



**Alzheimer's Disease
International**

Influencing public policy

January 2000

Influencing public policy

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Introduction	<i>3</i>
Campaigning steps	<i>4</i>
Setting a campaign aim	<i>6</i>
Doing your homework	<i>8</i>
Managing your campaign	<i>10</i>
Targeting your campaign	<i>12</i>
Campaign strategy	<i>14</i>
Campaign methods	<i>16</i>
Measuring success	<i>18</i>

Published by
Alzheimer's Disease International

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Introduction

This pamphlet is based on a workshop given by the authors at the 1997 Alzheimer's Disease International conference in Helsinki, Finland.

It is designed to help members of Alzheimer's Disease International (ADI) plan and run successful campaigns aimed at influencing public policy.

Whether your association is newly-formed or well-established this pamphlet is aimed at giving ADI members useful hints and suggestions to help you in that campaign work.

Campaigning not only helps to raise awareness and understanding of Alzheimer's disease and caring for dementia but it is essential if we are to change public policy better to meet the needs of people with dementia and their carers around the world.

While we often think of campaigning in terms of short-term objectives, it is in fact more about changing things for the better in the long-term. A factor that all campaigners must therefore bear in mind is the need to build long-lasting communication, dialogue and relationships with public policy-makers and opinion-formers.

While there is no magic formula for a successful campaign, the advice, materials and case studies contained in this pamphlet will demonstrate that campaigning works and should increase your own chances of success.

Good luck.

Harry Cayton
Simon Denegri

Campaigning steps

There are six basic steps to running a successful campaign. These steps apply whether your campaign is national or local, big or small. They are:

- 1 Setting a campaign aim:** deciding what issue you are going to campaign on and what you want to achieve.
- 2 Doing your homework:** collecting facts, figures and information in support of your campaign.
- 3 Managing your campaign:** planning and managing your campaign according to the resources you have available.
- 4 Targeting your campaign:** deciding who to aim your campaign at for it to achieve its aim(s).
- 5 Campaign strategy:** deciding on your campaign strategy and what methods you are going to use to highlight your cause.
- 6 Measuring success:** assessing your campaign.

In the following pages we look at each of these campaigning steps in more detail.

summary

CAMPAIGNING STEPS

The six basic steps to running a successful campaign:

1 Setting a campaign aim

2 Doing your homework

3 Managing your campaign

4 Targeting your campaign

5 Campaign strategy

6 Measuring success

Setting a campaign aim

Before embarking on your campaign you need to decide what you want it to achieve. For example, would your association like to see more respite care provided for carers or more funds provided for research into the causes and a treatment for dementia?

A good starting point is to define the issues which most concern people with dementia, carers, and members of your association. You can do this in a number of ways:

- Send a questionnaire to these groups asking them for their views on the issues which most concern them.
- Discuss campaigning at your annual general meeting.
- Discuss with other organisations such as carers groups to see whether you have some shared concerns and objectives.

In 1997 the Alzheimer's Society carried out a survey of carers views of standards of residential and nursing home care received by people with dementia. The Society's report received widespread national media coverage and helped the organisation define its objectives in this area such as the need for better training of care workers. The British Government has since set up a number of working parties to look at different aspects of standards in residential and nursing home.

When setting a campaign aim it is important to ensure that:

- Your campaign has a positive message or puts forward a constructive solution to a problem you have identified. Governments and politicians react better to this sort of positive approach.
- Your campaign aims are realistic and achievable. In terms of resources it is often better to focus on one or two issues.
- Everybody in your organisation is clear about the issue on which you are going to campaign and what your aims and objectives are.

Many organisations sum up their campaign aim in a campaign slogan or message such as the 'Help for Today – Hope for Tomorrow' slogan used by the Alzheimer Society of Canada. The Society supports ongoing research for the cause and cure of Alzheimer's disease but wants to raise awareness that there are 250,000 Canadians with dementia who also need help and support now.

summary

SETTING A CAMPAIGN AIM

Decide the issue you are going to campaign on and what you want your campaign to achieve.

- **Send a questionnaire to carers**
- **Hold a meeting to discuss campaign issues**
- **Discuss with other organisations to see if you share concerns**

Ensure that your campaign aims and objectives are:

- **Positive or put forward a constructive solution**
 - **Realistic, achievable and focused**
 - **Understood by everyone in your organisation**
-

Doing your homework

For a campaign to be successful it is essential that you spend time early-on in your campaign collecting facts, figures and other information to support your argument. People who you want to join your campaign and those who you are seeking to influence will expect you to be able to provide evidence to support your case.

