

Dear Chairman, Vice Chairman and Fellow Board Member

ADI STRATEGY – WHERE TO NOW

I am writing to you to set out my reflections on our London Strategy session, and to propose that we put to Council the goal of gaining international recognition of dementia as a global health priority.

As background, in my work experience of strategic planning and policy development, vision and mission is developed during a strategic brainstorming day, and is normally followed on the next day by feedback and development of goals and strategies to achieve them. I returned from the London meeting anxious that we seemed to have left much in the air, and I started to set down some ideas drawing on the brainstorm session.

I have sorted through these ideas with my care-partner Paul (who has much experience in international policy development), and also sought advice from Glenn Rees (the Executive Director of Alzheimer's Australia). Glenn has over the past 5 years been instrumental in developing policy advocacy which has achieved the goal of having dementia accepted by the Australian Government as a National Health Priority.

While working through my ideas, the ADI draft paper (which recommends increased advocacy and another junior member of staff) arrived. I see my own ideas as providing a reason for such advocacy, and describes a role for ADI Members and the Board, in contributing to measurable inputs, as part of a defined strategy, aiming for an achievable goal based on a clear and relevant vision.

I suggest that the Board make an effort to consider my paper, alongside the ADI draft paper, Out of Session, to do what we can to achieve full or partial agreement before Istanbul. Whatever we can do by e-mail will give more time in Istanbul to do what might remain to be done. We cannot continue to move in 6 or 12 month steps when electronic means are available to keep things moving. When we meet face to face, we need to focus on broader, strategic and policy issues, measure progress and assess outcomes, and provide useful guidance to the Secretariat and Executive Committee.

It would be my hope that by Istanbul we could move quickly to build on ADI's current effort in awareness and Member support, to begin to prepare material for advocacy with a purpose. The campaign could commence around the time of World Alzheimer's Day next year, with the goal of achieving a global health priority for dementia within 5 years.

In conclusion, any organization must adapt and reshape itself as it grows. Goals need to be reassessed, strategies reshaped. ADI must be prepared to adapt and change, otherwise it risks becoming limited in its value to its Members.

International advocacy is not the role of national Members. ADI, with its Members cooperating strategically, can meet this challenge. It is the Elected Board's role to lead this effort.

On a personal note, this is probably the last paper I will put forward, as I am running out of energy, particularly when it seems to lead nowhere. I hope it is of value to you.

With my best regards

Christine Bryden

**THE NEXT FIVE YEARS – ADVOCACY WITH A PURPOSE:
ACHIEVING A GLOBAL APPROACH TO DEMENTIA**

Background

ADI has much to be proud of in having established a strong profile as the major international organization bringing together people with dementia, their carers and professionals from 69 countries. However, ADI has yet to explore and articulate a role as a global advocate for achieving improved care and the prevention and cure of dementia.

As in the paper recently circulated by the ADI Office, this paper also proposes a role for ADI in advocacy as a key strategy, but defines the inputs for this to occur, and a goal for which to aim. It suggests that there are three key measurable inputs for ADI's advocacy to governments and global organizations - consumer involvement, awareness and member support, and intellectual capital.

Any well defined strategy, such as advocacy, needs to aim for an achievable goal based on a clear and relevant vision. This paper suggests that the goal of ADI advocacy should be for dementia to be identified as a global health priority, and that a new vision for ADI be improved dementia care, prevention and cure.

Proposed Mission

I suggest the Mission for ADI be expanded to reflect its emerging identity as a global advocate for dementia as follows:

As the international peak body for people with dementia, their families and carers, to provide global leadership in policy and advocacy through supporting and facilitating Members.

Proposed Vision

I suggest the Vision for ADI be a world with improved care and ultimate prevention and cure of dementia as follows:

Improving care for people with dementia and their families, while working towards the prevention and cure of dementia.

Proposed Goal – Dementia as a Global Health Priority

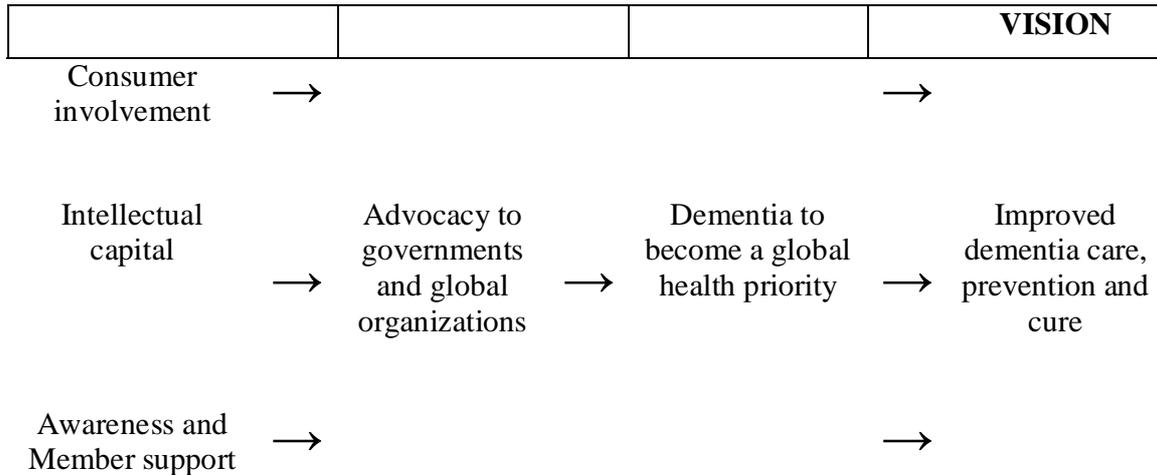
ADI can build productively on its awareness and Member support to strengthen its global advocacy role. This would be advocacy with a purpose – the goal being:

