WORLD ALZHEIMER'S MONTH 2016

ALZHEIMER'S DISEASE CHINESE

GLOBAL PERSPECTIVES OF DEMENTIA CARE AND CREATING DEMENTIA-FRIENDLY COMMUNITIES

GLENN REES AM

CHAIR, ALZHEIMER'S DISEASE INTERNATIONAL

SEPTEMBER 2016

I congratulate the Alzheimer's Disease Chinese (ADC) and the China Population Welfare Foundation on taking the initiative to organize this symposium to mark World Alzheimer's Month.

As Chair of Alzheimer's Disease International I have made it a priority to work with ADC. The reasons are obvious.

China has the largest number of people with dementia, almost 10 million. This number will increase to over 30 million by 2050, if we do not find a cure. The ageing of the Chinese population is both a successful outcome of public health policy and an immense challenge.

How China meets this challenge will influence global health, because the innovations and strategies developed in this region – which is home to a fifth of the world's population - will provide insights for other countries.

It is important that China plays a leading role in international organizations like the World Health Organization (WHO) and G20 and that there is a strong leadership from low and middle income countries.

It is important to have a Chinese Dementia Care Plan.

There is much happening internationally including:

- National dementia plans and the prospect of World Health Organisation (WHO) resolution on dementia
- Dementia friendly communities
- New models of care
- Dementia friendly health systems
- Dementia friendly information

Dementia Plans

There are now 26 countries with care plans in place of varying degrees of comprehensiveness and some with funding

These plans are the pre-condition for political awareness and future action.

In 2015 the Organisation for Economic Cooperation and Development (OECD) published ***Addressing Dementia*** which provides an overview of policies employed by member countries to tackle dementia. Most of the policies reported upon have their counterparts in Australia and other high income countries.

OECD concludes that ensuring that the consistent implementation of these policies remains a challenge and that there is still too much uncertainty around which policies are effective.

They also conclude that dementia receives the worst care in the developed world.

The ambition of ADI is that all countries have a national dementia plan. It is anticipated that a resolution of the World Health Assembly will set out a global action plan on dementia with clear actions for Member States in May 2017.

ADI in the 2015 World Alzheimer Report proposed that the elements of dementia plans necessary to support the person with dementia to stay at home for as long as possible include:

a) Awareness raising

b) Creation of dementia friendly communities

c) Dementia risk reduction measures

d) Measures to improve diagnosis

e) Support for family carers

f) Access to long term community and residential dementia care services and good care in hospitals

g) Person centred care and minimum use of medical and physical restraint

h) Workforce strategies including training

i) The use of technology

j) Good quality end-of-life care with respect to their dignity and personal wishes.

This is a long list but I suggest there are four priorities:

1. Dementia Friendly Communities
2. New models of care that respond to the needs of the person with dementia and the family carer
3. Dementia friendly health systems that provide for dementia risk reduction, timely diagnosis, of dementia, enhance dementia care in acute care
4. Provide information on dementia care outcomes and impact of policies

Dementia Friendly Communities

The concept of dementia friendly has captured the imagination of people around the world.

The dementia friends program was pioneered in Japan in 2005 and most recently adopted in the UK. Both governments provide some funding. There are currently 6.3 million dementia friends with a target of 8 million by 2018 and over 1 million in the United Kingdom.

The program’s aim is to transform people’s perception of dementia by creating dementia friends who commit to learn what it is like to live with dementia though

basic training. They then turn that understanding into social actions that lead to the development of dementia-friendly communities.

These social actions can take many forms, for example, by helping out in a dementia café or by raising awareness about dementia among work colleagues, family and friends.

Dementia friends in turn recruit and create more dementia friends.

Business organisations including banks have recognised it is in their business interests to train staff and make their service more dementia friendly.

There are excellent resources to help Alzheimer's organisations develop their own approaches on the websites of ADI, the UK society and Alzheimer's Australia.

The concept of dementia friendly communities and the different ways in which it has been implemented around the world is described in two Alzheimer's disease International publications on dementia friendly-communities.

The concept of dementia friends and dementia friendly communities is important because it has the power to change the way we think about living with dementia.

It marks a fundamental shift from a focus on meeting the physical and health needs of the person with dementia to an approach that recognises the need to support the person to achieve the best quality of life possible.

There are two very different underlying objectives of dementia friendly communities which have as their end goal a better life for people with dementia.

First, the objective of reducing stigma and understanding of dementia by greater awareness and meaningful engagement for persons with dementia of all ages - that is the lived experience approach.

Second, the objective of empowering people with dementia in their own communities by recognising their rights and capabilities so that they feel respected empowered to take decisions about their lives – the rights approach.

Across the world the concept of dementia friendly communities is being given practical expression in four different ways by.

1. Being **inclusive** and supporting and protecting the rights of a person with dementia.
2. Tackling **stigma** and lack of community understanding of dementia.
3. Increasing the **capability of the health and care workforce** and availability of key services.
4. Improving the **physical environment** – a topic that is central to the ageing cities movement.

