



**Alzheimer's Disease
International**

The global voice on dementia



Influencing public policy

Cover photo: ADI Executive Director Marc Wortmann joined Stefanija Zlobec, Chair of Spominčica Alzheimer Slovenia, at a meeting with Slovenia's President Borut Pahor in 2014. Slovenia's national dementia plan was signed by the Minister of Health in 2016.

Influencing public policy

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Introduction

This publication provides the building blocks to make dementia a government priority and to use advocacy to build the reach, credibility and human resources of national movements. This information is aimed at Alzheimer associations and other organisations working to improve the lives of people with dementia and their care partners.

This booklet highlights the reasons why Alzheimer associations are engaging government bodies as a means to move their mission and strengthen their organisations. It offers guidance on:

- identifying policy issues and methods of building internal consensus on priorities
- developing a strategic plan for a public policy issue or campaign activity
- supporting and enabling people with dementia and their care partners to join a campaign and share their first-hand experience
- establishing methods of increasing and distributing leadership for advocacy activities
- singling out sources of data to advance policy and awareness, and presenting the data to policy makers and the general public
- building effective relationships with elected officials and potential civil society allies
- recognising opportunities to give testimony and effectively making a case

Throughout this booklet examples of successful campaigns are included as evidence of the theory in practice. Further examples can be found on the ADI website at www.alz.co.uk/publicpolicy

Alzheimer's Disease International (ADI) has adopted a role in global dementia advocacy and offering campaigning advice to our member associations. As governments around the world, regardless of country or government style, have control over health and social care, much of the advice given in this booklet is focussed on influencing governments.

However, as an international organisation we recognise that no two countries are the same, and country laws and traditions vary a great deal. While this booklet aims to offer useful suggestions for influencing public policy, we recommend that any advocacy efforts undertaken are done in a manner that is in keeping with, and acceptable for, the country in which they are carried out.

We wish you a successful campaign.

Marc Wortmann

Executive Director, Alzheimer's Disease International



ADI is often present at meetings of the WHO and UN in an attempt to influencing global health policy

ADI's global advocacy strategy

Alzheimer's Disease International is the leading global voice for dementia advocacy, fighting for dementia policy, research, prevention and care initiatives. ADI views dementia as one of the toughest challenges in healthcare and a threat to financial and social systems around the world. One of ADI's key strategic aims is to make dementia a global health priority by leading global advocacy efforts and supporting the national advocacy of member associations to make dementia a public health priority.

There is an urgent need for national governments worldwide to review their country's existing healthcare systems and budgets in relation to dementia, and to draw up and implement new dementia policies. The target is to enable the growing number of people living with dementia and their care partners, as far as possible, to have a good quality of life with access to appropriate and effective services.

ADI's role in campaigning for these changes to be made is to advocate to, and work with, global health and policy bodies, such as the World Health Organization (WHO) and United Nations (UN). With the task of directing and coordinating international health within the UN, the WHO is in the important position of bringing together its member countries to discuss and prioritise areas within health policy.

ADI regularly attends meetings of the WHO and UN, some of which provide an opportunity for ADI representatives to give a statement. We also work with national Alzheimer associations worldwide to support them in their call for national dementia plans and strategies.

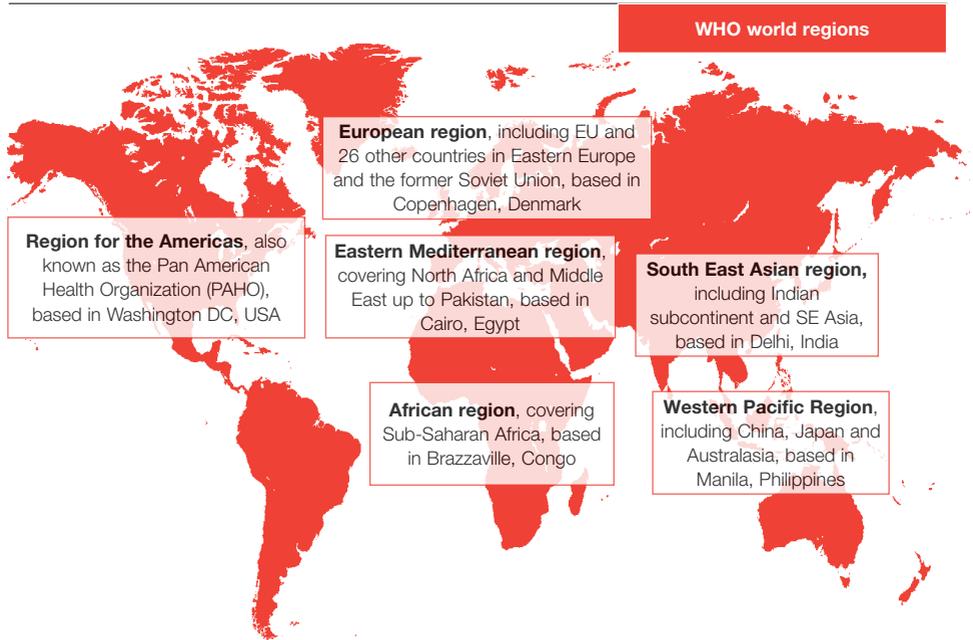
ADI proposes that the key elements to be addressed in planning for dementia at the global and country level include:

- Awareness raising of dementia
- Creation of dementia friendly communities that reduce stigma associated with dementia
- Promotion of risk reduction measures
- Measures to improve diagnosis and reduce the average time of diagnosis
- Support for care partners including through information, social support, respite and counselling
- Access to long term community and residential dementia care services and to enhanced care for people with dementia in hospitals
- A commitment to person centred care and to care that minimises the use of medical and physical restraint
- Workforce strategies including training
- The use of technology to assist the person with dementia in the home and to extend service reach in rural areas
- Recognition that people with dementia deserve good quality end-of-life care with respect to their dignity and personal wishes
- Inclusion of people with dementia within the implementation of the UN Convention for the Rights of Persons with Disabilities (CRPD) and other human rights instruments
- Mechanisms to improve all aspects of drug development
- Greater transparency in care and quality of life outcomes and the best ways to provide support and care

Results should be monitored and evaluated, and plans renewed on a regular basis.

