

## GLOBAL ACTION PLAN ON THE PUBLIC HEALTH RESPONSE TO DEMENTIA

I am delighted to have the opportunity to talk to you today about the Global Action Plan on the Public Health response to Dementia and what we should seek to achieve over the next 7 years.

My especial thanks to the Taiwan Alzheimer's Disease Association for this invitation and to the Social and Family Affairs Administration and Ministry of Foreign Affairs for their support.

We had a dream in ADI which was to make dementia a world public health priority. The challenge now is to make it a reality.

Yesterday, President Tsai graciously received TADA and myself to discuss dementia and the Global Plan. The President talked about the 2013 Taiwan Dementia Plan, the recent initiatives in respect of Community Service Stations, and Community-based Support Centres and the work being done on developing a new Taiwan Plan in response to the Global Plan.

The World Health Organisation cannot compel governments to act, but it is nonetheless a powerful agent for change.

The Plan provides an excellent basis on which to tackle dementia. The goal of the Plan is to improve the lives of people with dementia, their carers and families, while decreasing the impact of dementia on them as well as their communities

The Plan identifies seven priority areas for action, with a target set for each.

Reporting is an important element of the GDAP. The Ministry of Health, Social Care or other department in each country to report to the Health Assembly in 2020, 2023 and 2026

The Plan provides the necessary framework for countries to introduce or revise their dementia plans. For each action the Plan includes proposed actions for Member States,

the WHO Secretariat and international, regional and national partners and detailed indicators for measuring progress towards defined targets.

The Plan takes a whole of government approach and links to other key work streams of WHO activity including the plans for Non-Communicable Diseases, Mental Health and Ageing. It also recognises that improving the lives of people with dementia and their families is a human rights issue.

The Plan is grounded in seven principles

So, let us consider each action area in turn.

### **Dementia as a Public Health Priority (Action1)**

Action 1 - Dementia as a Public Health Priority - requires that “75% of countries will have developed or updated national policies, strategies, plans or frameworks for dementia, either stand-alone or integrated into other policies/plans by 2025.”

The responses of countries will vary greatly depending on the nature and strength of their health and care systems.

While it is encouraging that 30 countries around the world have plans many will need revision and the commitment of additional resources. A total of 145 plans are needed to meet the target.

No country is exempt. There are strategies which countries whether high or low income can adopt. In some, like Germany and Japan, it will be possible to act through long term care insurance programs to improve access to dementia care and support. In low income countries, the focus is likely to be on awareness, training and education and support for family caregivers.

There are two overarching and complementary objectives in planning for dementia.

First, to achieve **systemic** change in **mainstream** health and long-term care services by making them as dementia friendly as possible.

Second, to fund additional services that recognize that many people with dementia and their carers will have care, **social and health needs** that go beyond those that mainstream services can provide.

So, we have a challenge! And we must start now because the social and economic impact of dementia worldwide is getting greater by the year as the numbers of people with dementia increase from 47 million today to 137 million by 2050.

ADI and WHO, separately and in partnership, have an important role to play in explaining the significance of planning, the content of plans, their implementation and their monitoring and evaluation. But it is national governments who are critical.

### **Dementia Awareness and Friendliness (Action 2)**

Action 2 is Dementia Awareness and Friendliness. Increased awareness and understanding of dementia has long been recognized as the pre-condition for tackling dementia.

There are two global targets in the Plan. First, that by 2025 “100% of countries will have at least one functioning public awareness campaign on dementia”.

Second, that “50% of countries will have at least one dementia friendly initiative to foster a dementia inclusive society”

I suggest that if we are to overcome stigma and social isolation, we must go further than awareness campaigns by acting directly on human rights and promoting dementia friendly communities.

The Plan makes 30 references to the rights of persons with dementia and 8 to the Convention on the Rights of Persons with Disabilities (CRPD). The need is to link the action proposed in the Plan to the articles of the CRPD and to monitor progress.