Here are some sources of information that may be helpful in your research:

Government and politicians
 Libraries
 Universities
 Health and social care professionals
 Other organisations

Carers are an important source of information. Not only may you be able to base statistics on the survey or questionnaire of carers you conducted in setting your campaign aim. But, if this is not possible, the letters and voices of carers describing the difficulties they face can be invaluable in making others understand what you are trying to achieve.

Your research at this stage can also be helpful in deciding who you should target your campaign at, what your campaign strategy should be and what campaign methods you should use.

Questions your research might therefore address include finding out what current government policy is; how public policy is formed, whether it is necessary for the law to be changed to achieve your aims and, if not, what needs to happen for your campaign to be successful; and whether there have been similar campaigns on your issue in the past and whether you can learn from these.

In 1992 the Boulder County Eldercare Coalition was formed by the Rocky Mountain chapter of the Alzheimer's Association, USA, the Boulder County Ageing Services Division and the City of Boulder Senior Services Division. The coalition carried out extensive surveys with leading agencies in the region and discovered that there was a lack of services for frail elders and their carers, and there was a need for quality services to assist the elderly in maintaining active roles in the community and in their homes.

summary

DOING YOUR HOMEWORK

People who you want to join your campaign, and those who you are seeking to influence, will expect you to have evidence in support of your case:

- **Collect facts and figures to support your campaign**
- **Collect testimonies from carers to support your campaign**

Your research at this stage can also be helpful in determining later on:

- **Who to target your campaign at**
 - **What your campaign strategy should be**
 - **What campaign methods you should use**
-

Managing your campaign

Running a campaign will have implications for your organisation in terms of both human and financial resources. These have to be set against other priorities your organisation may have such as providing information and advice to people with dementia and their carers; providing help and support to carers; and raising funds.

Limited resources are a common problem faced by all campaigners. Ensuring that your campaign aim is realistic and achievable can help avoid a situation where your campaign runs out of steam because of lack of resources.

But your campaign can also be made more manageable by:

- Setting up a small committee (three or four people) to co-ordinate your campaign.
- Having a campaign organiser to co-ordinate your campaign.
- Sharing out campaign tasks such as envelope filling among people in your organisation so that one or two individuals don't have too much to do.

Having a campaign committee and campaign organiser means you also have more control over your campaign.

The Alzheimer's Society has found that campaigning is often made easier by forming alliances with other organisations representing older people or carers. Alliances enable you to pool resources. They also demonstrate to others that you have widespread support in the community and therefore make you more visible.

For World Alzheimer's Day 1997 Alzheimer's Disease International ran a successful campaign to raise public awareness of Alzheimer's disease. Under the theme 'A Race Against Time' a charter and a newspaper were distributed across the world. Thirty countries participated and government leaders, politicians and celebrities signed the charter committing themselves to support people with dementia and their families.

summary

MANAGING YOUR CAMPAIGN

Managing a campaign can be made easier by:

- **Setting up a small committee to manage the campaign**
- **Having a campaign organiser to co-ordinate campaign activities**
- **Sharing out campaign tasks among people in your organisation**

Forming alliances with other organisations makes campaigning easier and can increase your chances of success by:

- **Enabling you to pool resources**
- **Demonstrating to others that you have widespread support for your aims**
- **Making your campaign more visible**

Targeting your campaign

Aiming your campaign at the right people makes all the difference. Remember, it is who you know as well as what you know that matters.

Your research at the beginning of your campaign will have told you a great deal not only about how public policy is formed and what you need to do to achieve your aims, but also about those people in positions of influence that you need to talk to and persuade. These people will be the 'targets' at which your campaign will be aimed.

Your targets may include: government ministers, officials and advisers; national and local politicians across the political spectrum ; other organisations; health and social care professionals; the media; and the general public.

For instance, if your campaign is aimed at improving the provision of respite care it is more than likely that your country's health minister will be one of the key targets of your campaign whereas the foreign minister would not be.

We have already mentioned how important it is for a campaign to be visible to attract widespread support in the community and be more influential with public policy-makers. The media can play a crucial role in getting your message across to carers, the general public and your targets. Remember, politicians read newspapers as well.

Spend some time getting to know those newspapers, tv and radio programmes, and journalists who are more likely to deal with issues of concern to you. Send them press releases and information about your campaign and follow-up any material you send with a telephone call.

