you seek feedback from advocates on your activity or decisions. There is limited two-way communication.
3. **Involve** – you work with advocates throughout the process to ensure their issues and concerns are understood and considered.
4. **Collaborate** – you partner with advocates in every aspect of your project to develop a mutually agreed plan and outcome. This is sometimes called co-design.
5. **Empower** – you place final decision-making power with advocates.

As the levels of ‘inform’ and ‘consult’ involve limited two-way communication between you and advocates, solely using one of these levels does not constitute meaningful consultation.

Co-design requires a nuanced and informed approach. Dementia Australia has a library of free co-design resources as part of the **A Stronger Voice Together** consumer engagement strategy. You can find a link to the library on page 45.

Choosing the right consultation method will also depend on your:

- timeframe
- budget
- short and long-term goals
- target audience.

> **“ I am a Chinese migrant from Hong Kong so I belong to the CALD (Culturally and Linguistically Diverse) group. Minorities need to be represented. The needs of CALD groups are different to the Aussie group. ”**
>
> Family carer

Choosing a method according to your goal

You are likely to use a variety of consultation methods throughout the duration of your project. A combination of two or more methods might help you best achieve your consultation goal.

Goal: Inform

- newsletter
- poster
- community talk
- local radio
- fact sheet
- on-hold phone message
- website
- social media
- letter drop
- media release
- report
- brochure.

Goal: Ask

- feedback form
- suggestion box
- poll or ballot
- forum
- roadshow
- focus group
- survey
- interview
- open day
- public meeting.

Goal: Collaborate

- advocates’ panel
- advisory committee
- steering committee
- dementia alliance
- working group
- direct employment
- co-design workshop
- symposium
- task force.

Face-to-face consultation

Face-to-face consultation can happen in person or through a video conferencing platform. It is suitable for one-off events or ongoing projects.

The strengths of face-to-face are:

- encourages in-depth discussion
- accommodates different needs and abilities
- suitable for visual aids, translators and other communication tools
- encourages social interaction and shared understanding
- it's easier for advocates to pick up on non-verbal, emotional or social cues
- advocates feel more comfortable and relaxed
- more inclusive for First Nations people, diverse communities and older people.

Video conferencing

Video conferencing allows advocates to participate from home which can be preferred by:

- people who live in regional, rural, or remote areas
- people who cannot drive or use public transport when travelling alone
- carers without respite or support
- people with physical comorbidities.

Note that people with advanced dementia may have difficulty using video conferencing.

A consultation through video conferencing should be accompanied by a practice session to ensure advocates are comfortable and familiar with the technology.

Hosts of video conferences have the same responsibilities as those running a face-to-face consultation. Dementia Australia has video conferencing guidelines created by people living with dementia who are experienced advocates. You can find more information about this resource on page 45.

Document reviewing

When creating a document for people impacted by dementia, it makes sense to engage advocates in its production. People living with dementia, families and carers are experts at assessing documents for readability, appropriate content, language, and market need.

Advocates can review documents alone or in a group. Reviewing a document in a group allows people to share their thoughts and ideas and reach an agreement. However, it can be hard to cover large amounts of content.

Reviewing content alone lets advocates work at their own pace. They may need support from a volunteer, staff member or carer to complete the review. Some advocates will prefer to talk through their feedback rather than write it down.

You should plan to consult during the development, design and user-testing stages.

> “**Too often, organisations make decisions about what we can manage to consult on without asking us. Sharing the whole document or paper is important, not just selecting excerpts for consumers to provide feedback on.**”
>
> Person living with dementia

Surveying

As a consultation method, surveys have many benefits.

- Surveys can be completed at home at a time that suits.
- There is little cost to you or advocates.
- You can gather quantitative data, like statistics.
- You can gather qualitative data, like stories.
- You can include pictures, graphs or visual aids.
- You can reach a large audience in a short amount of time.
- Answers can be anonymous.
- Surveys can be shared across organisations, committees and communities.

Improving dementia accessibility

What is dementia accessibility?

Dementia is more than memory change. It can change the way a person sees, understands or responds to the world around them.

Some of these changes include:

- difficulties with vision, depth perception, and defining objects and space
- disorientation in time and place
- difficulty with speech or reading
- an inability to ignore distractions like background noise
- reduced ability to navigate unfamiliar spaces.

Dementia accessibility involves modifying the physical environment to lessen the impact dementia has on the person.