Such articles include those that relate to:

- **Awareness Raising** and **Accessibility** to address stigma and discrimination and to facilitate access to transport, shops and community amenities (Articles 8 and 9)
- **The Right to Health** without discrimination and obtain the diagnosis and information needed to understand the progression of their condition (Article 25).
- **Living Independently** and **Habilitation and Rehabilitation** to provide access to post-diagnostic support such as occupational, speech and physiotherapy,

specialist nurses and other health professionals including counselling, psychological support and social work (Articles 19 and 26).

- ***Liberty and Security of the Person*** (Article 14) and the right to ***Freedom from Exploitation, Violence and Abuse*** (Article 16) which are major issues in dementia particularly with the risk of medical and physical restraint.

ADI with Dementia Alliance International has prepared a brief for members on the CRPD. <https://www.alz.co.uk/sites/default/files/pdfs/crpd-brief-alzheimer-associations.pdf> Over the next few years Alzheimer's organisations should partner with human rights and disabilities organisations to contribute to reporting processes on the Convention as Canada has recently done. This resulted in the first specific reference by the CRPD Committee to 'Alzheimer's and dementia'.

It is important that dementia friendly has been included in Action 2. Dementia Friendly Communities have the power to change the way we think about dementia by increasing awareness and reducing stigma and by empowering people living with dementia to take decisions about their lives.

Dementia Friendly Communities have taken off across the world including Taiwan. It has been given expression in many practical ways – awareness through dementia friends, school programs; social engagement and activities through cafes, men's sheds, choirs; building capacity by dementia training in banks, retail services, health services; dementia champions in hospital services and improving the physical environment.

ADI has set out the principles that should govern the approach and reported on the many forms it has taken in practice. The publication will be updated shortly in World Alzheimer's Month.

In summary, we need both legal and social action to ensure we do everything we can to protect the rights of people with dementia and to translate that into practical action.

### **Dementia Risk Reduction (Action 3)**

Action 3 is Dementia Risk Reduction and the target is that "the relevant global targets defined in the ***Global action plan for prevention and control of non-communicable***

**diseases 2013 -2020** and any future revisions are achieved for risk reduction and reported”.

In the words of the Report of the Lancet Commission on Dementia published on line in July this year “Prevention or delay of dementia onset is a public health priority with potential not only to reduce the disability of individuals but the associated societal and economic burden”. The experts conclude that “the interventions most likely to be beneficial include increasing education in early life, increasing physical activity and social engagement, reducing smoking, treating hypertension, diabetes and hearing impairment”.

ADI believes that strong action is needed by:

- Developing an awareness campaign 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 (Action 4)**

Action 4, is Dementia Diagnosis, Treatment and Support. The global target is that “in at least 50% of countries, as a minimum, 50% of the estimated number of people with dementia are diagnosed by 2025”. This is perhaps the most ambitious of all the global targets and rightly so.

This action covers a huge area so let us consider separately timely diagnosis, dementia friendly hospitals and long-term care systems

##### **a) Timely Diagnosis**

ADI has estimated that currently less than half of the people with dementia in high income countries have received a diagnosis, and fewer than 10% of people with dementia in low to middle income countries. This means more than 35 million people living with dementia do not have access to information, care and treatment.

Timely diagnosis is a focus for developing national dementia strategies in Denmark, France, Netherlands, Norway, Switzerland, and the UK. Scotland have increased their diagnostic rate to over 60 per cent.

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** at the service level 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 to patients, and what lifestyle factors may help reduce the risk of and the progress 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 with the screening process of those who have concerns about their memories.

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.

In the 2017-2020 Scottish Dementia Plan the guarantee is strengthened in three ways

First, there is a commitment to test and independently evaluate the relocation of post diagnostic dementia services in primary care hubs.

Second the 1-year post diagnostic support guarantee will be extended beyond one year or until such time that needs become more complex.

Third, those individuals who are diagnosed later, and who need services will receive their post diagnostic support from a named Dementia Practice Coordinator from that point onwards.

## **b) Dementia friendly hospitals**

Across the world acute care systems are struggling to care for people with dementia. Already a quarter of hospital beds in the UK are occupied by people with dementia and many of these people are not receiving care that meets their needs.

