

Engaging the Voice of People with Dementia: A Practical Guide to Successful Advocacy

This guide provides tools that will support national and local advocacy work undertaken by staff, volunteers and branch members of The Alzheimer Society of Ireland.

Introduction to Advocacy

What is advocacy?

Advocacy is a process that allows us to address inequality and to bring about change. By using different advocacy tools we can raise public awareness of issues affecting people with dementia and influence those in power. As advocates we need to present clear messages and build relationships that will help us to change policies, practices and attitudes. Advocacy happens at all levels – local, national and international.

Why is advocacy important?

Advocacy is important as it allows us to identify problems and achieve change. Through advocacy we increase awareness of different issues and we ensure that those who have power use it well. Advocacy empowers people and provides a mechanism by which they can speak out for themselves or for others.

Advocacy Campaigns

There are a number of different methods you can use in your advocacy campaigns:

- **Political Lobbying**– engaging with political representatives and public officials is an important part of advocacy. This allows us to put issues that affect people with dementia and family carers on the political agenda. By presenting clear solutions we can build political support to achieve lasting change. It is helpful to build relationships with a number of cross-party politicians as they will be able to support a campaign in different ways. It is also useful to build support at different levels, i.e. County Councillors, TDs, Senators, MEPs and Government officials.
- **Public Mobilisation**– many advocacy campaigns will involve mobilising supporters to take action. For example, we can ask supporters to make direct contact with their elected representatives or to sign a petition to address a particular issue. It is useful to have a number of different actions that supporters can take, depending on their level of availability and commitment.
- **Awareness Raising**– traditional and social media can be used to raise awareness of issues affecting people with dementia and family carers and to support political lobbying and public mobilisation activities. Public opinion can influence the actions of Government and is therefore a very powerful tool in bringing about change.



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Tips for Successful Advocacy

Knowledge

- **Know the facts**— as advocates we must have knowledge of the core facts about dementia, for example the number of people with dementia living in the community. If you can demonstrate an in-depth knowledge of the issue you will become known as a reliable source for politicians and media in the area.

Relationships

- **Know your stakeholders**— if you are representing the interests of people with dementia and family carers you need to know what they want to achieve. All advocacy work should be informed by or directly involve people living with dementia and family carers.
- **Know your target audience**— decide who can help you to bring about the desired change. Will a local elected representative be able to assist you with this issue? Do you need to raise public awareness and get local supporters involved? You may need to target several different groups to achieve your advocacy aims.
- **Build relationships**— building relationships with politicians, public officials, journalists and other NGOs is essential for effective advocacy and will allow you to gather support quickly when different issues arise.

Delivery

- **Have a clear aim**— what is the change you want to bring about? Are you trying to achieve large-scale, systemic change or address a specific issue that affects a small group of people in your area? The type of advocacy work you undertake will depend on the change you're trying to achieve.
- **Have a clear message**— it is essential to have a clear message in all your advocacy work. Keep it simple and make sure the message is not too technical or detailed. If you want the recipient to take a particular action then make that very clear. For example, if you want a politician to take action on your behalf then set out clearly exactly what you want them to do.
- **Share your story**— people are most interested in the impact on individuals so if you have direct experience of the issue consider sharing your story, or share a case study example from your service or branch. People will remember a personal story far longer than they remember general facts and figures.
- **Know when to advocate**— there will be certain windows of opportunity for particular issues and you can use these to your advantage. For example, World Alzheimer's Day might be a good time to launch a campaign or highlight a particular issue affecting people with dementia. The run up to an election is a good time to engage in political lobbying and the launch of a report or a conference can be a good time to raise public awareness of a particular issue.

Advocacy Tools

You can use a number of different advocacy tools to deliver your key messages:

-  **Political meetings**— arrange a meeting with your local TDs, Senators, MEPs and/or Councillors to discuss the impact of dementia in your area and to gain support for a particular issue.
-  **Petitions and letter writing campaigns**— mobilise local supporters to take action by asking them to sign a petition or to send a letter to their elected representatives.
-  **Public events**— a public event, such as an information evening or a launch, can help to raise awareness of a particular issue. Consider carefully who this event is aimed at, for example, politicians, the press and/or supporters. Use the event to communicate your key messages.
-  **Media engagement**— liaise with the ASI's Communications team to highlight issues at a local or national level.
-  **Presentations**— liaise with the ASI's Advocacy & Public Affairs team about making a presentation to your local county council or to local community and interest groups.
-  **Ongoing communications**— maintain regular contact with politicians, public officials and supporters by email, letter or through a newsletter/e-zine.
-  **Information materials**— use ASI posters and leaflets to keep people in your area informed of ongoing advocacy work.

