



**Alzheimer's Disease  
International**

# How to develop an Alzheimer's association and get results

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*Creating an  
Alzheimer's association  
is the most efficient way  
to achieve help  
for the largest possible  
number of people*

## How to develop an Alzheimer's association and get results

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# Introduction

Alzheimer's disease and the related dementias are chronic progressive diseases and ultimately fatal. Research is rapidly progressing but it may be many years before cures emerge. In the meantime people with dementia and their carers need support and practical help. Creating an Alzheimer's association is the most efficient way to achieve help for the largest possible number of people. An association helps to co-ordinate, guide and advise local activities. Once an organisation is up and running, it raises public awareness which leads to increased resources for both care and research.

# First steps

- Involve a few interested people – carers and professionals
- Find out if your country already has similar organisations (ask Ministry of Health, ADI, WHO, Church)
- Establish a contact name, address and telephone number
- Organise a public meeting
- Advertise the public meeting in newspapers, local radio, hospitals, clinics, libraries
- Agree at the public meeting to set up an organisation

## Initial decisions

- Form a small committee
- Appoint a chairperson and treasurer with term of office
- Nominate medical / scientific advisors
- Hold regular meetings
- Define initial aims
- Divide up tasks
- Establish priorities you need money for
- Find administrative / secretarial help
- Advertise and appoint an executive director, if resources are available
- Find office space
- Write a simple constitution

## Identifying aims

- Establish self-help groups
- Publish a newsletter
- Provide information
- Raise public policy issues
- Set up membership
- Provide support services
- Offer training
- Raise awareness
- Raise money to pursue the above aims

## Useful characteristics of volunteers

- Capacity to get on with other people
- Experience of caring
- Capacity to listen
- Time to give
- Business or fund-raising experience
- Appropriate professional skills – eg doctor, social worker, nurse, occupational therapist, lawyer
- Absence of major personal problems
- People with energy, ideas, motivation

## Recruiting volunteers

- Ensure adequate preparation in the organisation before recruiting – by providing induction, support supervision and practical resources such as phone, desk and chair!
- Decide on the role of volunteers in the organisation – caring, administrative, practical etc – and their relationship with paid staff
- Agree on the skills needed by the volunteers – financial, PR (public relations), caring, administrative etc
- Think of where to find volunteers – other organisations in the community, colleges, universities etc
- Work out how to find suitable volunteers – advertising, word of mouth etc
- Decide what the organisation can offer volunteers – experience, satisfaction of meeting and helping people, training etc
- Try to provide what volunteers want from the organisation – job description, information, guidance, support and, not least, recognition.

## Likely reasons for needing money

- Telephone
- Answering machine
- Fax
- Postage
- Rent of room / office
- Computer equipment, including email
- Stationery
- Photocopying
- Travel expenses
- Newsletter
- Publications
- Minimum of one part-time or full-time person in office (if paid)
- Ideally an executive director plus administrative assistance

## Ways of raising money

- Subscription from members
- Donations from members
- National and local government grants
- Grants from other charitable organisations
- Grants from national religious organisations
- Sponsorship from drug companies (but with no strings attached)
- Legacies
- Sponsorship from businesses and industry
- Fund-raising events
- Mail shots

## How to provide information

- Answer enquiries quickly, efficiently and sensitively by telephone and letter
- Have professional advice available
- Fact sheets
- Publications
- Newsletter
- Videos
- Helpline
- Web page

## Ideas for a newsletter

- Publish regularly – eg every 3 months
- 2–4 pages each issue
- Questions and answers regarding the disease
- Letters
- Carer's story
- An aspect of good practice in caring
- Research article
- Interesting local and national events in your country
- Information and advice on benefits and services
- Information on the national society and its meetings
- Funding and fund-raising information
- Attractive appearance, photographs
- Useful names and addresses
- Avoid advertisements if finances allow
- Book reviews

## Basic fact sheets and publications

- Newsletter
- The society and its aims
- What is Alzheimer's disease?
- Caring for people with dementia
- How to start a self-help group
- Up-to-date research
- Legal issues
- Training materials

## Support services

- Information and advice service – eg telephone helpline
- Self-help groups
- Day care
- Sitting services
- Legal and financial assistance

**Note** – it is a big problem for small organisations to provide services:

- Collaboration is required with statutory, voluntary and private organisations
- Training has to be provided
- Emotional support should be given by *trained* volunteers

## Ways of raising public awareness

- Good publications
- Efficient information service
- Membership
- Newsletter
- Carers and professionals giving public talks with slides/overheads
- Links with politicians
- Broadcasting on radio and television
- Having people on telephone lines after a radio/television programme
- Always giving name and address of organisation
- Distributing posters and leaflets through main outlets
- Promotion materials: display stands, videos, T-shirts
- Supporting research
- Awareness events – eg World Alzheimer's Day (21 September each year)

## Public policy issues

- Establish high political priority for carers
- Increase resources (ie money) for dementia
- Gain recognition of national society as voice of carers
- Create and improve services for carers
- Create and improve benefits for carers
- Set standards for care
- Provide training for care workers
- Improve assessment and diagnosis

## Research

- Supporting research raises awareness
- Both biological and psycho-social research are important
- Members need regular updated information (best done by newsletter, both national and ADI)
- Very expensive; difficult or impossible with limited resources

You can help by:

- Providing access to patients and carers
- Subsidising existing research activity
- Involving research scientists as advisors
- Ensuring focus of society remains support of carers

## How ADI can help you

Alzheimer's Disease International (ADI) is a federation of national Alzheimer associations around the world whose mission is to improve the quality of life of people with dementia and their carers and to raise awareness of the disease.

One of ADI's key roles is to support members in their activities and encourage the formation of new associations by disseminating information, supporting an annual international conference, encouraging research and stimulating public and political awareness at the national and international level.

ADI produces a series of booklets and factsheets to guide and support developing Alzheimer associations. For details visit our website at [www.alz.co.uk/publications](http://www.alz.co.uk/publications)

### You can contact ADI for:

- Any of our publications and materials (these are available free of charge)
- Further guidance in developing an Alzheimer association in your country
- Contact details of Alzheimer associations in other countries

### Please call or write to:

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