As well as the WHO, UN and national Alzheimer associations, ADI also partners with a number of other organisations on their advocacy work, including:

- People with dementia and care partners. ADI provides opportunities for people with dementia and their care partners from around the world to attend and speak out at key international policy events to give a first-hand perspective and experience, and strengthen the case. This work is largely carried out through ADI's collaboration with Dementia Alliance International.
- Alzheimer Europe. ADI and Alzheimer Europe work together to campaign for improvements to dementia policy within Europe.
- WHO regional offices. We partner with the WHO at the global level, but also within their world regions. They have 6 regional offices as shown by the map opposite.
 - The region assists country offices in 150 countries, who can also be supportive of our work. However, they all work based on agreed WHO policies that are approved by the World Health Assembly, all 194 member states of the WHO, who meet annually.
 - Pan American Health Organization (PAHO) is the only region to have already adopted a dementia action plan. ADI and PAHO are collaborating on the implementation of the plan, which was launched in October 2015.
- NCD Alliance. The work of the NCD (Non Communicable Disease) Alliance is establishing a basis for cooperation on prevention across the major chronic diseases.
- The Global Alzheimer's and Dementia Action Alliance (GADAA). GADAA was formed in response to the G7 dementia initiative by international non-governmental organisations (NGOs) to enhance global efforts to combat stigma, exclusion and fear.
- The World Dementia Council. The World Dementia Council was established as a platform for governments, industry, NGOs and people with dementia to set the agenda for tackling dementia.



- The Organisation for Economic Cooperation and Development (OECD). The OECD is concerned about the economic impact of dementia on social and financial systems and works together with ADI and others on improving dementia care policies, including quality of care and removal of barriers for successful drug development.
- Asian Development Bank (ADB) has shown an interest in ageing in general and dementia more specifically as an important topic for the future. They have agreed to work collaboratively on policy briefings on dementia for countries in Asia.
- The United Nations has a number of bodies that work on human rights who have started to look at ageing issues as well. An Open Ended Working Group was created by the UN General Assembly to look into a possible convention on the rights of older people. Another possible advocacy tool is the Convention on the Rights of Persons with Disabilities (CRPD). A separate publication, developed on this topic by Dementia Alliance International, is available from www.dementiaallianceinternational.org/human-rights. The booklet contains information about how Alzheimer associations can contribute to this area of advocacy.

What are national dementia plans?

ADI is urging governments around the world to develop and implement national dementia plans because they are the single most powerful tool to transform national dementia care and support. Plans help governments ensure that health and social care systems are adequately structured and funded to ensure high-quality care and support is available to people living with dementia today, and in the future.

National dementia plans should be country-specific. Challenges faced in dementia care will differ from country to country due to differences in culture, the structure of the healthcare system and in the quality of the care provided by healthcare professionals and providers. Other factors, such as the availability of funding and the commitment of stakeholders to improve care, will also influence the choice of key areas to prioritise.

What is the difference between a National Dementia Strategy and a National Governmental Plan?

ADI defines national dementia strategies as documents generated by private non-governmental groups (often with the participation of governments) that can serve as the case statement to persuade governments to create a national or sub-national governmental plan.

A national governmental dementia plan is a policy; a national or sub-national government holding itself accountable for the accomplishment of specific objectives and policy changes, even if objectives are accomplished with non-governmental collaborators.

In most cases, national Alzheimer associations are, and should be, involved at all stages in the development and implementation of a country's national dementia plan. Often it is the Alzheimer association that instigates the creation of plans and their renewal once one plan ends.

Advice on, and examples of, this area of work can be found in *Improving dementia care worldwide: Ideas and advice on developing and implementing a national dementia plan*, released by ADI in partnership with Bupa in 2013. This publication, as well as details of existing national dementia plans, can be found on the ADI website at www.alz.co.uk/alzheimer-plans

What are advocacy and public policy and why are they important?

Advocacy refers to the act of championing a cause by showing support and offering recommendations. The word comes from the Latin *advocare* which means: speaking on behalf of someone else. The term *public policy* is difficult to define in detail, but is generally used to describe government policies: laws and regulations relating to issues that impact on the lives and well-being of the general public.

Based on these definitions, it can be said that advocacy is the method used to influence public policy.

The simple fact that public policy affects the daily lives of every person is evidence of its importance. Laws and regulations relating to health often determine the standards of care and support people with dementia and their care partners receive from diagnosis to the final stages, as well as the education required to enable people to recognise dementia. All organisations or individuals working to improve the lives of people living with dementia and their care partners will be aware of many of the issues around stigma and ignorance, isolation and exclusion, poverty and poor nutrition, inadequate service provision, and abuse.

The role that advocacy aims to play, in terms of dementia, is to support and call for key decision-makers to consider these issues and what is known about dementia, both in terms of research and personal experiences, when drawing up or revising all relevant policies. In many countries dementia is a low priority for governments and advocacy is an attempt to change this by presenting not only the issues, but also potential solutions. The overall aim of dementia advocacy is to improve the lives of people living with dementia and their care partners.

Planning your campaign

A clear and well thought out campaign plan is essential for strong advocacy. It helps all volunteers, staff or organisations involved see what you want to achieve, how you hope to achieve it and what the next steps are at each stage. It can be disheartening when you feel you are not being listened to or if a meeting with a government official does not go as well as you had hoped, but a good plan will help to keep you motivated.

Plans should also be reviewed regularly to make sure that they are still guiding your organisation effectively. Governmental changes, changes to government policies or funding for certain areas being lost are just some of the reasons why your approach may need to be altered. Your campaign plan will need to reflect this. It is important to stick to your original goal, as jumping from one issue to another will only lose you credibility and weaken your campaign.

Alzheimer's Australia's Fight Dementia campaign

Alzheimer's Australia's Fight Dementia campaign, which ran from 2011 to 2012, succeeded in making dementia a national health priority area with the support of the country's Health Ministers. It also changed the dynamics and focus on dementia by the government, resulting in greater support for the voices of people with dementia and care partners.

