

Developing National Dementia Plans and Setting Priorities

I am delighted to have this opportunity to persuade you that adopting a national dementia plan is in the interests of Vietnam.

I congratulate all those involved in making this event possible, especially Prof Thang Pham from Vietnam National Geriatric Hospital, Chair of the Conference organising committee and Dr Tuan Anh Nguyen from University of South Australia, Chair of the Scientific committee. I would like to also acknowledge that the conference is partly funded through a seed grant from the Global Affairs at University of California, Davis in which Prof Ladson Hinton is the Principal Investigator

Alzheimer's Disease International (ADI) believes that the key to winning the fight against dementia lies in a unique combination of global solutions and local knowledge. As such, ADI seeks to strengthen and support Alzheimer associations in 94 countries, to raise awareness about dementia worldwide, to make dementia a global health priority, to empower people with dementia and their care partners, and to increase investment in dementia research.

I will address five questions.

First, what is the imperative to adopt a national dementia plan?

Second, how to achieve a planning dynamic?

Third, the policy issues are clear so where is the problem and what are the priorities?

Fourth, how to engage the support of civil society?

Fifth, what does a dementia friendly society look like?

1. What is the imperative to plan?

The Members of the World Health Organisation including Vietnam with its representative, Minister of Health Prof Nguyen Thi Kim Tien, unanimously adopted a comprehensive and action based Global Dementia Action Plan in May 2017.ⁱ The Plan is a recognition of the economic and social impact of dementia on communities and on health and long-term care systems around the world.

The Global Plan identifies seven priority areas for action, with targets set for each. Action Area 1 ***Dementia as a public health priority*** sets a target that ***75% of countries will have updated or developed national dementia plans by 2025***. It commits the Ministry of Health, Social Care or other department in each country to periodically report to the WHO on the progress of each area of the plan between 2017 and 2025.

Action 4 ***Dementia diagnosis, treatment, care and support*** sets a particularly important target namely, that ***at least 50% of countries, as a minimum, 50% of the estimated number***

of people with dementia are diagnosed by 2025. Currently even in high income countries less than 50% of people with dementia are diagnosed and in most low and middle-income countries the figure will be very low. A journey with dementia cannot start well without a diagnosis and post diagnostic support.

There are approximately 50 million people with dementia worldwide, a number that will rise if there is no cure to 150 million by 2050. 68% of all people with dementia live in low to middle income countries. The cost of dementia both direct and indirect already totals over 1 trillion US dollars and has been projected to rise to 2 trillion US dollars by 2030. For the person with dementia and their families the impact is stressful as dementia is the most disabling of diseases.

Inevitably, more resources will be spent both directly by the health and social support systems and by families, so it makes sense to plan to use available resources effectively.

To date there are 32 countries with a dementia plan and to meet the target of the Global Plan 146 are needed. Those with a plan in this region are South Korea, Japan, Australia, Indonesia, Taiwan, Singapore and Macau and others are work in progress.

Professor Wimo at the Karolinska Institute in Stockholm provided me with these figures for Vietnam. You can expect the numbers of people with dementia to about double between now and 2030 from 660,000 to 1.2 million. And note that in Vietnam as in most countries it is the family carers who bear the main burden of dementia.

Through adopting a national dementia plan the opportunity exists to:

- a. Promote understanding at the political, administrative and community level that dementia is a major health and social challenge in this century
- b. Optimize the use of available resources to improve and coordinate care, treatment and prevention and to invest in research
- c. Reduce stigma and social isolation by promoting understanding of dementia as a chronic condition
- d. Recognise the importance of family carers and their need for support if people with dementia are to remain in the community and avoid premature institutionalization.

The failure to plan can have profound and costly consequences. For example, an under investment in home and community-based care services, including respite care, which may result in premature institutionalization of people with dementia and greater demands on hospitals. Underuse of the primary health system and overuse of specialist resources to diagnose dementia – resulting in higher diagnostic costs. A failure to address dementia risk reduction.

2. How to achieve a planning dynamic.

It is not hard to write a comprehensive plan.

Planning has its well-established processes in terms for example of undertaking a situational analysis, resource assessment, setting objectives and priorities, preparing an operational workplan, budget and monitoring and evaluation. The WHO have published a comprehensive guide Towards a dementia plan - A WHO Guide.ⁱⁱ

The challenge in each country is not writing a plan but making it come alive. Critical is identifying the political and administrative leadership most likely to secure multi-sectorial collaboration, stakeholder engagement in delivering the national plan and the required funding. That is Vietnam's challenge too given your own particular government structures and culture. The key actors who must to come together in partnership are the health and social services departments, medical professionals, service providers and care staff and people with dementia and their families. An Alzheimer organisation can be helpful in bringing together the voices of family carers and people with dementia.

3. Policy priorities are clear so where is the problem?

From a policy perspective I believe we know what to do.

The Organisation for Economic Cooperation and Development in their 2015 report Addressing Dementia ⁱⁱⁱ identified ten key policy issues within which planning needs to take place. Every picture is worth a thousand words and this one from the 2015 report captures the ten issues that need to be addressed in policy.

And within those issues the priorities set in plans over the last decade have a continuity in their focus on awareness, diagnosis, support for family carers, training and the development of community and home care which suggests the initial priorities are not in dispute.^{iv}

I suggest the challenge is not knowing the key policy objectives or priorities but how to implement them. The need is for an evidence base that gives confidence in determining which approaches might be the most effective - for example in respect of critical issues such as diagnosis and post diagnostic support and support for family carers.