The identification of dementia as a global health priority, as part of achieving the vision of the improved care, prevention and cure of dementia.

What is the strategy to achieve this goal?

The following diagram suggests how, with this vision and goal, the defined strategy of advocacy draws on three key measurable inputs:

MEASURABLE INPUTS	DEFINED STRATEGY	ACHIEVABLE GOAL	CLEAR RELEVANT
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What are our measurable inputs?

Consumer involvement

The involvement of consumers (family carers and people with dementia) is a vital input for advocacy. The increasing participation of people with dementia and their families in the work of ADI Members is helping to focus awareness on dementia, by drawing attention to the human faces behind global and national issues.

People living with dementia and their families are available in all Member countries in all languages and have a story to tell. Building on the achievements of some member countries such as Scotland, UK, Canada, Australia, and the US, ADI should develop mentoring and partnerships to achieve consumer involvement in all member countries, and in regional and international ADI campaigns.

As Glenn Rees (Australia) has said “It is consumer advocacy – the courage of consumers telling their stories and the power of individual experience – that in the final analysis reinforces the statistics and sway a political argument.”

Intellectual Capital

Another key input for advocacy is intellectual capital. Many Members have strong research, analytical and advocacy skills, as well as experience in defining and quantifying the social and economic impact of dementia. There are thousands of people working for Alzheimer’s organizations around the world. ADI should enlist this intellectual capital, seeking the support and input of Members, including where appropriate on a fee-paying Consultancy basis.

ADI should engage professional short-term consultants to prepare succinct readable regional reports for an audience that will be largely uninformed about the nature of dementia. The Asia Pacific study of the impact of dementia, “Dementia: The New Tsunami”, commissioned at the recent regional Conference in Singapore, will provide a model for these studies.

These regional reports can be brought together, again by a short-term consultant, in a global summary, which highlights the disability burden in comparison to other diseases,

and draws on the ground-breaking work of the 10/66 Group to present projections of the future prevalence of dementia on a global and regional level. The report needs to include an analysis of the probable social and economic impact of dementia in terms of costs to governments, and the indirect costs of community and family care. Interventions for addressing dementia issues and supporting carers, and an analysis of the result of a forecast reduced supply of informal carers, also need to be covered.

Awareness and Member support

Awareness forms an important input for advocacy. ADI is helpful to many Members by raising awareness through Conferences, newsletters, and World Alzheimer's Day materials. By expanding Membership, this will increase awareness in other countries.

Each region needs appropriate targeted campaigns – to the public, to workers, to governments - to develop an improved knowledge of dementia, and how it can be diagnosed, treated and managed. This continues to be a key role for regional Conferences and Meetings.

At present World Alzheimer's Day and the ADI conference are the flagship events for raising awareness of ADI and dementia internationally. The recent decision to have biennial rather than annual conferences needs to be reconsidered in the light of the need for greater awareness. The web site and all materials need to be reviewed so as to make promotional information readily available at a low cost of production in as many languages as possible.

How do we implement the defined strategy?

Advocacy with a purpose

The challenge is to build intellectual capital which is consistent and useful across regions for Members to draw on in advocacy at the national and regional level. This is already happening with the 10/66 work, and is in train in the Asia Pacific region.

Raising awareness at the multilateral level would be the responsibility of a small Strategic Group representing ADI (with regional spread, consumer involvement, and representation from major developed and developing country Members) which would lobby the WHO in Geneva (and also the Permanent Representative to WHO of each of the Members of the Contact Group), and the OECD in Paris (calling on Ambassadors as appropriate). Regional ADI groups could also coordinate approaches to regional WHO Offices.

This multinational coordinated approach – involving consumers and based on the facts about economic costs and impacts - will have as its goal the identification of dementia as a global health priority. As these calls are underway, Member organizations would be encouraged to present their regional reports to their own Governments.

The costs of the project would be the costs of short term consultancies to prepare the regional and global reports, and travel costs for the ADI Contact Group. Through the use of Member resources and consultants, additional junior staff at ADI would not be needed. The Elected Board would provide the guidance and clearance for the work.