With the campaign, Alzheimer's Australia also hoped to secure government funding for a number of areas, including stigma reduction and awareness raising, initiatives to reduce time to diagnosis, dementia research, improvements to dementia care and support, and a risk reduction programme. Key partners in the campaign were people with dementia, care partners, the Council on the Ageing, and the Nurses Union, among others.

Tactics used during implementation included; a march on parliament; social media promotion and activity; speeches and submissions; and meetings with politicians attended by Alzheimer's Australia representatives, people with dementia and care partners.

Other campaign successes included:

- Helping to achieve the 2012 Aged Care Reforms passed into law in June 2013. These reforms provided more community services and greater choice of services through consumer directed care. They also reflected a new determination to tackle dementia both as a health and aged care issue.
- A commitment, announced in September 2013, to invest \$200 million in dementia research over five years.
- The appointment of 40 key workers by Alzheimer's Australia to provide support to people with younger onset dementia and their families, and to assist with service development.
- Work by the Australian Commission on Safety and Quality in Health Care in developing strategies that will ensure dementia is part of the mandated standards of acute care.
- The rollout of the world's first publicly funded dementia risk reduction programme *Your Brain Matters*.
- Funding of the new dementia supplements in community and residential care in recognition of the extra costs of dementia care.

Policy planning cycle



Past is prologue

An important first step in developing a new campaign is to consider the history of dementia policy in your country/region. If you were to write a book about your campaign, this would be the “prologue” where you look at the work of your organisation as well as any government efforts and ask yourself ‘Where are we now?’ followed by ‘What has gone/is going wrong, and why?’ The basis for your campaign should always be specific to your country situation, although this is not to say that you cannot learn from others who have been along similar paths.

Identify issues

Public policy advocates organise around issues, not problems. Issues, as defined by community advocates and organisers, are solutions, usually partial solutions to problems. Thus, you don't organise around the fact that there are no adult day care centres in the community: that's the problem. You organise around getting a day care centre: that's the solution. You can discuss problems, you can even educate about problems, but you organise and advocate around issues - solutions to the problem. Not every problem that a person with dementia or their family may face is fixable through these means. Here are some examples of issues that have been worked for by dementia advocates in different countries.

Recognition days or months

Proclamations or laws supporting World Alzheimer's Day or Memory Walks or other significant activities. Some countries have a national Alzheimer's or dementia month proclaimed.

Visibility and outreach

Iran Alzheimer Association had their government promote awareness through issuing a set of special postal stamps and promoting their helpline number.

One year guaranteed post-diagnostic support

Campaigned for by Alzheimer Scotland and part of Scotland's National Dementia Strategy 2013-2016.

Consumer protection

Many governments have passed "disclosure laws" that require providers who advertise specialised dementia care to disclose exactly how that care is different from ordinary care.

Dementia training for care partners or professionals

Some public programmes have been created to train family care partners in good dementia care and many places have legal requirements for direct care workers to have some dementia training either pre-employment or on a continuing education basis.

Respite services

Some governments have been persuaded to fund relief services in the home or community in order that family care partners can take a break.

Relieving age bias in public programmes

Dementia advocates have persuaded governments to expand income security or other benefits, for example transportation, for people over age 60 to include persons under 60 with a confirmed diagnosis of dementia.

Case management

Alzheimer Netherlands campaigned for one case manager as a navigator through the health and social systems for everyone diagnosed, a function that already existed in Japan.

Double the funding for research

Alzheimer's Association (US) campaigned for an increased level of research funding. In several steps this went up from \$450 million annually to over \$1 billion as part of the government funds for medical research.

Other examples of issues are:

- Access to healthcare
- Payment for dementia drugs
- Availability of care options
- Support for family care partners
- Rights of individuals
- Rights of charities to advocate

Once issues are clearly identified, advocates face the challenge of selecting which to work on. Here are some criteria that could be used for choosing an issue, adapted from the Midwest Academy www.midwestacademy.com

Will the issue:

- result in a real improvement in people's lives?
- give people a sense of their own power?
- alter the relations of power?
- be consistent with your values and vision?
- be worthwhile?
- be winnable?
- be widely felt?
- be deeply felt?
- be easy to understand?
- have a clear decision-maker?
- have a clear time frame that works for your group?
- be non-divisive?
- build leadership?
- set your organisation up for the next campaign?
- save money (or make it go further)?
- increase resources to your organisation?



As part of the official conference programme for the second Regional non-Latin Caribbean Conference in 2015, Stichting Alzheimer Curaçao presented their draft National Dementia Action Plan to Curaçao's Minister of Social Affairs and Minister of Public Health.

Policy solutions

Approaching any government official with a problem and asking them to find a solution is, most likely, going to waste valuable time and energy. Decision-makers have a multitude of competing priorities and a small amount of time to spend on each. During the planning of your campaign, a key activity is to look at the issue you have identified and decide how it can realistically be achieved. At this point it is important to do your research and find out how much your government has allocated financially to this area in the past and how much they allocate to other similar areas. Governments are always attempting to balance budgets and if your issue can be resolved by the sharing of existing or lower-cost resources rather than large amounts of money, you are more likely to have a successful campaign.

Creating a platform

Once you have chosen your issue and identified solutions, the next stage is to establish a platform from which to campaign. This step is about strengthening your call and seeking opportunities for collaboration. A platform can broadly be defined as an environment in which people are connected and share their skills and expertise to address problems together.

Most organisations working in the dementia field have the same aim: a better life for people living with dementia and their families. Each organisation may have a different focus - for example, service provision, awareness-raising, or research - but working together can bring a wider range of skills and expertise. This is often the basis on which alliances are created and you may facilitate this kind of collaboration to take your campaign forward.

When bringing together groups for collaboration it is important to make sure that you have good coverage of as many specialist areas as possible. A collection of groups whose main aim is to raise awareness of dementia will be helpful, but your campaign will be lacking in other areas if your platform is just limited to these organisations. Remember that people with dementia and their care

partners are valuable collaborators and should also form part of your platform if possible.

Involving people with dementia and care partners

It is safe to say that no one knows better what people with dementia and their care partners need to improve their quality of life than they do themselves. This is why it is essential that people experiencing dementia first-hand are involved in your campaign from the very beginning.

