



**Alzheimer's Disease
International**

The global voice on dementia

Twinning Programme Guide

The need for Twinning Programmes

Dementia is set to become the health epidemic of the 21st century and prevalence rates are already soaring. Today, people with dementia receive hugely varying levels of care according to the country they live in. In developing countries, trained doctors and effective patient-care strategies can be very rare. Unless solutions are found, this inequality will only increase and the strain on families, caregivers and health systems in developing countries will be enormous.

Alzheimer associations play a crucial role in providing support for people with dementia and their families. They provide direct services, information and support. They also advocate to policy makers on behalf of people with dementia and their carers. Alzheimer associations are often the main source of information and support. In many developing countries, they are the only source. Health and social-care services in these countries tend to be focused on basic healthcare needs such as child and maternal health, HIV and infectious diseases. Assessment and treatment is primarily orientated towards acute conditions rather than chronic ones such as dementia. It is therefore essential that Alzheimer associations are equipped with the skills to provide high quality services and support and know-how to influence policy-makers. Alzheimer's Disease International (ADI) has a solution to this challenge.

Among ADI's members, much expertise exists about caring for and supporting people with dementia and their carers. The ADI Twinning Programme launched in 2005 at our International Conference in Istanbul, and aims to harness this knowledge and disseminate this throughout the world. Our ultimate vision is to ensure that people with dementia and their carers receive the best quality care and support, regardless of where they live. Dementia knows no economic or geographic boundaries; neither should the expertise for enhancing the quality of life for those living with it. The Twinning Programme is an opportunity for capacity building within Alzheimer associations, giving organisations the chance to work together to resolve organisational issues.

ADI has already twinned a number of Alzheimer associations and will continue to build on the success of these relationships by extending the reach of the impact of twinning and supporting further associations.

What is a Twinning Programme?

Twinning is an approach that enables peer-to-peer exchange of knowledge and experience between two partners. In a twinning partnership, a member that seeks to improve its performance and service delivery (recipient twin) pairs with a stronger member (mentor twin) to learn from them. Twinning partnerships typically focus on selected performance areas which the recipient twin aims to improve, and the mentor twin is able to provide the required knowledge for.

ADI's Twinning Programme is a formal, two-way partnership between two Alzheimer associations that is characterised by mutual cooperation and responsibility for the achievement of agreed goals. Working together provides benefits to both organisations.

Established national Alzheimer associations have knowledge, experience and resources. These can be shared with the developing associations to enable them to reach a level of provision and performance that directly benefits people with dementia and their caregivers.

ADI is not prescriptive about the skills and knowledge that should be transferred; these will differ in each case, depending on the needs of the associations in the partnership. Skills may relate, for example, to advocacy, governance, fundraising or media relations.

The twinning partnership is formal. The organisations involved complete a written agreement about their commitment to the twinning project after the assessment visit. ADI will be providing some financial assistance, which requires transparency and accountability. This formality will also allow ADI to give timely advice, acting as a mentor to all twinning relationships.

Twinning arrangements follow a set of key principles to ensure that the partnership is mutually beneficial and results in tangible improvements of service delivery.

Criteria for Twinning

To obtain funding from ADI for a twinning relationship, the following criteria must be met:

- The association is a national Alzheimer association and a member of ADI
- If the association has a federal structure, with the approval of the national office ADI will consider applications to twin from more than one branch/chapter and will agree to support more than one twinning relationship per country
- Priority is given to members not already involved in a twinning relationship and where the developing twin is an emerging association
- Twins must develop an action plan to share with ADI. This will outline the objectives of the relationship and how it will operate
- Both the developing and established twin must name at least one individual as the main point of contact. This person will have time allocated within their job description to the ADI Twinning Programme. A second person must be identified to take on a supporting role. This will ensure that the project continues even if the main point of contact leaves the association
- Twins must adhere to the evaluation criteria. This includes:
 - Regularly updating the ADI office at least every three months of developments in that period
 - Two conference calls per year - the two contact points will liaise half yearly on the phone. ADI should be invited to sit on these calls

- Annual progress reports - review overall progress for the 12 month period in relation to the objectives outlined at the outset of the relationship
- Twins are encouraged to participate in ADI workshops at conferences and regional meetings to share their twinning experiences
- The relationship will be supported by ADI for three years in the initial phase

Twinning activities

Activities undertaken in a twinning partnership should be based on the strengths of one association and the needs of another. In collaboration with ADI, an action plan will be drawn up to define the goals for these activities.