Dementia accessibility supports independence, personhood and a sense of wellbeing. It also enables a person living with dementia to participate in consultation with confidence and in safety. Family members and carers can have their own accessibility requirements.

> **“People don’t want to ask for help. Offer help in a way that empowers the person.”**
>
> Person living with dementia

Printed documents

Whether a survey, brochure, or committee minutes, the best way to ensure your document is dementia-accessible is to involve advocates in its development and design. Accessibility and dementia language guidelines can also inform your work.

When writing for people who speak a language other than English, always use a professional translating service. As some communities have cultural sensitivities around dementia, include an advocate from that background in the development of your document.

Language tips

- Use concise language that is easy to understand.
- Keep sentences short.
- Address one topic at a time.
- Each paragraph should make sense on its own without needing to remember previous sections.
- Break up text with lists, bullet points or text boxes.

If you must use an acronym, the standard approach is to write the name in full, with the acronym in brackets after it. You can then use the acronym in the rest of the document. Avoid the use of jargon. Include a glossary to define unfamiliar or industry-specific terms.

Design tips

- Use a large, sans serif font.
- Don’t use italics or thin fonts.
- Single columns are easier to read than multiple columns.
- Leave plenty of white space on each page.

Pictures and infographics can enhance understanding, but you should avoid using unnecessary pictures. Too many pictures can overwhelm and confuse.

Choose colour schemes with good contrast and readability. Colour can help to separate content, but don’t use this method alone. Not all people can see the whole colour spectrum.

> **“ Make sure the document is properly organised. Use your high school essay writing skills: clear premise, clear examples, clear reasons and most importantly, logical format. ”**
>
> Person living with dementia

Environmental audits

An environmental audit is the assessment of a building to understand whether it is dementia-accessible. When deciding on a venue for your consultation it is advisable to perform an environmental audit with a person living with dementia. Look for:

Signage

- Wayfinding signage (to meeting room, lifts, toilets) at eye level. If there are no signs, can you put up your own?
- Signs on the doors.
- Directions to toilets using words and symbols.

Furnishings

- Carpets that are plain or with simple patterns. Busy patterns can cause motion sickness or disorientation.
- Chairs that are stable, easy to get in and out of, and comfortable to sit in for long periods.
- Good colour contrast between tables, chairs, doors and doorframes. Avoid all-white spaces.
- Good lighting, with at least 300 lux.
- No reflective glass or mirrored walls.

Facilities

- Ramps or lifts.
- Staircases with handrails.
- Bathroom hardware (taps, flushes, locks, dryers) with a familiar design. If possible, avoid sensor-activated facilities. If in doubt, put up a sign with clear instructions.

Sound

- Good acoustics
- No distracting background noise, such as traffic or loud air conditioning
- Hearing loop system
- Public address system, if a large room.

Other considerations when choosing a venue

- Will advocates need to travel a long way?
- Can advocates get to the venue by public transport?
- Is the venue familiar to advocates?
- Is the venue neutral? Or is it affiliated with a service or agency that might make advocates feel unsafe?
- Are there facilities to make and serve refreshments?
- Is there a nearby space to serve as a quiet break-out room for people living with dementia?
- Is there adequate parking for cars and mini-vans?
- Is there a taxi rank, or a well-lit, safe place to wait for a taxi?

> **“The venue should be accessible by public transport, as most advocates are older and do not want to drive too far. If driving is the only option, then free parking should be provided. I live in a regional town and it will take me two and a half hours by train to get to the capital city.”**
>
> Family carer

Travel and accommodation

If people living with dementia, families and carers need to travel and stay in accommodation, consider the following tips from experienced advocates.

- Perform an environmental audit on the rooms, lobby, and common areas.
- Accommodation should be close to the consultation venue (ideally walking distance).
- Choose accommodation with 24-hour concierge or reception.
- Help advocates arrange travel to and from the airport.
- Travel to and from the accommodation, airport, and consultation venue is covered by taxi vouchers or reimbursed as soon as possible.
- Provide a daily allowance or reimbursement for meals and expenses while away.
- Offer an honorarium or sitting fee for the consultation and travel time.

Flight assistance

Dementia assistance dogs can travel on Australian flights with prior approval. Australian air carriers offer special assistance to help people living with disabilities navigate the airport. You need to book these services in advance.