Priorities included many dementia plans relate to:

- i. Promoting a greater awareness of dementia through information, the adoption of dementia friendly projects and the potential for reducing the risk of dementia (Actions 2 and 3)
- ii. Capacity building through training and education for health professionals, care staff and family carers (Actions 4 and 5)
- iii. The implementation of pilot programs designed to lay the basis for the adoption of new models of support for family caregivers and effective approaches to diagnosis and post diagnostic support (Action 4 and 5).

iv. Building an evidence base for the development of policy and services (Action 6)

I have noted where those four priorities correspond broadly to the seven action priorities in the Global Dementia Action Plan.

The 18 ADI members of the Asia Pacific Regional Organisation have worked together for many years and have resources and experience to share. There are exciting examples of dementia plans in region. For example, Japan is a world leader in the implementation of dementia friendly communities and new models of community and residential care. Taiwan adopted a comprehensive and funded dementia plan in 2017 which gives priority to dementia diagnosis, treatment and care and to prevention. Australia has funded successive dementia plans since 2004 and has given priority to training, community-based dementia care services and investment in dementia research.

Vietnam can benefit too from the lessons that high income countries have learnt over more than three decades. For example, that:

- Dementia is a chronic disease.
- Systemic change in **mainstream** health and long-term care **AND** funded **special dementia services** are required to meet the needs of people with dementia
- Dementia should be included in preventive health programs alongside heart, diabetes and smoking.
- There should be a move away from institutionalized care to community care.
- Rates of diagnosis are totally inadequate at about 50% of estimated cases.
- Services need to be coordinated to make them more accessible.
- The quality of dementia care is often poor and not person centred care on the needs of individuals
- Younger people with dementia have special needs

The initial focus in Vietnam's first plan is likely to be awareness, diagnosis, training, development of community based services and support for family carers.

4. Engaging the support of civil society

Dementia is both a medical and social issue. The immediate issue for the millions who have dementia is stigma and social isolation.

The driving force of action in many countries has come from family carers and in more recent times from people with dementia themselves. People with dementia and their families are the experts!

The task is to develop a national plan that tackles dementia as both a medical and social issue in making the health and care system dementia friendly and the society inclusive of people with dementia. This will best be achieved by ensuring that people with dementia and their

family carers are fully engaged from the outset and in many countries, this has been achieved by Alzheimer's organisations.

It is important to develop health and social care pathways to show how access to services is working from the perspective of government, service providers and people with dementia and their families.

5. What does a dementia friendly society look like?

Through dementia plans we are seeking to create a dementia friendly society which has the goal of a better life for people with dementia and their families.

What we are also seeking to do is to change the way we think about dementia. We are seeking to shift thinking from a focus on meeting the physical and health needs of the person with dementia to a holistic approach supporting the person to achieve the best quality of life reasonably possible. There are two objectives.

First, to reduce stigma by greater awareness of dementia

Second, to be inclusive of people with dementia by recognising their rights and capabilities so that they feel respected

The concept of dementia friendly has captured the imagination of communities, policy makers and researchers around the world. It is a social movement rather than a program and dementia friendly projects can be given practical expression in many ways:

1. **Through social support:** for example, memory cafes where people with dementia meet often with family carers and the wider community; volunteer programs in community gardens: activity programs to enable the person to continue their interests.
2. **Greater public awareness:** this approach is exemplified by the dementia friends programs in Japan (over a million dementia friends) and the United Kingdom which provide basic dementia awareness training in the community
3. **Inclusive communities:** for example, setting up an alliance in the community involving local government, people with dementia and their families, health services with a view to identifying ways in which the community could be made more inclusive
4. **Better quality health and dementia services:** increasing capacity of the workforce to be dementia friendly through training and identification of staff in health services such as hospitals as dementia friends,
5. **Improving the physical environment:** whether in private homes or residential facilities, public spaces or government buildings

These approaches are not exclusive and there is no one size fits all. But dementia friendly must involve people with dementia as equal partners. That is non-negotiable.

You can read about the principles of dementia friendly communities and global developments in respect of dementia friendly communities in two publications on the ADI website.^v And there are many resources on the website of countries like the UK and Australia

Conclusion

In summary the answer to my five questions are that:

- The imperative to respond to the WHO Global Dementia Action Plan is driven by the numbers of those with dementia and the need to make effective use of available resources by health and care systems in tackling dementia
- The planning dynamic is dependent on political leadership, the capacity to secure multi sectorial collaboration and funding
- Initial priorities are likely to include awareness, training, diagnosis, carer support and development of community-based care services
- Engage civil society, including through an Alzheimer organisation
- Adopt the values and action appropriate to Vietnam in planning for a dementia friendly society inclusive of people with dementia

I wish Vietnam every success in planning for dementia. ADI looks forward to working with Vietnam

I invite you to celebrate World Alzheimer's Day on 21st September

See you in Singapore in March 2020

Thank you.

ⁱ GDAP http://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/

ⁱⁱ Towards a dementia plan - A WHO Guide <http://apps.who.int/iris/bitstream/handle/10665/272642/9789241514132-eng.pdf>

ⁱⁱⁱ OECD Addressing Dementia <http://www.oecd.org/health/addressing-dementia-9789264231726-en.htm> See Chapter 2

^{iv} ADI from Plan to Impact <https://www.alz.co.uk/adi/pdf/from-plan-to-impact-2018.pdf?2>

^v <https://www.alz.co.uk/dementia-friendly-communities/resources>