If you are a larger organisation in a country where people are less afraid to speak out about their experience this will be easier and you may know how to make contact with local or regional groups of people with dementia and/or care partners. In countries where awareness is lower and stigma is a greater barrier, locating and finding an opportunity to speak with a person with dementia or care partner can be a real challenge. In these areas it is most likely that your campaign will focus on raising awareness of dementia to help reduce the stigma. It is still important, however, to continue to seek input from people with dementia and/or care partners as you progress through the campaign where possible.



The Alzheimer Society of Canada used an opportunity during the 26th International Conference of ADI to sign a partnership agreement with the Canadian Institutes of Health Research.

Photo: Irene Borins Ash

Ways to involve people living with dementia and care partners at various stages of your campaign include:

- Forming an advisory group made up of people living with dementia and care partners to provide guidance to your campaign. Alternatively, if you are unable to bring together enough people with dementia and care partners, invite those people living with dementia and care partners that you do have contact with onto your campaign working group.
- Conducting a survey of people with dementia and care partners to determine their key concerns.
- Supporting a person with dementia or care partner to speak about their experience at an in-person meeting with a key decision-maker or, if they feel comfortable to do so, at a public meeting, or both.

Dementia Alliance International (DAI) is a valuable group if you are looking for any advice relating to working with people with dementia. DAI also carries out its own advocacy work.

More details about their activities can be found at www.dementiaallianceinternational.org

Obtaining platform approval

Making sure that you and your collaborators are in agreement over your chosen issue from the very start will help the following stages in your campaign to run smoothly. This can, on occasion, lead to some differences in opinion which will need to be resolved before you begin to look at preparing a strategy. Organisations with different areas of work can provide new perspectives and it is important to be open and willing to listen to others' thoughts and ideas. If you have a very clear vision of what you want to achieve and this does not match those of your collaborators you will need to make a decision as to whether you wish to continue on your own path without the support of these collaborators, or if you are willing to compromise in some way so that both organisations can feel like a valuable partner.

Alzheimer Europe's Glasgow Declaration campaign

The Glasgow Declaration was adopted by Alzheimer Europe (AE) and its members at its annual conference in 2014. The Declaration committed individuals and groups to promoting the rights, dignity and autonomy of people living with dementia, and supporting the creation of a European Dementia Strategy and national strategies in every country in Europe. An ambitious target of gathering 10,000 signatories over 9 months was set in early 2015. The campaign solicited signatures among European policy makers, national and international organisations and also individuals. AE worked on this campaign alongside its members and the European Working Group of People with Dementia.

Key actions were:

- Presenting the proposed Declaration to members and eliciting their support.
- Developing documentation in 16 languages, creating graphics for social media and a “QR code” for mobile phones.
- Promoting the campaign at AE events, through regular mailings via AE's communication channels and inclusion in a number of other publications and networks.
- AE members conducted mailings and promotion and contacted individuals, national policy makers and organisations. AE focused more on contacting Members of the European Parliament (MEPs), other European policy makers and European/International organisations.

At the end of the campaign 11,613 individual signatures had been collected from more than 50 countries worldwide. An additional 204 national and international organisations signed the Declaration as well as 153 policy makers from 25 countries, including 84 MEPs.

The results of the campaign were presented to the European Parliament, the European Commission and two EU Presidencies in Brussels on 1 December 2015. Shortly thereafter, the conclusions of the Luxembourg EU Presidency term were adopted by the Employment, Social Policy, Health and Consumer Affairs Council of the EU. The conclusions included text that was very similar to the Glasgow Declaration, such as the need for better EU collaboration and a call for a national dementia strategy in every country in Europe.

Forming a strategy

Your campaign objectives, or goals, will form the basis of your strategy so it is important to get them right. These objectives should clearly explain what you want to achieve in the short, medium and long term. Your objectives need to be realistically achievable. While you may want your government to agree to double its dementia budget the likelihood of this occurring, for many countries, is very small. Remember that your short and medium term goals should link directly into your long term objectives to enable you to follow the progression of your campaign towards your ultimate goal(s). For example, setting yourself an objective in the short or medium term to educate a certain number of people about dementia would not be appropriate if your long term objective was for a new respite service. A more suited short term goal might be to earmark a building with available space where the new service could be based.

At this point you will begin to look into the finer details of your campaign. You should expect a number of drafts of your strategy and be sure to share these drafts with all involved and be open to feedback and new ideas. The strategy should include: your issue and goals; the resources you have available to you; how you wish your organisation to benefit from the campaign; who you can call upon to support you during the campaign; who the key decision makers are that you wish to target; any opponents you might have; and, most importantly, what you are going to do to try to achieve your campaign goals.

The form on the opposite page gives a good overview of the information you will need to develop a strong strategy.

CAMPAIGN STRATEGY FORM

Issue: *What is your chosen issue?*

.....
.....

Goal: *What is your long-term goal?*

.....
.....

*What are the medium-term goals that will guide you toward this?
Make sure you are realistic with your goals.*

.....
.....

If your campaign was to fail what could be your back-up goal (note that you may have set-backs or rejections, but these should not be considered as a failure of the campaign)?

.....
.....

Resources: *What resources (volunteers, members, money) do you have available to support the campaign?*

.....
.....

What improvements would you like to see to your organisation and its resources if your campaign is a success?

.....
.....
.....
.....

Partners and supporters: *Which organisations are you aware of that have similar objectives to yours?*

.....

.....

Who are your existing and potential supporters, including individuals, groups and organisations?

.....

.....

Key decision-makers: *Who is the decision-maker that has the power to make your campaign a success?*

.....

Who are the individuals that may have influence over this key decision-maker?

.....

.....

Who are your competitors?

.....

.....

Which individuals or organisations could restrict the success of your campaign?

.....

.....

.....