Recruiting advocates

Planning will increase participants

A thorough consultation plan will ensure that you are working in the most dementia-accessible way possible. This, in turn, will support and attract more advocates.

What attracts potential advocates:

- A clear and concise invitation.
- They have enough notice to plan their participation.
- It is scheduled at a suitable time.
- The venue is dementia-accessible.
- Information about privacy and informed consent is provided upfront.
- Project goals are articulated and align with the advocate's goals.
- Flexibility in how advocates participate (for example, video conference or in person).
- People living with dementia are welcome to bring a support person.
- Personal invitations, when possible.
- Help with transport, travel, respite, or accommodation.
- Honorariums or sitting fees.

> **“Researchers are getting better at this. They are involving us much earlier. They want to make sure they are on track.”**
>
> Person living with dementia

> **“Organisations need to include proactive engagement with consumers and enlist representatives when they are developing policy and programs.”**
>
> Family carer

Participation barriers

People living with dementia, families and carers value the connection, stimulation and sense of satisfaction that comes from meaningful consultation.

Despite this, recruiting advocates can sometimes be challenging. Health-related, personal, or societal barriers can make it difficult for people living with dementia, families and carers to participate.

These barriers can include:

- social withdrawal or isolation
- discrimination, stigma or rejection (or fear of it occurring)
- dementia making it harder to manage day-to-day tasks
- no access to respite or support
- difficulty with travel (cannot drive or find public transport challenging)
- low English proficiency or dementia-caused reversion to a language other than English
- negative consultation experiences in the past
- negative experience with an associated organisation or venue
- physical disability, frailty, or ill health
- the consultation is not dementia-accessible.

Respect that people living with dementia, families and carers also have a right not to participate.

> **“Where practical … go to the member’s location. Perhaps have a multimedia presence in other areas and invite people to participate. Don’t expect people to travel to capital cities all the time.”**
>
> Person living with dementia

Using a marketing approach

Researchers have found that a social marketing approach can help you attract people living with dementia, families and carers[3]. There are six steps:

Participants
Identify who you want to consult. Is it people living with dementia, carers, or both? What is their age or background? Do they use a service or product?

Product
Imagine your consultation is a product. To attract advocates, your product must be important or meaningful to people living with dementia, families and carers.

Price
Consider how much it will cost advocates in money, time and effort, to participate in your consultation. Can you make participating price-neutral for advocates?

Place
The setting should be neutral, safe and dementia-accessible. Avoid asking advocates to travel long distances. Whenever possible, bring the consultation to the advocate.

Promote
Advertise your consultation as you would any other product. Consider where you might find your target advocates. You can find suggestions on page 30.

Partnership
Approach other organisations to broaden your reach. If you share common goals, you may wish to collaborate.

> **“Explore ways that people living with dementia can be easily reached without breaching confidentiality or privacy. Do it in a way that makes them want to be a part of the program or an idea that’s being considered.”**
>
> Family carer

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[3] Nichols L, Martindale-Adams J, Burns R, et al. Social marketing as a framework for recruitment: illustrations from the REACH study. J Aging Health. 2004;16(5 Suppl):157S-76S. doi:10.1177/0898264304269727

Reaching potential advocates

> **“I believe if you want to find a consumer representative you can.”**
>
> Person living with dementia

Experienced advocates suggest promoting your consultation through:

- your customers or clients
- waiting rooms
- community clubs
- support groups
- multicultural community groups
- senior centres
- respite care and day centres
- recruitment agencies
- dementia-friendly community alliances
- relevant websites
- local media
- online dementia and carer groups
- campaigns using a public ambassador
- peak bodies and agencies
- community health and service centres
- social media
- doctors and medical specialists
- posters or flyers in public areas.

> **“I think it would be good to establish more opportunities to develop dynamic networks. Encourage people to reach out to their own contacts. Ask, ‘Can you think of anyone else that could contribute?’ Sometimes an advocate’s own experience might not be relevant, but they could be connected to many other people that have the relevant experience.”**
>
> Person living with dementia

Expressions of interest

You may wish to use an expression of interest process. Expressions of interest can be helpful if you:

- have a limited number of positions to fill
- want advocates with particular skills or experience
- need a diversity of backgrounds.

