



**Alzheimer's Disease  
International**

*The global voice on dementia*

## **IMPLEMENTING THE WHO GLOBAL DEMENTIA ACTION PLAN**

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Jakarta, Indonesia

My thanks to Alzheimer Indonesia for their kind invitation to speak to you today about the implementation of the WHO Global Dementia Action Plan.

The WHO have done a wonderful job in developing the Global Plan, but change will be dependent on strong national political leadership, additional resources and Alzheimer's organisations who are willing to and able to advocate strongly to national governments

The Global Plan is a comprehensive document with seven action areas, targets and proposals for action by governments, international bodies and civil society. Importantly it is action based with a requirement that each country to report to the Health Assembly in 2020, 2023 and 2026. There is provision for the collection of information through the Global Dementia Observatory to support this review process.

On the basis of the GDAP ADI is looking for three outcomes:

First, systemic change in mainstream health and long-term care services which results in them becoming as dementia friendly as possible.

Second, access to dementia specific services that support and care for people with dementia and their carers who have care, social and health needs that go beyond those that mainstream services provide.

Third, dementia risk reduction and new treatments.

The requirement under Action 1 of the Plan is that 75 per cent of countries (145) develop a dementia plan. Some countries will adopt national plans while others will have frameworks, strategies or incorporate action into related policies such as aged care, mental health or non-communicable diseases.

Based on the action areas in GDAP let us identify some of the strategies to achieve a better quality of life for people with dementia.

### **Awareness and dementia friendly communities**

Action 2 in GDAP is Dementia Awareness and Friendliness - the pre-condition for tackling dementia including by information, education, training, and awareness campaigns. Awareness should include drawing attention to the rights of people with dementia and social engagement through dementia friendly communities.

GDAP makes 30 references to the rights of persons with dementia and 8 to the Convention on the Rights of Persons with Disabilities (CRPD). ADI and Dementia Alliance International,



the international body of people with dementia, have proposed monitoring the rights of people with dementia through the articles of the CRPD.

To that end ADI and DAI Dementia Alliance International have prepared a [brief for members on the CRPD](#) which identifies those issues that should be given special attention in monitoring the Convention such as the right to health without discrimination, and the right to Freedom from Exploitation, Violence, and Abuse.

In addition to legal action, social action is needed to translate those rights into practical action through dementia friendly communities. The dynamic of linking human to social action through dementia friendly communities to practical action has the power to change the way we think about dementia.

Publications on the ADI website set out the principles that should govern the approach and reported on the many forms it has taken in practice.

### **Dementia Risk Reduction**

Action 3 of GDAP is risk reduction. ADI believes dementia risk reduction is a public health priority and good awareness. Strategies include:

- Developing awareness campaigns to inform people about what they can do to reduce their risk of dementia.
- Including dementia in existing preventative health policies in respect of cardiovascular disease, smoking, alcohol, diabetes, and obesity.
- Prioritising research work that would further strengthen the evidence base on the factors that contribute the most to dementia risk reduction

### **Dementia diagnosis, treatment, care and support**

One of the most ambitious targets in GDAP, is in Action 4 - *“in at least 50% of countries, as a minimum, 50% of the estimated number of people with dementia are diagnosed by 2025”*.

ADI has estimated that more than 35 million people living with dementia do not have a diagnosis and no information, care, and treatment. Three strategies might be considered:

- Patient/carer strategies such as public awareness campaigns to increase awareness of dementia and empowering consumers, including checklists for those concerned about their memory, and what the 'normal' ageing process is.
- Strategies to better support doctors include increasing confidence in the diagnostic tools, use of memory clinics, training and education through workshops including changing negative views of dementia, the benefits of early diagnosis of dementia, how to communicate the diagnosis, and what lifestyle factors may help reduce the risk of dementia.



- System change in primary care through monitoring and targeting diagnosis rates at the primary care level, providing incentives to spend more time in the assessment process, including with carers to better understand the issues in relation to their patient, more emphasis on a team approach and use of practice nurses to assist those who have concerns about their memories.