Fundraising for advocacy

Depending on the nature of your campaign, you may need to raise some funds to allow you to implement your strategy. Unfortunately, advocacy is not always an easy area to find funding for, but you can make it a more attractive funding opportunity if you take a little time to consider what elements of your campaign could be funded. Many funders will not agree to pay for advocacy work aimed directly at politicians. However, some examples of related work that may fall under your campaign strategy and that could be funded are:

- Research and data collection
- Reports, including research costs, printing and dissemination, and a launch event
- A roundtable discussion on a certain topic
- Training for those who will play an active role in your campaign

When deciding who to approach for funding, consider a range of options, including individuals, foundations, care providers, pharmaceutical companies, or other corporations. You may wish to offer a form of corporate membership to a potential sponsor to bring in the funding if this is more suitable, or perhaps you could make it part of a funding package if a company would like to fund a number of your projects. You should also be sure that the companies or individuals you approach for funding fit with your organisation's ethos and don't conflict with the interests of your campaign, for example, approaching a pharmaceutical company to fund a campaign to reduce the use of antipsychotic medication for people living with dementia.

Before approaching any funders, you should have your strategy ready so you are able to give a potential funder a clear idea of what you plan to do. You should also have a clear and realistic budget for the work to be done. This should all be presented in a single package with your branding throughout. Before completing any funding application forms, try to talk to the company or individual to

begin building a relationship with them before your proposal is submitted. Also, check their website and annual reports to see what work they do and what they have funded in the past. By doing this, you can make sure that your work is a good fit with their criteria.

Your funding proposal should contain the following information:

- What the problem is
- Who your organisation is and why you can help resolve the issue
- How much funding you need for your campaign and how it is going to be used
- Why the funder should choose to support your organisation and not someone else

A tactic which could be valuable if you have already had some success through campaigning is fundraising on the results of your advocacy. In your fundraising materials highlighting your previous success followed by 'and we could do even more with your help' has the double benefit of promoting your good reputation and strengthening your fundraising efforts.

There are a number of ways in which ADI can help you with fundraising for your campaign. ADI's reports, particularly the *World Alzheimer Report* series, were developed to support ADI's advocacy work - and they can support yours too. ADI can supply a template country report if you wish to prepare your own national report on dementia, or can provide a letter of recommendation to support your fundraising applications. There may also be opportunities for ADI and your organisation to pull together for joint fundraising, or ADI may be able to put you in contact with like-minded groups in your country through its international partners.

Once you have secured funding for your work ensure that you have the commitment in writing. You can avoid a situation in which you have begun to spend money on your campaign and then find out the funding is not available by getting some written record or contract that it will be given.

You should have a clear idea of what your funder is expecting in return, such as whether they wish their logo to appear on your campaign documents and need to see/approve the documents before they are finalised. They might also request periodic updates as your campaign progresses or a press release at the start. If there are any conditions you are not sure about fulfilling this should be discussed with the funder prior to agreement so that both parties are happy with the plans and expectations from each other.

Some key points to remember while fundraising are:

- Fundraising should be fun
- Recognise the importance of reputation and relations (“friend-raising”), and commit time to this
- Deliver what you promise and manage expectations
- Fundraising and advocacy are very similar

Implementing your strategy

The Task Ask

The details within your strategy should allow you to break a big project into a series of volunteer jobs that one person can coordinate using the Task Ask.

Volunteers are an important resource for your campaign, particularly when used to their full potential. When working with volunteers on your campaign:

- Find out what skills, contacts or knowledge they have to offer and make the most of these
- Assign them a specific task and be clear about what you are asking them to do
- Set a time limit for the task with a deadline that is achievable and allows the campaign to keep moving

- Make sure the task is worthwhile and adds value to the campaign
- Show recognition of their work and contribution
- Keep them updated on the overall campaign progress throughout

An example of a good and bad Task Ask would be:

Good example



- We are running an educational event for ministers to educate them about national plans.
- We need a list of free venues that are available with and without food on 29 May 2016.
- We need the list and a map of all the potential sites by 1 April 2016 for our next phone meeting.
- Please make sure every space has parking and a family assist bathroom.

Bad example



- We need a place for a meeting.
- We are trying to reach out with our messages on social media.
- We need a volunteer to create a list of blogs and electronic mailing lists that we could post on, with an explanation of their rules for posting (frequency, types of content, ground rules).
- We think this will take 10-20 hours and the person doing this can use the office computer.
- The deadline is 1 July, and if you get stuck Marco is really good with computer stuff and he can give you advice.

Thanks.

ARDSI's Kerala State Initiative on Dementia

In 2014, the Alzheimer's and Related Disorders Society of India (ARDSI) launched the Kerala State Initiative on Dementia (KSID) - "Smruthipadham" in partnership with the Government of Kerala, Social Justice Department. The campaign aimed to:

- Identify locally available resources and personnel within existing facilities
- Incorporate dementia care training into programmes run by the health service department
- Raise awareness of dementia among healthcare workers
- Introduce community memory clinics
- Provide assessment, advice and referral to people with dementia during the annual household survey
- Prepare educational materials on dementia for the public
- Establish a state dementia helpline
- Encourage research and development

Two key successes of the campaign were the opening of a full time dementia care centre and day care centre, and a public awareness campaign. Suitable staff for the centres were identified, recruited and trained with continuous support supervision by ARDSI staff. The centres have been such a success that seven more are in the planning stages. The awareness campaign, *I am a Dementia Friend*, saw a specifically designed vehicle travelling a total distance of more than 2150km spanning 14 districts. The campaign distributed warning signs messages through pamphlets, displayed notices, and talks. Collaboration with the Social Justice Department, Indian Psychiatric Society and Kerala Neurologist Association strengthened the content value in reaching out to the public. The campaign was well received and culminated in a valedictory function attended by the State Minister for Social Welfare in the State Capital, Thiruvananthapuram. ARDSI's Memory Clinic Guidelines were also released at this event.

The campaign has seen increased awareness and altered the perception of dementia among the public and health officials, the memory screening protocol created by ARDSI has been accepted for practice by medical institutions, and ARDSI's reputation as a knowledge resource has resulted in more care centres throughout the state.

Building relationships with government officials

In most campaigns, government officials will be the people you are trying to win over and to do this it is important to recognise what their priorities are likely to be. They are busy people, often managing numerous - and conflicting - priorities. Taking an approach that recognises this is more likely to win you some support.

Before any arrangements are made to approach a government official, you should plan what it is that you wish to say to them and what you would like to ask them to do for you. You don't want to walk away from a meeting wishing you had given them more information or responded differently to a question they had.