To run a successful expression of interest process, you should:

- be clear it is an expression of interest, not an automatic registration
- have a fair and transparent selection process
- set clear expectations about what is and isn't possible
- allow enough time for people to apply
- make sure the application process is accessible to people living with dementia
- help people complete an application, if appropriate
- promptly contact both successful and unsuccessful candidates.

Writing an invitation

An invitation should contain all the information advocates need to make an informed decision about participating. However, you don't want to overwhelm people with too much information.

Invitations should include:

- a project title
- who you are or the organisation you represent
- how the consultation will take place
- your consultation goal or how you will use the information you gather
- the type of advocates you wish to consult (their background, skills, type of dementia, age or experience)
- time and duration
- any scheduled breaks and catering information
- the venue, including parking and public transport access
- any honorariums, sitting fees, or reimbursements available
- clear instructions on how to register.

Follow the language tips on page 23. You may wish to produce alternative versions in Easy Read or languages other than English, if appropriate.

Sample invitation

Make Daintree Gully Dementia-Friendly

The Daintree Gully Dementia Alliance is hosting a community forum. This is for people with dementia, families and carers who live in Daintree Gully and surrounding towns.

We would like to know what it is like living with dementia in Daintree Gully. Your stories and ideas will help us create our dementia-friendly action plan for the next year.

Lunch will be provided after the session. Taxi vouchers are available to help you get to and from the venue. Participants will be presented with a gift card of $25 as a token of appreciation.

Venue: Daintree Gully Town Hall

Date: Tuesday 1 March 2022

Time: 11am to 12pm

To register, please call **Beryl Andrews** on **0411 111 111** or email **bandrews@madeupaddress.org.au**

> **“Be upfront about what you want. Clear information needs to be given for people to decide whether to participate. Otherwise, it can be guesswork.”**
>
> Person living with dementia

> **“I receive an email asking whether I am interested in contributing, with a brief but informative description of the purpose and outcome of my input. If I indicate that I’m interested, I receive a detailed outline of what is involved and what is expected, including more detail about the purpose, possible risks, reimbursement details, proposed time, location and any financial incentives being offered.”**
>
> Family carer

Conducting meaningful consultation

Tips for facilitators

Facilitation is a skill that improves with practice. If it is your first time, you might be nervous. Some advocates may be nervous too. By acknowledging these feelings you can help build connection and mutual understanding.

As facilitator, your key role is to foster a respectful and rewarding relationship with the advocates.

You can do this by:

- Investing time with each advocate. Get to know them, their history, and their individual needs.
- Creating a welcoming and safe environment where people can participate without judgement, embarrassment, or recrimination.
- Giving advocates freedom to participate as they wish. The ability of a person living with dementia to contribute may fluctuate. However, this doesn’t mean the experience is not fulfilling or stimulating.
- Conducting the consultation to meet the advocates’ needs, rather than expecting them to fit in with a rigid agenda.
- Using empowering, respectful language, preferred terms and avoiding jargon.
- Thanking advocates for their contribution.

If the facilitator or chairperson is a person living with dementia, you can support them by:

- making sure other participants don't interrupt or take over
- dividing tasks and action items equally among participants
- offering the person assistance before the session.

> **“ Participating is a very personal experience. You need to have a relationship with the person facilitating because of what you are sharing—it is a very personal thing. ”**
>
> Family carer

Conducting a meeting or focus group

The following advice comes from people living with dementia, families and carers with advocacy experience.

Remember, each person will experience dementia differently. Work closely with the advocates you have recruited to tailor the meeting to their unique needs.

Contact each advocate and ask:

- What time and day is best for them? (Prioritise meeting at a time that suits people living with dementia.)
- Do they want meeting documents emailed or posted?
- Do they give consent to have the meeting recording and notes taken?
- Are they comfortable being identified as a person living with dementia, family member or carer?
- What are their preferred terms? (Refer to definitions on page 5.)
- Do they need assistance responding to the agenda?
- Do they feel confident, prepared and have everything they need?

> **“Contact me in advance and provide me with an introduction and general information. It can be intimidating meeting with senior people. Don’t marginalise me and leave me off to the side until the ‘person living with dementia’ is needed. It’s basic respect.”**
>
> Person living with dementia

In the weeks leading up to the meeting you should:

- Book any travel, taxi vouchers and accommodation required.
- Allocate sitting fees, honorariums, and reimbursements.
- Send minutes and agendas (seven to 10 days before the meeting)
- For linguistically diverse communities, provide documents in their preferred language.
- Assign people to be responsible for greeting advocates on arrival, giving directions, and helping with refreshments.
- Create name badges in a large, clear font. If including the person’s role, use a universal term like Dementia Advocate. Some people find wearing a label with ‘Person with dementia’ stigmatising.