In 1997 the Alzheimer's Society of India held its annual general meeting in Hyderabad. In order to attract media attention they put out a press release showing the growing population of older people in India and the increased number of people with Alzheimer's disease. The story attracted a lot of attention and drew press to the conference, where the chairman was able to brief them on the Society's work.

summary

TARGETING

It is who you know as well as what you know that matters.

Who you aim at depends on what your campaign is and how it can be achieved.

Some possible groups of people that you will aim your campaign at:

- **Government ministers**
 - **Government officials and advisers**
 - **Legislators**
 - **Local legislators**
 - **Other organisations**
 - **Health and social care professionals**
 - **The media**
-

Media coverage of your campaign will make it visible to a larger audience.

Spend some time getting to know your broadcast and print media and ensure that they receive information about your campaign.

Campaign strategy

When deciding on your campaign methods and strategy you should bear the following general points in mind:

- **Devise a timetable for your campaign**
Have some idea of where you want your campaign to go and when. Often this is determined by what is happening in your country's government or parliament.
- **Have a focus for the start of your campaign**
You could put on an event such as a conference or public meeting where all sides of the argument can put their case and which will attract some publicity.

- **Exploit every opportunity**
Good campaigners are opportunists and maximise opportunities when they come along as a chance to get their campaign message across.
- **Be flexible**
Campaigners should expect the unexpected and be able to adapt their campaign strategy accordingly.
- **Be visible**
The more visible your campaign is and the more publicity it gets the more likely you are to achieve your aims.

Overleaf we look at some common methods used by campaigners to highlight their case.

summary

CAMPAIGN STRATEGY

Devise a timetable for your campaign

Have a focus for the start of your campaign

Exploit every opportunity

Be flexible

Be visible

Campaign methods

Here are some common campaign methods employed by campaigners:

- **Letter-writing**

Letter-writing is a method often used by campaigners to highlight their concerns. Letters are written by the organisation and its supporters to those people they are seeking to influence. A letter-writing campaign is a good way of involving members of your organisation and carers in your campaign.

- **Petitions**

Collecting a petition can be an effective way of demonstrating that your campaign has widespread support in the community. Getting people to sign your petition is a good way of engaging them in discussion about your concerns and encouraging them to become involved. You can also use it as a focus for publicity when you hand it in to your country's parliament or government.

- **Press and media launches**

Hold a press conference to launch your campaign. Suggest to your national broadcast and print media that they should run a feature about your concerns coinciding with the launch of your campaign. Alternatively you might want to hold a conference or public meeting to launch your campaign. Ensure that all sides of the argument are represented and invite the media along to cover the event.

- **Celebrities and 'gimmicks'**

It can be very helpful to your campaign if you can get famous people to speak out in support of your cause. They may be willing to do interviews for the media. Another way of getting media coverage is to stage an event which conveys your message simply but effectively.

In 1997, Alzheimer's Netherlands was able to get a new variety of daffodil (developed by a Dutch grower) named 'Alois' after Alois Alzheimer. A whole bed of daffodils was planted in the shape of a clockface at the national garden festival and blessed by a bishop. This attracted a lot of interest. Plans are underway to sell the daffodil bulbs to raise funds.

- **Meetings**

Often a good short-term goal for any campaign is to seek a meeting with those people you have identified as targets. This is a way of putting your concerns on their agenda and a way of establishing an on-going dialogue.

summary

CAMPAIGN METHODS

Letter-writing

Petitions

Press and media launches

Celebrities and 'gimmicks'

Meetings and agendas

Measuring success

In measuring the success of your campaign you should remember the following points.

Campaigning is a long process. You need time and patience. While your campaign might not have achieved all its aims and objectives in the time that you had planned and you will undoubtedly have achievements to look back on and build upon such as more open public debate on about your concerns and dialogue with government.

Greater awareness and understanding of dementia and the needs of people with dementia and their carers is a by-product of all our campaigns.

Remember the maxim 'if at first you don't succeed, try, try again'.

Finally, there are three essential qualities that all campaigners must have to be successful. To be:

- **Positive:** to believe that they will succeed in the end and to put forward constructive solutions.
- **Persistent:** to never give up.
- **Patient:** to campaign in the knowledge that public policy is very rarely changed overnight but that by being positive and persistent they can achieve their ultimate aims and objectives.

summary

MEASURING SUCCESS

Campaigning takes time and patience

If at first you don't succeed, try, try again!

Greater awareness is a by-product of any campaign – successful or unsuccessful

There are three essential qualities that campaigners need to be successful. To be:

- **Positive**
- **Persistent**
- **Patient**