There is no one size fits all in designing dementia friendly communities. But to be successful there are some key steps.

First, to ask people with dementia and other stakeholders if they consider their community to be dementia friendly. And if not, why not.

Second, to determine what action is needed.

Third, to involve people with dementia as equal partners.

Fourth, to form local dementia alliances involving businesses, local government, service agencies, medical services and hospitals. This may help attract funds for the project and a project officer.

The model looks like this

People with disabilities fought hard to achieve their full participation in society on an equal basis with others. The outcome was the Convention on the Rights of Persons with Disabilities (CRPD).

Many of the concerns and frustrations that people with dementia express about their lives are addressed in the wide –ranging provisions of the CRPD which China has ratified. For example, in respect of decision making that respects their capacity, living in the community as independently as possible, access to health services without discrimination and opportunities for recreational and other activities.

ADI in partnership with Dementia Alliance International - an organisation of people with dementia – recently provided a briefing to the United Nations Committee on the CRPD and requested that the full resources of the UN family be used to monitor the extent to which persons living with dementia are included in the implementation of the Convention by Member States.

It will be important that ADC seeks partnerships with Chinese disabilities organisations in monitoring the application of the provisions of the CPRD in respect of the rights of people with dementia.

New models of care

In designing new models of dementia care the starting point is service flexibility. All too often in high income countries services are not available when they are needed, in the place where they are needed or in the form they are needed.

Three lessons may be learnt from the experience of high income countries.

First to shift the priority from hospitals and residential care to community based services.

Second to implement a person centred approach.

Third, to empower the person with dementia and their family carers to make decisions on the services that they need.

Let me tell you in a bit more detail about models of care in Japan, Taiwan and Australia.

a) Japan

The objective of the Japanese approach is to focus on the needs of the person so that whether their need is for transport, nursing, personal care, respite or food services the person with dementia and their families can access services that meet their needs.

The Japanese introduced micro multi-functional community care facilities in 2006 under the reform to the national long term care insurance (LTCI) system. There are now 4,000 facilities across Japan offering a care package including:

- 24/7/365 all-round open access
- Day care services
- Flexible 24 hour respite care
- Regular and on-demand health care by nurses
- Regular and on-demand home care by care workers.

Dementia day centres are another endorsed LTCI community-based model. There are 3800 such centres open throughout the year. These dementia specific day centres offer engaging activities which are person centred and attuned to individual needs and preferences.

Japan has 35,500 generic day centres (for older people) supporting 1.6 million – or 1 in 3 eligible older people.

The models are combined with intergenerational interaction that bring together LTCI funded provision with public funded facilities for the younger generation.

Family of Wisdom in Taiwan

Taiwan and now Singapore have formed support groups called Families of Wisdom which are open from 10am to 4pm. It is the family carers with some support and access to a building who are responsible for taking care of the people with dementia, preparing food and cleaning. Singapore has now adopted the same approach.

They organize activities such as yoga, flower arrangement, mahjong, cooking, singing and travelling. They support, learn from each other and enjoy their time in the Families of Wisdom which they regard as their second home.

Families of Wisdom has helped caregivers reduce their caregiving burden and to share their expertise spontaneously through the exchange of care receivers. For example, Ms. A plays mahjong with three persons with dementia. The mother of Ms. A, who is a person with dementia, sings karaoke with other persons with dementia and caregivers. Ms. A has respite care since she is free from taking care of her

mother.

c) Australia

The key word in aged care policy in Australia for over thirty years has been choice.

The most recent aged care reforms in Australia have set the scene to give the consumer greater choice in accessing the services they need and where and when they are delivered.

First, there has been a further prioritisation of community based services over residential care services.

Second, the Government is committed to having an aged care system that is consumer-driven and which supports a diverse range of providers to be responsive to the care needs of older Australians.

To achieve this within community care the government rather than providing funding to service providers will from February 2017 provide packages to the consumer. Consumers will have the chance to choose providers and also to choose which services will best meet their needs under a model of Consumer Directed Care.

But the challenge is still in implementation.

One of the biggest concerns about the ongoing changes and reforms to the Australian system is a focus on the market providing all of the solutions to concerns about quality. Both Government and providers repeatedly express the view that consumer choice will drive quality improvements.

So there is an interesting and sharp contrast between Japan which funds services through Long Term Care Insurance and Australia which increasingly will fund the consumer from the Federal Budget.

In the Australian there are concerns about the quality of residential care and whether it can be made dementia friendly. Some residential care providers in Australia have shown the way. The strategies include:

- A leadership committed to a person centred philosophy.
- Strategies to reduce excessive physical and medical restraint.
- Staff who value the residents and family carers and communicate with them.
- Flexibility in the timing of showers and meals.
- Access to allied health services.
- An activities program.
- Monitoring outcomes and resident’s experience.