> **“Communication is respectful and courteous. Negotiate dates and times to suit me, unless it is a group. Then the dates and times are clear.”**
>
> Family carer

> **“When I needed help, they offered emails and replied quickly. If they were unsure, they spoke with their manager to find out answers and replied. People would respond.”**
>
> Person with dementia

When conducting a meeting or focus group there are some unique conventions that will make it more accessible for advocates.

- Open the meeting by making everyone aware of support available, such as the National Dementia Helpline.
- Start with the day’s agenda and a summary of the previous meeting.
- Everyone should raise their hand and wait to speak. This stops people speaking at the same time.
- Invite comments from people living with dementia throughout the meeting.
- Take regular breaks and serve refreshments.
- Keep the discussion pace at a speed that will suit people living with dementia.
- When seeking input from a person living with dementia, ask them directly. Don’t defer to their support person, carer, or interpreter.
- Avoid actions that rely on short-term memory. This includes using phrases like ‘park that thought’ or leaving questions to the end.
- Ask everyone to not use acronyms.
- Use visual aids, such as picture boards, handouts, or slides.

After a meeting or focus group it is appreciated that you contact each advocate to:

- Thank them for their contribution.
- Settle any outstanding reimbursements.
- Address any questions or concerns they may have.
- Report on the progress and outcome of the project.

> **“A follow-up thank you and indication of the success of the exercise is a logical courtesy, whether by email or otherwise.”**
>
> Family carer

Conducting a document review

When conducting a document review, your first consideration should be accessibility. In addition to following the tips on printed documents on page 23, you should:

- Ensure each page has space for comments and questions.
- Use single-sided, numbered pages.
- Accommodate preferences for electronic or hard-copy documents when possible.

> **“Trial the materials before sending out to a wider group. Provide a contact person, feedback about the next steps, and how our feedback is to be used. Use appropriate language and set it out well.”**
>
> Person living with dementia

A successful document review process will include:

- Clear instructions on how to review the document and what feedback is needed.
- Realistic expectations about what can be achieved through the review process.
- Different options for returning feedback, such as via a focus group, phone call, or email.
- Choices for advocates who experience difficulty reading long documents, such as a summary, sections, or Easy Read versions.
- Plenty of time for advocates to read and absorb the information.
- A plan for managing difference of opinion.

Before the deadline, contact the advocates to ensure they have everything they need to complete the review.

Once the feedback has been submitted:

- Thank them for their contribution.
- Settle any outstanding reimbursements.
- Address any questions or concerns they may have.
- Report on the progress and outcome of the document.

Consider including an acknowledgement of the advocates’ contribution in the final document. Some advocates may like a copy of the final publication.

> **More people involved means better representation and the outcome will be more convincing.**
>
> Family carer

Conducting a survey

There are two main considerations when conducting a survey for people living with dementia, families and carers – ensuring that the physical survey is accessible, and that the process is easy to follow.

It is always preferable to have a person living with dementia on your survey development team to provide expert insights. If this is not possible, a document review prior to distribution is a good alternative.

As well as adhering to the tips on printed documents on page 23, the survey should:

- Have clear instructions on how to complete the survey.
- Provide a mix of closed (yes or no) and open-ended questions.
- Allow advocates to ask questions and make comments.
- Have numbered questions and pages.
- Be single-sided and well-spaced.
- Offer people the choice to remain anonymous or receive further updates.

Include a stamped, self-addressed envelope if you want advocates to submit their answers by mail.

> **The questions should be easy to understand, with clear instructions. Most of the time the answers to choose from are limited. A box that says 'Other, please specify' would allow us to give the most appropriate answer. I find it difficult to answer surveys as I cannot ask questions.**
>
> Family carer

These days, many surveys are conducted online. If conducting an internet survey:

- Allow advocates to move backwards and forwards through the survey.
- If the survey is longer, allow people to save their progress and return later.
- Provide a choice in how answers are submitted, such as phone interview or email.
- Have a hard copy alternative available for people who have difficulty reading from a screen.