Make the Most of a Political Meeting— Your Handy Checklist

-  Plan ahead— it is vital to be prepared. Be clear about what you want to achieve and research the background, views and stance of the elected representative. Bring copies of ASI materials for the politician and an extra copy for his/her staff.
-  Keep your group small— don't invite too many people to attend the meeting as this can dilute the message. Decide in advance who will cover which topics so that everyone gets a chance to speak.
-  Relax and listen— remain relaxed, friendly and be conscious of your body language. Let the politician express his/her point of view and ask questions to engage him/her.
-  Have a clear message and be brief— keep your message simple and get to the point quickly. Remain focused on two things— (1) what is the issue; and (2) what do you want them to do about it. If you are planning to give him/her a written brief keep it short.
-  Base your message in fact and on personal experience— highlight the background facts and share your own story or a case study example from your service or branch.
-  Follow-up— send a follow-up email or letter to thank the elected representative for his/her time. Remain in contact with his/her office— invite them to local events and send them information/stories that they might be interested in.

Advocacy in The Alzheimer Society of Ireland

The Alzheimer Society of Ireland works to ensure the voice of people with dementia and family carers are heard. In addition to the advocacy work undertaken at a national and local level by staff and volunteers, the organisation facilitates two advocacy groups– the Irish Dementia Working Group and the Dementia Carers Campaign Network.

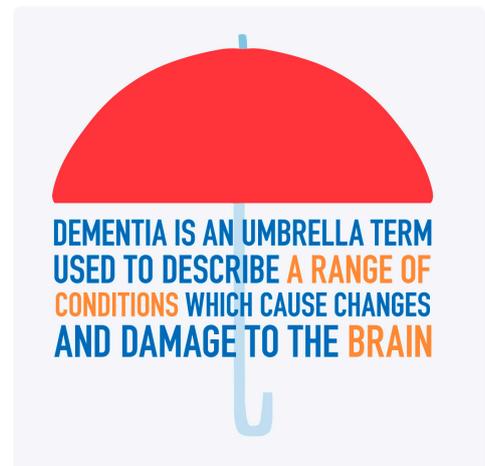
Members of these groups engage in ongoing advocacy and media work, lobbying political representatives, raising awareness at national and international conferences and speaking powerfully on radio and television on the needs of people living with dementia and on issues affecting family carers.

These groups are open to people living with dementia and to family carers who are interested in advocacy work. If you know anyone who might like to get involved please contact the ASI's Advocacy & Public Affairs team.

Additional Advocacy Tools

As an advocate for The Alzheimer Society of Ireland there are a number of additional advocacy tools available to you. To access these tools please contact advocacy@alzheimer.ie

- **Dementia & Your Area Factsheet**– this factsheet highlights the number of people living with dementia in your county, the ASI services available and general facts and figures on dementia. You can provide this factsheet to your local elected representatives during meetings.
- **Key Messages About Dementia**– this factsheet sets out some key facts about dementia. You can provide this factsheet to your local elected representatives during meetings.
- **Notes for Advocacy Work**– this sheet contains the background information you will need for a political meeting, including the ASI's key advocacy messages for the year. You can use this to prepare for meetings.
- **TD Lobby Form**– the ASI has created an online form that will allow supporters to send campaign letters to their local TDs.
- **Infographics**– the ASI has created a suite of infographics that can be used in presentations and printed materials.



Lobbying Act

The Regulation of Lobbying Act comes into effect on 1st September 2015. This legislation aims to bring about greater openness and transparency in lobbying activities. The Alzheimer Society of Ireland, as an advocacy organisation, must register on the Register of Lobbying and make returns several times a year. Any lobbying undertaken by staff of the ASI must be included in this return. Communications made by unpaid volunteers are generally not considered to be lobbying. If you are engaged in political advocacy work on behalf of the ASI please contact advocacy@alzheimer.ie for further information and advice.

Stay in Touch!

The ASI's Advocacy & Public Affairs team is here to support you. Please keep us updated on your local advocacy work and let us know what we can do to help.

CONTACT US:

- ✉ Email: advocacy@alzheimer.ie
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