Making the health system dementia friendly

If the health system is to be more dementia friendly there are three priorities – dementia risk reduction, timely diagnosis and acute care.

a) Dementia Risk Reduction

The World Alzheimer's report 2014 0n Dementia and Risk reduction report showed that the dementia risk for populations can be modified through reduction in tobacco use and better control and detection for hypertension and diabetes, as well as cardiovascular risk factors. In other words "What is good for your heart is good for your brain".

Based on the evidence, brain health promotion messages should be integrated in public health promotion campaigns such as anti-tobacco or non-communicable disease (NCD) awareness campaigns.

It is important people understand that dementia is not a natural part of ageing and needs to be tackled like other chronic diseases such as cancer and cardio-vascular disease.

Policies are needed that encourage physical, mental and social activity such as through the centres being developed in Japan which encourage older people to keep themselves healthy and delay for as long as possible the need for care.

b) 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 Europe, South Korea, Japan and Taiwan.

Scotland has tackled this problem head on and has increased the rate of diagnosis to about 60 per cent.

An important part of their approach has been to offer a post diagnostic support guarantee which gives the person with a diagnosis a guarantee of support from a named dementia link worker for 12 months.

This reduces the fear of seeking a diagnosis because it gives an assurance of support.

The objective is to develop a robust personal plan that utilises all the individual's networks alongside new community support.

A trained dementia link worker who functions as a member of the community mental health team provides the support.

This model and the Scottish approach to planning makes transparent for the consumer what they are entitled to, ensures co-ordination of services and lays the basis for relating services and support in an efficient way to the needs of the individual.

c) Acute care

Across the world acute care systems are struggling to care for people with dementia. For example, 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 people with dementia stay in hospital almost twice as long as those without dementia and invariably have worse clinical outcomes. For example, they are twice as likely to experience falls, pressure ulcers, fractures and delirium.

The UK has prioritised improving dementia care in hospitals, including developing and improving alternatives to hospital admission.

Dementia care in acute general hospitals has also been a key focus of the national dementia strategies in Scotland.

At the centre of this approach is the introduction of dementia nurse consultants in National Health Service Boards. These nurse consultants are experts at operating at a level of strategic influence within each board and have a lead role in taking forward the dementia care agenda.

The nurse consultants are joined by over 500 acute care dementia champions who are the operational change agents. Most of the dementia champions are nurses and allied health workers.

In Australia the Australian Commission on Safety and Quality in Health Care has provided leadership and vision in improving hospital care at the systems level for people with dementia.

They have implemented the “Caring for Cognitive Impairment Campaign” which promotes awareness about the need for appropriate care and support for people with dementia in the hospital system. It provides resources which outline Actions for Health Service Managers, Actions for Clinicians and Actions for Consumers to

promote better care. More than 130 hospitals have indicated a commitment to taking action to improve care for people with dementia as part of this campaign.

Dementia friendly information

Carers and people with dementia cannot make choices without good information.

In Australia there has been a significant investment in new information gateways to capture service information but what is still lacking is transparency in the outcomes being achieved or the views of older people and their families on the services they receive.

Australia is not alone in struggling with this issue. There is a greater recognition across the world that the time has come for a shift from a compliance, minimum standards approach to one which focuses on improving quality and providing information to consumers on care outcomes. Achieving this is proving hard in practice.

Less than a third of OECD countries collect quality care indicators systematically and even fewer countries make this information available or grade the performance of service providers based on weighted quality indicators.

In Australia the focus on quality in aged care over the last few decades has been on removing the poor providers in residential care and ensuring compliance with a basic set of standards. Indeed, more than two-thirds of OECD and European countries have compulsory long term care accreditation or accreditation as a requirement for reimbursement or contracting.

There are signs of change.

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

For example, in England consumers work with the Care Quality Commission and are involved in accompanying inspectors on visits to services and participating in the auditing process.

Australia is now piloting three outcome indicators in residential care – namely pressure injuries, weight loss and physical restraint. Consideration is also being given to the potential of reporting to capture resident’s experience and quality of life.

Conclusion

It is early days in realising the full potential of dementia friendly communities.

In changing how we think about dementia we have an opportunity not only to promote awareness in our communities but to re-think models of care including support for family carers, to make health systems more responsive to the needs of people with dementia and to better inform people with dementia and their family carers about the services that might best respond to their particular needs.

I believe we know what to do to take make our communities dementia friendly. Whether by establishing significant numbers of dementia friends, cafes and activities, dementia friendly businesses and workplaces or dementia friendly long-term care and health systems.

We should be setting two objectives.

First, to promote the lived experience of people with dementia through dementia.

Second, to empower people with dementia to exercise their rights in taking decisions about their lives

In summary we must establish dementia friendly communities and give priority to community based care, dementia risk reduction, timely diagnosis and post diagnostic support and dementia friendly hospitals.

I look forward to China planning nationally for dementia and implementing dementia friendly communities.

Thank you