> **“If you do not have the overview of the questions, you cannot grasp the context of the survey. You need to be able to read through the questions before you answer. Sometimes it is not easy to navigate backwards to check if you have answered a question as you intended.”**
>
> Person living with dementia

If your survey was anonymous, consider releasing the findings so that advocates can read the result. If you have provided an option to receive further updates, you can report back to those advocates directly.

Overcoming challenges

Meaningful consultation is still quite a new concept. Most recommendations have been learned through trial and error.

Despite our best efforts, sometimes consultations don't go according to plan. Don't be disheartened. Instead, reflect on the experience and possible improvements for next time. Using evaluation forms or asking advocates for feedback will support ongoing improvement.

Common challenges include:

- low registration numbers from people living with dementia
- people living with dementia not being given an opportunity to speak during meetings or events
- discussion that stays on one topic or drifts away from the agenda
- an advocate becoming angry or distressed, or behaving inappropriately due to their dementia
- the facilitator being caught off-guard by negative feedback.

> **“Sometimes the facilitator doesn't know about dementia and can't manage the group. People get off-topic or provide input at inappropriate times as they are not given the chance at an appropriate moment.”**
>
> Person living with dementia

> **“Occasionally, focus groups are very poorly facilitated, with negative and inappropriate contributions allowed to dominate the conversation. People may shout down the useful input of others and unfortunately waste the limited time these groups have.”**
>
> Family carer

Through preparation, you can reduce the impact or likelihood of these challenges occurring.

Before the consultation

- Think about how you will acknowledge issues that are likely to be raised, but not on the agenda.
- Have a plan for responding to aggressive, distressed, or inappropriate behaviour.

During the consultation

- Be calm, empathetic and understanding.
- Maintain a respectful and welcoming environment.
- Allow advocates to leave and come back as they need.
- Follow the conventions on page 37.
- Don’t open with confronting, personal or sensitive questions.
- If there is hostility or distress, call for a short break to refresh.
- Ask advocates if anyone has different experiences or opinions to share.

After the consultation

- Ask advocates how they felt the session went.
- Offer to follow up on any issues with the relevant agencies or individuals.
- Offer to discuss outstanding issues at a future session.
- Don’t cease contact after receiving negative feedback or assume an advocate doesn’t want to continue.
- Reflect on negative feedback. Is there an unmet need you haven’t considered? Does your project plan need revising?

Respect advocates’ rights and boundaries

- Listen to them and acknowledge their feelings.
- Don’t push them to share stories they’re not comfortable disclosing.
- Don’t ignore or talk over distressed advocates.
- Make allowances for behaviour that people living with dementia cannot control.

Respect your boundaries too

- Don’t try to manage a situation beyond your skills, comfort level, or training.
- Make sure you have the right support and advice.

Closing the loop

Meaningful consultation requires honesty and transparency. Advocates want to know how their contribution has made a difference. Keeping advocates updated on their impact is called ‘closing the loop’.

From the outset, be open about your project’s goals and how advocates will help you achieve them. Be realistic and honest about what your project can achieve.

Maintain regular communication and report on your progress. This builds trust, keeps people motivated and holds everyone to account.

You can close the loop by:

- thanking advocates by letter, email, or phone call
- paying a sitting fee or honorarium
- arranging prompt reimbursement of costs
- following through on concerns
- updating on progress or developments
- providing complimentary copies of the final document or product
- informing advocates about media interest
- acknowledging advocates contributions in newsletters or social media (names or images with consent)
- inviting advocates to attend or present at launches or events associated with the project.

> **“Everyone needs to know they are not alone. Living with dementia doesn’t have to be all doom and despondency or mean that life is over. We must embrace this stage of our lives, as it may still be richly rewarding. True, things are not as we planned. Life is now just taking a different road.”**
>
> Family carer

Dementia Australia is here to help

National Dementia Helpline

The National Dementia Helpline is a free telephone service that provides information and advice. The National Dementia Helpline team can:

- provide emotional support and guidance
- connect you to Dementia Australia services and other community support programs
- discuss government support options.

Call **1800 100 500**

Dementia Advocates

Dementia advocates are people living with dementia, families and carers from around Australia who are interested in consultation, public speaking, media and research. Dementia Australia's consumer engagement team manages the Dementia Advocates program. Dementia advocates receive a regular newsletter, Advocacy in Action.