It is also important to choose the right officials. While the most senior health official may seem like the obvious choice, in some cases it may be more beneficial in the longer term to approach an official who is most likely to champion your cause or could get their fellow decision-makers talking about the topic. If you are aware of a government official who has a personal connection to dementia then you may wish to speak to them as they will already have some prior knowledge. Who you choose to speak to will affect how you handle your first meeting with them and this should be reflected in your plan.

A good time to approach government officials is in the lead-up to an election. At this time government officials, or election candidates, will be looking to raise their profile and being seen to champion a cause will support this.

The power of the voice of a person with dementia or care partner should not be underestimated in any dementia campaign. This is why you should consider, if you are able to, attending the meeting with someone who can speak about their experience of dementia. If you are in a position to be able to take a person with dementia with you it is important to discuss it with them beforehand and run through what may be said and what you are going to be asking the government official to do. This will help the person to feel more

comfortable, allow them to prepare and ensure that you are in agreement.

Any conversations you have with the staff of the government official during your campaign are also key. Good communication between you and their secretary, for example, should mean that arranging meetings or getting messages to the official will run a lot more smoothly. Also, returning calls to their staff, or the official themselves, as soon as possible is extremely important.

Once you have managed to secure a meeting, you may find that some government officials will be more forthcoming or appear to have more time for you, particularly if they have personal experience of dementia. Meanwhile, others may seem less enthusiastic, which can be off-putting, but try to stick to your plan and remember that some relationships are harder to build than others. You should present your case in a simple way and be in a position to provide them with more details if they ask for them. Your new relationship should not be all about them giving and you taking - be sure to offer your support or any resources they may need. Ask them if they are willing to be added to your mailing list to receive regular updates about your work. You should attempt to stay in contact with them if possible, but without overloading them with emails, phone calls or information.

If you find yourself in the fortunate position of being able to count government officials as supporters of your work, you may wish to make their commitment more formal by developing an alliance, which would bring you and these decision-makers together for meetings or working lunches, for example. This is one way to encourage more government officials to get involved in your work as they will see that their colleagues are championing your cause.

It is important to show public recognition of a government official's input into your work or campaign. Making them an ambassador or giving them a similar title will help to raise your profile, but will also enhance their public image and, as a result, encourage them to continue supporting your cause.

You may choose to invite them to attend or speak at a social event or conference. This will present opportunities to promote their involvement through publications or the local/regional/national media.

Finally it is important to try to go beyond political differences and make dementia an all-party issue. This lowers the risk of having to start over again in building the case with your government should there be a change of political direction in your country or region. In some countries interest groups have been formed within their parliament across political lines, sometimes referred to as all party or bi-partisan coalitions.

Using reports and data to make a case

Policy makers rely on data as part of the rationale for the decisions they make about priorities, allocation of resources and overall priorities. Being able to put numbers on a problem with the compelling faces of the problem of dementia is a solid combination for getting public officials' attention. If you have access to local or national data about dementia that you believe to be reliable, this could form an important part of your case.

The importance of this issue cannot be stressed enough! There is hardly any country where dementia policies have started without a wake-up call from a report published, most of the time by an Alzheimer association, including data on prevalence and cost of dementia.

At the international level, the *World Alzheimer Report 2010* on the global cost of dementia was the eye-opener that triggered the World Health Organization, the Organisation for Economic Co-operation and Development (OECD) and later the G7 to take it seriously.

Some examples of international reports that could support your campaign are:

- **ADI's World Alzheimer Reports www.alz.co.uk/worldreport**
The World Alzheimer Report series are annual reports that provide the most up-to-date data on a wide range of topics, including global dementia prevalence, the economic impact of dementia, the benefits of early intervention, stigma and dementia, dementia risk reduction, and long-term care for people living with dementia.
- **World Health Organization (WHO) report www.alz.co.uk/WHOreport**
Dementia: a public health priority, launched in 2012, provides the most authoritative overview of the impact of dementia worldwide. In addition to valuable best practices and practical case studies from around the world, it contains the most comprehensive collection of data, including hard-to-get statistics from low and middle-income countries.
- **ADI template for a country report**
If your government is not willing to do the research, you may want to consider doing it yourself and you don't have to start from scratch. ADI has a template for a country report with health statistics worldwide, in your part of the world and from your country. In addition there is a section on what dementia is and what the main issues are. You can add to this any more information about your country, services and activities from your association and a call to action about what you think should happen in your country. To receive the template, contact the ADI office.
- **Learnings report on national dementia plans**
This report compares the plans from Australia, South Korea, USA, Norway, England, Netherlands and France on content, development process and success factors. This report is available in English, Spanish, French and Portuguese at www.alz.co.uk/alzplans

- **10/66 Dementia Research Group www.alz.co.uk/1066**

ADI supports the 10/66 Dementia Research Group, which gets its name from the fact that, when the group was formed in 1998, less than 10% of all population based research into dementia was directed towards the 66% of all people with dementia who lived in low and middle income countries. The network is made up of over 100 active researchers from more than 30 low and middle income countries who are studying the prevalence and impact of dementia in communities where it had not been studied before.

Getting on the record and giving testimony

Providing testimony, whether in person or submitted, allows your organisation to have your informed positions officially made a part of the record on a given issue. It is one of the most important ways of interacting with legislators, allowing you to impress upon them the urgency, importance, or dangers of specific legislation. Being on the record allows you to point to a specific time and day where you gave your insights and hold legislators accountable for being at least broadly informed.

Your formal organisational presence and participation not only demonstrates your knowledge and expertise on dementia issues, but also sends a clear signal that you intend to be part of the conversation. It is a higher-level tactic, designed to educate as well as reinforce that your organisation is the strongest voice for those with dementia.

How to get on the record

Getting the where and when

- Go online and look at the schedule for relevant committees. Health Committees are the natural places to start.
- Sometimes committees do not announce a hearing until a week in advance.
- Request to be added to any email alerts that Committees provide.

