

A responsibility to care

Alzheimer's disease, which accounts for 60 to 80 per cent of dementia cases, is a progressive, degenerative brain disease affecting a person's memory, thinking, and the ability to interact socially. Unfortunately, there is yet no cure for it and scientists are still searching for causes of this disease which affects about one in 10 people over the age of 65 and almost one in four over 85 years. People under the age of 65 years also are prone to the disease which is known as early onset of Alzheimer's.

Certain estimates indicate there are over four million affected by dementia in India and as per the India Dementia Report 2010 about Rs 43,000 annually per family is spent to take care of a person affected by dementia. The cost is high for many. As the ageing of the population is rapidly increasing, the economic and social burden of the disease is going to rise in the coming years. Ways to reduce the burden of the disease need urgent attention particularly in countries like India, which along with China, has the highest number of older people and where geriatric services are under-developed and talking of mental health issues carries stigma.

The World Health Organisation (WHO) global plan on dementia adopted at the 70th World Health Assembly in May this year prompts nations to take action now. It calls on governments to meet targets for the advancement of dementia awareness, risk reduction, diagnosis, care and treatment, support for care partners and research. Only 29 out of 194 WHO member countries have a plan of action on dementia, with India not having taken the initiative yet. Critically, countries need to take immediate steps to fight the disease as the treatment gap in most countries is huge and particularly in developing nations where the WHO estimates that only about 10 per cent of individuals are diagnosed

Current treatments merely address the symptoms and not the underlying biological cause of the disease. Next year, dementia is projected to become a trillion-dollar disease and Alzheimer's Disease International (ADI) recommends spending at least 1 per cent of the global cost of dementia on public funding for dementia research. In India too, Alzheimer's and Related Disorders Society of India (ARDSI) calls for the government to have its plan or policy on dementia which must be implemented in all states and funded and monitored by the health ministry.

ARDSI has been successful at in initiating a Kerala State Initiative on Dementia which is the first public-private partnership for dementia care and awareness. Kerala has the highest proportion of older persons in the country. It is also a state where many young people migrate leaving older parents behind to fend for themselves. Residential care centres for dementia-affected people are limited.

There is an urgent need to include dementia as a national health and social priority with provisions to identify dementia as early as possible and have adequate services for its treatment with sensitivity towards the care-givers, who are mostly from the family and ageing themselves.

Garnering support from the corporate sector to fund programmes, especially training of care givers and initiatives for research on the disease, is the need of the hour. Support from the Ministry of Social Justice and Empowerment becomes crucial in India as the disease has many social aspects which need awareness and service facilities at the community level.

Action on dealing with dementia calls for public health approach where social, health, legal and economic components for facing the various aspects of the disease need to be integrated. Legal provisions to safeguard and protect the rights, dignity and respect of those affected and in minimising economic costs and the burden of the disease, building public campaigns and

dementia-friendly initiatives are necessary in the next few years as the number of those affected by dementia will reach alarming proportions — from 50 million people worldwide currently to three times the number by 2050.

The Global Plan of Action on the Public Health Response to Dementia 2017-2025, adopted by 194 countries of the WHO, calls for a national dementia policy, recognition of human rights of people with dementia and the potential of dementia friendly-communities to give those rights practical effect. It is pertinent for India that the framework provided by the UN Convention of the Rights of Persons with Disabilities (CRPD) is monitored with regard to guaranteeing the rights of people with dementia. Living well with dementia is a health and social goal which should be maintained as part of the national response to the disease.

An important aspect of action in dealing with dementia is to work towards risk reduction of the disease. The non-communicable diseases plan of action should include building resources for strengthening brain health by associating it with physical and spiritual health. Above all, it is important that there be focus on supporting people with dementia to maintain their independence as much as they can and retain their inclusion in families, community and society. Stop discrimination against them.

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