Activities could include:

- Exchanging information and knowledge for example publications or educational materials
- Arranging translation of publications or materials considering cultural differences
- Supplying equipment or donating resources – for example office supplies
- Arranging formal or informal training on aspects of running a successful Alzheimer association or on clinical/care training programmes for staff, volunteers or health professionals
- Job shadowing and exchange visits for staff, Board members or volunteers from the association
- Help with advocacy, by using the experience of an association to help raise awareness, reach out to government and other important stakeholders
- Networking, associations share their contacts in the global dementia community and recommend valuable resources
- Working together on special projects for example workshops, campaigns or social activities

ADI's role in twinning

Helping to find a twin

ADI will pair twins appropriately where necessary, i.e. when an association would like to twin but does not have a specific partner in mind. Developed associations willing to offer their

skills and experiences to aid the development of another organisation will provide ADI with information of what they have to offer. Developing associations wanting to take part in the scheme will detail the areas that they wish to develop and the skills/experience they are lacking.

ADI will review applications and pair Alzheimer associations appropriately. If the requirements of a developing twin do not exist within the pool of developed associations, ADI will proactively seek an appropriate twin.

Where possible, associations will be paired in the same region to ensure resources are used effectively. This will also enhance cultural sensitivity, knowledge of context and ease communication.

- **Financial support** - ADI will provide financial support for each partnership for the necessary arrangements for the assessment visit
- **Supplying ADI material** - ADI will provide supporting materials, including guidelines, information on action planning and evaluation forms
- **Guidance and coaching** - ADI will share the experiences and successes of previous twinning relationships. ADI will provide support to each partnership individually. Our Membership Development Officer will keep in touch with all the twins and provide follow-up support as needed
- **Evaluating** - We will evaluate the progress of the relationship quarterly. There will also be conference calls every six months and a full evaluation at the end of each year. Once the assessment visit has been completed, the plans for the partnership will be evaluated. Annual evaluations at the end of each year will be a requirement to secure funding the following three years

The benefits of twinning

ADI believes the twinning relationships will help improve global dementia care and quality of life for people with dementia and their caregivers across the globe. Both associations will gain new knowledge, skills and experiences to continue to build and strengthen their association.

Some of the benefits of twinning are outlined below:

- **Capacity Building** - The transfer of skills and knowledge will lead to more capable organisations better able to provide support and services to people with dementia and their caregivers
- **Sharing best practice** - Best practices are methods and strategies tried by other organisations and found to be effective when adapted to a different country. Learning about these best practices saves associations' time and effort
- **Building relationships** - Twinning will encourage collaboration and help build strong relationships. Associations can mutually support each other and can turn to their twin for support or they can work together on a specific issue or project

- **Strengthening presence** - Twinning can help add leverage to a campaign, fundraising activity or reaching out to government
- **Broadening horizons** - Twinning will be a way to reach out to others, break down barriers and learn about other cultures and seeing how dementia affects people in other parts of the world
- **Building a global movement** - Dementia knows no geographical boundaries; it affects people all over the world. Twinning will help build an even stronger dementia movement and create a feeling of belonging to a global family. Global events influence dementia healthcare policy, funding and development
- **Achieving measurable results** - The results of a twinning relationship could for example be the creation of a new branch/chapter, increased membership, identifying new funding sources or development of new publications.

If you would like further information on ADI's Twinning Programme, please contact;

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