International studies have shown that older patients with cognitive impairment admitted to hospital are at a significantly increased risk of adverse outcomes and preventable complications. Compared with patients without cognitive impairment, they are more likely to:

- experience a fall resulting in harm
- experience significant functional decline
- develop complications such as pressure injuries, pneumonia and urinary tract infections
- have increased length of stay in hospital
- require new residential care placement following their stay
- die while they are in hospital
- experience delirium.

There are many strategies to improve the care experience in acute care. For example:

- Strategies that have been adopted outside the hospital to avoid unnecessary hospital admissions and to provide access to alternative to hospital care in the community and residential care settings (e.g. hospital at home, special care units

in residential care, integrated primary care services, Dementia behaviour Advisory teams).

- Strategies within emergency departments that improve identification of dementia and appropriate referral and admission practices (e.g. development of aged care services in emergency teams, rapid assessment and response teams);
- Strategies within the hospital to improve quality of care during the hospital stay (e.g. hospital education programs, specialist services or wards, liaison psychiatry units, better management of associated health conditions such as delirium);
- Cross-sectoral strategies include a range of quality improvement measures (for example integrated approaches such as multi-disciplinary teams, discharge planning, transition care, dementia link workers, end-of-life care);
- The development of evidence based resources for safety and quality dementia care in acute care settings to guide health service managers, clinicians and consumers.
- Reviewing and monitoring hospital standards to address gaps in relation to dementia care and delirium
- Environmental strategies that relate specifically to improving the physical and social environment where care is delivered.

What is needed is a multifaceted and integrated approach between hospital, mental health and community services to help ensure that dementia care is delivered in the most appropriate and beneficial setting.

### **c) Long Term Care Systems**

Strong Long-Term Care systems are critical to achieve the objective of enabling people to stay at home for as long as possible and to experience a better quality of life. In the absence of effective medical treatments for stopping or modifying the progression of dementia, it is social care that is key to the quality of life of people with dementia and their families.

The financing and design of LTC systems and their relationships to other parts of the health and care system is complex. The different approaches that have evolved in high income countries is a warning that one size does not fit all and that policies will vary greatly in response to the needs and cultures of countries and that difficult lessons will be learnt over time.

So, what are the key elements of LTC services ADI and member associations should advocate over the period of the Plan?

First, that the design should respond to the needs of informal carers who in all countries provide most of the care and support. I will come back to this in Action 5

Second, LTC systems that in the words of the Plan “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”. Residential care services should be targeted to those with special needs or who are socially isolated and the quality monitored, for example to minimize the use of medical and physical restraint.

Third, to make mainstream services (e.g. aged care services, mental health) accessible to people with dementia through training and workforce strategies and to fund additional specialist dementia services for those who need them. Access is needed to the rehabilitation skills of the allied health workforce, for example in activity therapies and the provision of adaptations for the home and falls prevention.

Fourth, service design that is flexible so that the needs of the person with dementia and their family can be met in terms of the type, timing and location of delivery. Services need to be available 24/7.

Fifth, enabling people with dementia and their informal 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 benefits in the form of cash payments, vouchers, or personal care budgets rather than services.

Sixth, 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 who need more help to access services including those living alone to access services.

Lastly, end of life care that encourages advance care planning and prioritises management of pain and discomfort, training residential care and hospital staff and enabling the person where possible to die where they prefer.

### **Support for Dementia Carers (Action 5)**

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”.

Whatever the LTC system of a country – or in many countries the absence of LTC – most care will be informal and the majority provided by women.

In high income countries over two-thirds of people with dementia live at home, receiving most care from informal carers, about 40% of whom have clinically significant depression or anxiety. This impacts on the person with dementia, families and society, and leads to care breakdown.

The WHO has developed and implemented iSupport for Carers, a comprehensive e-tool to enhance self-help, skills, and support for caregivers of people living with dementia, including in low and middle-income countries. And resources for carer support are readily available on the websites of Alzheimer’s associations in Canada, UK and Australia.

ADI believes that an active approach to strengthening support for informal carers should include:

- Giving priority to respite care. Good respite care not only responds to the needs of the carers for a break but the needs of the person with dementia to have social engagement and an activity of interest. The services need dementia trained staff and have the flexibility to respond to emergencies, the needs of working carers, planned respite and the interests of people with dementia.
- Access to help through link workers or case management to access needed services for the duration of the dementia.

