

## **Consensus Statement on Quality Services for Asian People with Dementia (April 29–30 2005 – Hong Kong)**

Being the second Consensus Statement of the Consensus Program on Improving the Quality of Life for Asian People with Dementia (QoLDEM)

### **Introduction**

For people with dementia the four essential direct service domains identified are:

- Service systems
- Human resources to support quality services
- Training towards quality care
- Consumer participation

Two additional “indirect” domains which can significantly impact on the direct service domains are the role of the media, and the development and innovative use of technology for people with dementia.

This Consensus Statement on Quality Service will address these domains.

## **Service systems for quality care**

### **I. Early diagnosis**

1. In the pathway to dementia, the most critical element is early accurate diagnosis. Although specialist memory clinics in tertiary settings should be made available and accessible to all, it is in the primary care setting that this is most appropriate. Strengthening and supporting primary care health services for early recognition and accurate diagnosis of dementia should be a priority in health policy.
2. To assist the early recognition of cognitive change/decline in primary care settings, although the internationally accepted cognitive instruments such as Mini-mental State Examination (MMSE) and Abbreviated Mental Test (AMT) are generally accepted in western countries, the consensus is that a more specifically Asian instrument should be developed. To this end, the group will design and test an Asian cognitive instrument with satisfactory psychometric properties, drawing on the currently accepted instruments in use by western countries.
3. Quality assessment service for cognitive decline should be in locales that are: non-threatening, non-stigmatizing, affordable and accessible. The inclusion of cognitive assessment services for older people in general health and wellness programs is encouraged.
4. Once the diagnosis of dementia is made and confirmed, the patient and family should be informed in a caring, psychologically and culturally appropriate manner at a suitable time and with necessary support. In plain language, the pathology, signs, symptoms and course of dementia should be explained in an atmosphere of optimism.
5. Recognizing that in some countries, the currently used word for dementia has stigmatizing, demeaning and devaluing connotations, a more positive translation of the word “dementia” should be actively sought. Participants of this Consensus Meeting will work with consumers and fellow health professionals towards finding a name in each country which reflects the condition accurately, at the same time has a more positive, or at least, neutral meaning.

### **II. Care services in the pathway to dementia**

1. The quality of existing and to-be-developed care services in Asia should be marked by a higher degree of coordination. Where coordination is

currently lacking, urgent attempts should be undertaken to improve this lack.

2. All countries in Asia should aim to establish holistic elder care systems, which include care for people with dementia, with opportunities for staff to visit patients at their place of domicile, enabling comprehensive assessments of the domestic and family environment to assist in care planning.
3. Coordination of available services for people with dementia contributes to quality service delivery. Lack of coordination will lead to duplication, problems with access and confusion, thus reducing the quality of services offered.
4. A care plan for all persons with dementia should be established, primarily with family carers and support services. Whenever possible, care-plan coordinators should be appointed for each person with dementia. Care-plan coordinators (also known as case-managers in the developed world) should coordinate all aspects of care for the person with dementia, working closely with family members to achieve the best quality of life. Interface with significant others (friends, neighbors, relatives) by care-plan coordinators will further enhance quality of care. Significant others, in Asian countries, are seen as additional valuable resources to people with dementia and should be recruited, supported and coordinated by the care-plan coordinator.
5. It is noted that in the region there is a policy vacuum in dementia care. Planning for primary dementia care should be part of the total health care development policy. The disparity in distribution of resources between rural and urban areas must be a priority to be addressed. Community development to address this disparity should be a priority. Innovative community development (such as the Medical Mission Outreach of Philippines) in each country and community is strongly encouraged.
6. Where policy for dementia care exists, active implementation, supported by appropriate budgetary allocation, will require political will, strong commitment in the bureaucracy and powerful local support in the community.
7. Partnership in quality dementia care should be developed between people with dementia, families, significant others, community leaders, non-health community members (e.g. police, shopkeepers, banking staff), the legal profession, policy-makers, welfare and N.G.O. sectors, philanthropic foundations, the pharmaceutical industry, media, religious organizations, Alzheimer's Disease Societies, academic and professional organizations and primary-care health professionals. The establishment of such close partnerships in quality dementia care can make a difference in the totality of dementia care in each country.