Leading up to the hearing

- Call ahead to verify location, and again indicate your intention to participate.
- Ask if there are any testimony submission guidelines. Does testimony need to be provided in advance? If so, when? How many copies should you expect to provide? Are there formatting issues you must be aware of (for example, submitted in a folder, two or three-hole punch)? What are the time limits to speak and answer questions?
- Contact supportive legislators prior and let them know of your plan to testify. Are there any opposing points you should be aware of?
- Most committees allow you to co-testify with someone who has been or would be affected by the proposal. These real-life examples are particularly powerful. Seek out people who can effectively put a face on an issue.
- Practice making your points several times, so that you can make eye contact with members while you speak and are not just reading off a paper. Delivery can be as important as substance.

Providing your testimony

- Expect to provide copies of your remarks to legislators and staff. Customarily, it is addressed to the Committee Chairs and Honourable Members of the Committee.
- Time is generally limited. Make your points concise and memorable. Explain what you are asking, and why it is important.
- Avoid repeating what others have said before you. Acknowledge previous remarks and indicate your agreement with them.
- Thank the Committee before you speak, at the end, and if you have time, wait until end of hearing and thank them in person.
- Have a friend take photos and post them on your website.

Follow-up

- Write a follow-up thank you letter to the Committee Chairs offering to provide more expertise or to set up a meeting, continuing the dialogue.

If you can't make the hearing

- Contact the committee and ask for their rules on how they prefer written testimony to be submitted.

Other opportunities to get your message across

Seeking other opportunities to speak, not only at government events, is also key to getting your voice heard. It may be that a partner organisation is hosting or attending a conference or meeting at which they are willing or able to let you present your case. Taking up such an opportunity could gain you more supporters from civil society or other organisations, and perhaps from government representatives if they are in attendance.

Other ways of getting your message across include working closely with the media. The media has enormous power in influencing public opinion and can therefore play a role in gaining widespread support for your campaign. At key stages of your campaign prepare a strong media release and distribute to local, regional and national media as appropriate. Journalists are often working to very tight deadlines so an article that requires very little editing and has the most important information at the beginning will help to get your news published. Do not be surprised or take it personally if your article is edited down, it is likely that the editor has very little space available for each story.

The PAHO Regional Plan of Action on Dementia

In 2011, ADI began meeting with Pan America Health Organization (PAHO) staff to advocate for a Regional Plan of Action on Dementia. A plan would oblige countries within the Americas to develop their own national dementia plan. Key partners in the campaign included ADI member associations, 10/66 Dementia Research Group researchers, HelpAge International, the NCD Alliance and the Worldwide Hospice Palliative Care Alliance.

From 2012 ADI staff along with its members and other key partners attended and provided testimony during Sessions of the Regional Committee of the WHO for the Americas. In 2013 ADI worked closely with PAHO staff to develop a draft plan while members in the region communicated with Health Ministers to discuss the plan. A report, *Dementia in the Americas*, examining the prevalence and predicted costs of dementia in the Americas was released in partnership with Bupa. The report was disseminated to all Health Ministers in the region.

The following year, PAHO staff attended ADI's 29th International Conference in Puerto Rico to encourage members to take action in support of the plan. Later that year, the Health Minister of Costa Rica proposed to the PAHO Executive Committee that the plan be added to the 2015 Sessions of the Regional Committee of the WHO for the Americas. ADI hosted a side event during the 2014 Sessions to raise awareness of the plan.

In 2015, during the 67th Session of the Regional Committee of the WHO for the Americas, PAHO country representatives voted unanimously in favour of the Regional Plan of Action on Dementia in Older Persons. The PAHO region became the first WHO region to adopt a Plan of Action on Dementia.

In 2016 Argentina and Chile will publish their national dementia plans. In October 2016, ADI's member association in Costa Rica, ASCADA, partnered with PAHO to host the first sub-regional meeting of Ministries of Health from Central America to discuss the universal adoption of national dementia plans.



Prof Peter Mittler is a member of and Human Rights Advisor to Dementia Alliance International. At the 16th Session of the UN Committee for The Convention on the Rights of Persons with Disabilities (CRPD) Prof Mittler called for people with dementia to have access to their rights under the Convention.

Evaluating your campaign

Your campaign should be considered to have ended if you achieve your aim or if the timeline you set for yourself has passed, whichever comes first. In some instances you may wish to extend the campaign, particularly if you feel that progress is being made and that taking the pressure off could damage your chances of reaching your target. It may be that, at the time you were hoping to have had a commitment from your government that, for example, dementia training would be provided to all professional carers, you have just managed to secure commitment from a couple of government officials who will push the issue forward imminently. It is important, though, to be honest with yourself and recognise that if your campaign appears to be going nowhere or is going around in circles, you may need to stop what you are doing and re-consider your approach and how the issue can be progressed from the point it has reached. This would be a good time to evaluate your campaign.

It may be that this is time for you to celebrate your success, if you have achieved your aim or are significantly closer to improving the lives of people with dementia and care partners than you were at the start. If this is the case, it is likely that you will have offered to support, or even drive, the change. Any action should be started as early as possible, while the enthusiasm and momentum is there, and it is likely that you will need to push for the changes to be made in order to move forward. In some respects your campaign is just the start of the change process.

Whether your campaign has been a success or not you should organise a meeting of your campaign group to discuss, in detail, the process and outcomes. Any partners involved in the campaign should also work with you on your evaluation, including people with dementia and care partners. You may find it worthwhile to gather thoughts from all involved prior to or following the meeting, so those who are unable to attend can have their say.

It may be that participants have comments that they do not feel comfortable raising in-person or that were missed during the meeting, so time should be given for them to share these.

In your evaluation you should consider:

- What went well and what did not go well
- With hindsight, how you might have run the campaign differently
- Any areas in which you feel progress has been made - and examine how these can be built upon in the future
- Identifying any organisations or groups that you have come across who could help you in the future, or any you would avoid working with
- Whether there are any issues that may have come to your attention during the campaign that you had not been aware of before
- What you have learnt about working with policy makers/people with dementia/care partners/the media/the public
- What your next steps will be: implementation of the new policies; continuing on the same issue, but with a different approach; addressing a different issue in response to your learnings or changes in your country

Once you have this information make sure it is used. A lot of time and energy will have gone into your campaign and the learning from it is a valuable tool.