- Evidence based clinical support designed to cope with individual problems, plan for the future and relaxation (e.g. START - STRategies for RelaTives))
- Making carers partners in care and providing choice to select the services that best meet their needs in the form of cash or services.
- Systems available to carers to raise concerns about worrying changes in a person's condition while in hospital or residential care

### **Information Systems for Dementia (Action 6)**

Action 6 Information Systems for dementia sets an action target that requires “50% of countries routinely collect a core set of dementia indicators through their national health and social information systems every two years 2025”.

On Action 6, the WHO and a group of Member States is currently developing a Global Dementia Observatory (GDO), a web-based data and knowledge exchange platform to collect and disseminate key dementia information from WHO Member States ([http://www.who.int/mental\\_health/neurology/dementia/GDO/en/](http://www.who.int/mental_health/neurology/dementia/GDO/en/)). The first stage of the project – to create a framework for data collection – is expected to be completed by the end of 2017.

The GDO will collate and disseminate dementia data from Member States to support service planning and policies and health and social care systems. The information will include global and regional dementia reports and country-specific information sheets summarizing a country's capacity to support people with dementia. The GDO will also track the implementation and progress of the Global Action Plan.

This a significant initiative which is a critical part of monitoring the Plan. It may also encourage those countries who have poor information on service delivery and coverage across the care spectrum from risk reduction to end of life to have a better-informed basis to plan and implement policies.

Information is needed for consumers too, not just on the availability of services but on their quality and the outcomes being achieved.

Worldwide there is a greater recognition that the time has come for a shift from a compliance, minimum standards approach to one that focuses on improving quality and providing information to consumers on care outcomes. Achieving this is proving hard in practice.

There are signs of change in some countries in using consumer involvement in the evaluation and accreditation of health and aged care services to both inform the process and improve consumer engagement.

Consideration is also being given to the potential of reporting to capture resident's experience and quality of life with a view to having a kind of "tripadvisor" on aged care services.

### **Dementia Research and Innovation (Action 7)**

Action 7, Dementia Research and Innovation and requires that "the output of global research on dementia doubles between 2017 and 2025".

This consistent with the recognition that dementia research is underfunded. ADI believes that 1 per cent of the societal cost of dementia, at least in high income countries, should be spent on dementia research. Research expenditures are not easily tracked but it seems probable that cancer research is funded at about seven times that of dementia.

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

A much stronger evidence base is needed to assist low and middle-income countries learn from the mistakes of high income countries in developing their long-term care systems. ADI and Member Associations need to actively engage in research on models of care.

Technology has the potential to transform dementia care, improve the lives of people with dementia and reduce strain on carers. The Lancet Commission on Dementia divided health care technologies into five categories namely, diagnosis and assessment, monitoring, therapeutic technology, activity and carer-supportive technology

## **Conclusion**

I understand the Taiwanese Government is committed to revise the 2013 Taiwan Dementia Plan by end year. The leadership of the Government will be critical as will the support of organisations like TADA.

Taiwan is well positioned to build on what it has already achieved in supporting people with dementia and their families through the family of wisdom, cognitive rehabilitation, dementia friendly communities and the commitments made by the Ministry of Health and Welfare to additional Community Service Stations and Community-based Support Centers for Dementia Care.

The response to the seven actions in the Global Plan could be an opportunity to:

- Monitor the rights of people with dementia through the CRPD and expand dementia friendly communities to give those rights practical effect (Action 2)
- Adopt a public awareness program on dementia risk reduction (Action 3)
- Commit to timely diagnosis and a post diagnostic support guarantee (Action 4)
- Give priority to expanding access to community and home-based person centred care services (Action 4)
- Improve the quality of acute and residential care and reduce the use of chemical and physical restraint (Action 4)
- Recognize the informal carers as a care partner in decision making through all parts of the care journey and provide flexible services, including respite (Action 5)
- Support the GDO and provide better quality information to consumers (Action 6)
- Invest more in research for new treatments and to develop the evidence base for new services and new technologies (Action 7)

Thank you