Scotland have increased their diagnostic rate to over 60%. A key feature of the Scottish approach is the 1 year post diagnostic support guarantee through a link worker. This gives the person with dementia a RIGHT to post diagnostic support.

The objective is to develop a person-centred plan based on the individual's networks and local services to enable each person to live well and independently with dementia for as long as possible.

This approach may reduce the fear of seeking a diagnosis because there is a guarantee of support, assist coordination of services and increase the resilience of the informal carer.

### **Long Term Care**

In the absence of effective medical treatments for stopping or modifying the progression of dementia, it is long term care and in particular community and home-based care and support that is key to the quality of life of people with dementia and their families. In the words of GDAP there is a requirement to *“systematically shift the locus of care away from hospitals towards community based home and care settings and multi-disciplinary, community based networks that integrate social and health systems and provide quality care and evidence based interventions”*.

There is no target for LTC but advocates should work hard to make LTC dementia friendly. First, that LTC services must be flexible if they are to be person centred. Service design should be flexible in terms of the type, timing, and location of delivery. Services need to be available 24/7.

Second, to empower people with dementia and their family carers to make decisions about the services they need. The Organisation for Economic Cooperation and Development report that more than two thirds of OECD countries have introduced user directed support into their LTC systems usually by offering the choice of benefits in the form of cash payments, vouchers, or personal care budgets as well as services.

Third, the introduction of mechanisms to improve the coordination of care within LTC and across health and care systems especially for those with complex needs and those living alone to access services.

For example, multi-disciplinary teams have been established in many countries with geographical coverage and responsibilities which may combine assessment and diagnosis of dementia, referral to services and case management.

Another example is the employment of a dementia worker to provide continuing support, information and assistance in access to services.



## **Quality of residential and hospital care**

People with dementia in institutional care are among the most vulnerable in our society, which places them at considerable risk of serious abuse, especially in the form of medical and physical restraint.

Accreditation, government regulatory action and training are used by governments to improve quality in residential care and are much needed.

In acute care there is good evidence to suggest that dementia patients are more likely to be at greater risk than other aged people in respect of falls, functional decline, complications such as pneumonia, longer stays, delirium and death.

Strategies in acute care include systems to identify and manage dementia at admission; involving family carers in the care and support of patients; training all staff to better understand dementia and communicate with people with dementia; using psychosocial interventions and only as a last resort antipsychotic medication and sedatives; adapting the physical environment to reduce distractions and help orientate patients with dementia and the use of regulatory mechanisms.

## **Support for carers**

Action 5 is Support for Dementia Carers and the target is that *"75% of countries provide support and training programs for carers and families of people with dementia by 2025"*.

In high income countries over two-thirds of people with dementia live at home, receiving most care from informal carers, a figure that would be much higher in LMICs. This impacts on the mental and physical health of the family carer and leads to care breakdown. Support for family carers should include:

- Providing respite care and day care with trained workers that responds to the needs of the carers for a break and the needs of the person with dementia to have social engagement and an activity of interest.
- Training and support designed to cope with individual problems, to plan for the future and to reduce stress and depression
- Making carers partners in care and providing choice to select the services that best meet their needs in the form of cash or services.

## **Research**

Action 7 of GDAP recognizes the need for more investment in dementia research. ADI believes that 1 per cent of the societal cost of dementia, at least in high income countries, should be spent on dementia research. Dementia is grossly under-funded compared to cancer and heart.

Within an inadequate amount of funding for dementia research there is a long-standing concern about the underfunding of research into prevention and care and the potential for the use of technology.



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## **Conclusion**

It is for Alzheimer organisations to make the case to governments to implement a dementia plan to respond to GDAP. Each country has to set priorities and implement action appropriate for them and that has to be done in partnership with people with dementia and their family carers. But I suggest the core elements of national plans are awareness, human rights and dementia friendly communities, timely diagnosis and post diagnostic support and, lastly carer support through training and community and home-based programs.