Resources

ADI – www.alz.co.uk

World Alzheimer Report - a series of annual reports containing the latest research on a variety of topics including dementia prevalence, diagnosis, care and impact.
www.alz.co.uk/worldreport

The WHO report *Dementia: a public health priority*, launched in April 2012, is available at
www.alz.co.uk/WHOreport in English, Chinese, Russian and Spanish.

A disability rights for persons with dementia position paper, *Harnessing the United Nations Convention on the Rights of Persons with Disabilities to improve the lives of persons with dementia*, was commissioned jointly by Dementia Alliance International (DAI) and ADI. The report is available, along with a number of other policy briefs, at www.alz.co.uk/reports

National dementia plans

Information about the various government dementia plans around the world can be found at
www.alz.co.uk/alzplans

The ADI-Bupa report *Improving Dementia Care Worldwide: Ideas and Advice on Developing and Implementing a National Dementia Plan* is available in English, Spanish, French and Portuguese and can be downloaded at
www.alz.co.uk/plans-review

An evaluation of the French dementia plan was released in June 2013. The evaluation reviews the successes of the plan and provides 56 recommendations for the future. The plan is available in French at
<http://social-sante.gouv.fr/IMG/pdf/Rapport-evaluation-plan-alzheimer-2012.pdf>

ADI member associations

Alzheimer's Australia

www.fightdementia.org.au
Visit their Submissions to Australian Government section which shows the proposals Alzheimer's Australia has made to various Government Departments www.fightdementia.org.au/research-publications/submissions-to-australian-government.aspx. Visit their reports section www.fightdementia.org.au/access-economics-reports.aspx. You can see more information about their Fight Dementia campaign at <http://campaign.fightdementia.org.au>

Alzheimer's Society of Canada

www.alzheimer.ca
Visit their advocacy section www.alzheimer.ca/en/Get-involved/Raise-your-voice

Alzheimer's Society (England, Wales and Northern Ireland)

www.alzheimers.org.uk
Visit their policy section www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200128 which includes information on the national dementia plan.

Deutsche Alzheimer Gesellschaft (Germany)

www.deutsche-alzheimer.de
Deutsche Alzheimer Gesellschaft (the German Alzheimer Association) launched Allianz für Menschen mit Demenz in 2014 alongside the German government. The alliance campaigns for a national dementia strategy or working group to encourage greater collaboration on dementia between government ministries. More information can be found at www.allianz-fuer-demenz.de

Alzheimer's and Related Disorders Society of India (ARDSI)

<http://ardsi.org>

ARDSI's We Demand page which contains details of their campaign issues <http://ardsi.org/wedemand>. The Dementia India Report, launched in 2010, can be found at www.alzheimer.org.in/assets/dementia.pdf

Alzheimer Society of Ireland

www.alzheimer.ie

Visit their campaigning and advocacy sections www.alzheimer.ie/Get-Involved/Campaigning.aspx and www.alzheimer.ie/Get-Involved/Advocacy.aspx which include information about European and local election campaigns, information on their national strategy and their advocacy newsletter.

Alzheimer Scotland

www.alzscot.org

Visit their campaigning section www.alzscot.org/campaigning which includes their policy reports, information about the Scottish Dementia Strategy and how Alzheimer Scotland aims to influence public policies.

Alzheimer's Association (USA)

www.alz.org

Visit their advocacy section to learn more about the Association's public policy work and lobbying efforts www.alz.org/advocacy

Advocacy from the perspective of people with dementia

Dementia Alliance International (DAI)

www.dementiaallianceinternational.org
DAI is a collaboration of individuals diagnosed with dementia providing a unified voice of strength, advocacy, and support in the fight for individual autonomy for people with dementia. In May 2016 DAI launched the booklet *The Human Rights of People Living with Dementia – from Rhetoric to Reality* www.dementiaallianceinternational.org/human-rights, available in English, Spanish, Arabic and Italian.

Other organisations

Alzheimer Europe

www.alzheimer-europe.org

Alzheimer Europe aims to improve care and treatment of people with dementia through collaboration between its member associations. Visit the policy section of their website for information on policy work being done on a European and country level www.alzheimer-europe.org/EN/Policy-in-Practice2

Campaign Strategy

www.campaignstrategy.org

Campaign Strategy has tips and guides on how to run a campaign.

HelpAge International

www.helpage.org

HelpAge International is a global organisation striving for the rights of disadvantaged older people to economic and physical security; healthcare and social services; and support in their caregiving role across the generations. Visit their policy section www.helpage.org/what-we-do/policy

International Psychogeriatric Association

www.ipa-online.org

IPA is a professional healthcare community promoting better geriatric mental health – across disciplines, across borders, and across geriatric issues. IPA promotes research and education, facilitates an international exchange of ideas on psychogeriatric issues, and fosters cross-cultural understanding of the latest developments in the field.

NGO Committee on Ageing

www.ngocoa-ny.org

The NGO Committee on Ageing, New York, works to raise global awareness of the opportunities and challenges of global ageing. The Committee advocate within the United Nations community to further integrate ageing in UN policies and programmes and encourages member states to include ageing needs in social and economic policy considerations. ADI is a member of this committee.

The NCD Alliance

www.ncdalliance.org

The NCD Alliance is an alliance of international federations of which ADI is a member of the steering group. They were originally founded by federations representing the four main non communicable diseases (NCDs) outlined in the World Health Organization's 2008-2013 Action Plan for NCDs – cardiovascular disease, diabetes, cancer, and chronic respiratory disease. They have an advocacy section on their website www.ncdalliance.org/advocacy

United Nations (UN)

www.un.org

The UN is an intergovernmental organisation which encourages international collaboration among its 193 Member States. ADI has had consultative status with the UN since 2012.

World Health Organization (WHO)

www.who.int

The WHO is the public health arm of the UN. The WHO has a practical guide for advocates of chronic diseases, *Stop the global epidemic of chronic disease: A practical guide to successful advocacy*, which is available in English and French at www.who.int/chp/advocacy. ADI has been in official relations with WHO since 1996.



**Alzheimer's Disease
International**

The global voice on dementia

Alzheimer's Disease International:
The International Federation
of Alzheimer's Disease and
Related Disorders Societies, Inc.
is incorporated in Illinois, USA,
and is a 501(c)(3) not-for-profit
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