Email **advocates@dementia.org.au**

Dementia-Friendly Communities

Towns and cities all over Australia are coming together to build inclusive communities. Dementia-Friendly Communities aim to reduce the stigma, isolation and discrimination associated with dementia and increase accessibility at a local level.

Visit **dementiafriendly.org.au**

Dementia Language Guidelines

The words we use to talk or write about dementia can have a significant impact on how people living with dementia are viewed and treated in our community. The Dementia Language Guidelines can advise you on respectful and inclusive language.

Visit **dementia.org.au/resources/dementia-language-guidelines**

Dementia-Friendly Zoom guidelines

The Dementia Australia Advisory Committee has developed a suite of tools to help people run and participate in dementia-friendly video conferences. The guidelines cover:

- holding a dementia-friendly meeting
- participating in meetings, for people living with dementia
- joining a meeting
- getting the best out of the experience
- tools and examples.

Visit **dementia.org.au/about-us/advisory-groups/dementia-australia-advisory-committee#Zoom**

A Stronger Voice Together

A Stronger Voice Together is an inclusive, practical consumer engagement strategy, developed through co-design, that underpins Dementia Australia's internal and external stakeholder engagement. Here you will find an extensive library of resources relating to co-design.

Visit **dementia-org.libguides.com/A-stronger-voice-together**

Further information

Alzheimer’s Disease International

Alzheimer’s Disease International is the global federation of Alzheimer’s associations, with official connections with the World Health Organisation. There are many helpful reports and resources for organisations, communities and individuals looking to champion dementia advocacy.

Visit **alz.co.uk**

Dementia Alliance International

Dementia Alliance International is a non-profit, membership-based organisation exclusively for people with a diagnosis of dementia. Dementia Alliance International offers peer-to-peer support to members, as well as helpful resources on inclusion.

Visit **dementiaallianceinternational.org**

Dementia Engagement and Empowerment Project (DEEP)

DEEP is the United Kingdom’s network for dementia voices. Members have developed a suite of excellent guides on inclusive meetings, events and advocacy, written by people living with dementia.

Visit **dementiavoices.org.uk**

Dementia Enabling Environments

Run by Alzheimer’s WA, Dementia Enabling Environments provides helpful information on what makes a building, room or outdoor space dementia-friendly.

Visit **enablingenvironments.com.au**

International Association for Public Participation (IAP2)

IAP2 is a member association and peak body for the community and stakeholder engagement sector. Its aim is to advance and educate the community on the principles of public participation and achieving effective community and stakeholder engagement (public participation).

Visit **iap2.org.au**

Additional guidelines and resources

Alzheimer Society of Canada

Meaningful engagement of people with dementia, a resource guide

archive.alzheimer.ca/sites/default/files/files/national/meaningful-engagement/meaningful-engagement-of-people-with-dementia.pdf

Alzheimer's Society UK

Tips for dementia-friendly documents

alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/real-life-examples/tips-dementia-friendly-documents

Dementia experience toolkit

alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit

Dementia North, Northumbria University

Listen to us: Involving people with dementia in planning and developing services

mentalhealthpromotion.net/resources/listen-to-us.pdf

Eastern Metropolitan Region Home and Community Care Alliance

Consumer feedback toolkit

kpassoc.com.au/resources/consumer-engagement/

National Health and Medical Research Council (NHMRC)

Becoming involved in research: a guide for people living with dementia, their care partners and family members

nhmrc.gov.au/sites/default/files/documents/attachments/Dementia/Dementia consumer toolkit.pdf

Guidelines for guidelines: consumer involvement

nhmrc.gov.au/guidelinesforguidelines/plan/consumer-involvement

New South Wales/Australian Capital Territory Dementia Training Study Centre

The Environmental Audit Tool Handbook

enablingenvironments.com.au/uploads/5/0/4/5/50459523/eat_handbook_july_13.pdf

Victorian Government

Make Content Accessible, an Online Guide

vic.gov.au/make-content-accessible

About Dementia Australia

Dementia Australia is the source of trusted information, education and services for the estimated half a million Australians living with dementia, and the almost 1.6 million people involved in their care. We advocate for positive change and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible. Founded by carers more than 35 years ago, today we are the national peak body for people living with dementia, their families and carers.

We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

No matter how you are impacted by dementia or who you are, we are here for you.

National Dementia Helpline

1800 100 500

For language assistance
call **131 450**

Find us online

dementia.org.au

The National Dementia Helpline is funded by the Australian Government