8. A particularly Asian situation in dementia care has been noted. The increasing use of “foreign maids” (which include domestic workers from another country, as well as rural to urban internal migration of domestic workers) as paid domestic carers and residential care staff has created a need for finding innovative methodology for their training in communication and quality dementia care.

### **III. Minimum service provision**

1. The minimum service provision for promoting quality of life should comprise a comprehensive and a well-established government policy, coordinated social and health care services, a holistic approach concerning mental, physical and social domains, a care-plan coordinating system, tailor-made domestic and non-home facilities for this specific group of people with dementia.
2. To lift the standard of service provision, such minimum service should be imbued with a quality-improvement ethos, with anticipated advances towards the development of additional services beyond that of the minimum list.
3. The following table outlines the minimum service provision to improve the quality of life in persons with dementia and their family.

### **Human resources to support quality care**

1. As home care is recognized and affirmed as being central to any quality system of care, family carers are the most important human resources for quality care for quality of life.
2. Significant others (neighbors, friends, other relatives) are another group which can support quality care in the Asian context.
3. The increasing availability of family substitutes in foreign/rural domestic workers in the family setting is a social phenomenon which should be noted and recognized as an emerging human resource.
4. Primary health-care professionals come in short supply in this region and, where available, should be deployed effectively and efficiently. Innovative approaches to develop the best methodology should be tested, and, if successful, be widely promoted and promulgated.
5. Specialists in dementia diagnosis and management are in shorter supply. Their secondary or tertiary roles and their contributions to policy advice, training, and advocacy should be effectively capitalized.
6. Policy-makers (politicians and bureaucracy) are necessary human resources. They should be recruited to a partnership of quality-care service planning, community development, implementation and evaluation. Persons with dementia and their families, together with health professionals must establish active partnership with policy makers.

**Table 1.** Minimum service provision to improve quality of life for persons with dementia and their families

SERVICES	CARE		ACTIVITIES
	LOCALE	LEVELS	
Health	Community	Primary	Early detection and screening; Health education and health promotion
	Hospital	Secondary	Diagnosis and treatment Education of patient and family
		Tertiary	Memory clinics Diagnosis, treatment and rehabilitation Programs for caregivers Training of primary health care staff as well as secondary care providers and members of the NGOs Involvement in public health awareness programs
Social services	Community	Not applicable	Financial aid to the elderly Arranging shelter for elderly without family or with poor family support Provision of equipment
NGOs	Community	Not applicable	Provision of day activities Education for caregivers Counseling to caregivers Public awareness programs

7. The recruitment and education of media persons to become powerful human resources in public education, de-stigmatization, the defeat of agism and influencing policy for quality of life, are other high priorities.
8. As the general public is ignorant and often fearful of dementia and people with dementia, activities in public education should be undertaken to influence and recruit their positive support of those with dementia in their community day-to-day life.

### **Training towards quality care**

1. The training of informal family carers should be supported through local Alzheimer's Societies. Their efforts in this area should have the unstinting voluntary participation of all health professionals in this field of work. Reciprocity between Alzheimer's Societies and health professions in a partnership arrangement should be promoted and enhanced. Persons with dementia where possible and their families should be invited to participate in education programs.
2. For the foreign/rural substitute carers (which can be included with the group of formal/paid carers), training should be included in

their job preparation. Agencies in their community of origin should seek the assistance of the local Alzheimer's Societies and dementia workers to develop and implement basic training programs in quality dementia care. Failing this, the host community should be engaged in such training. A reward/recognition system, in the form of certificates of training or employment references, could be developed to recognize their additional skills in quality dementia care as domestic workers.

3. Volunteers in quality dementia care should be encouraged. The large available group of retirees in Asia with earlier retirement ages could be recruited, and provided with appropriate training in quality dementia care. Formal volunteer training programs may be developed by appropriate authorities.
4. Education in all health care undergraduate curricula should include dementia care. Advocacy to all tertiary health care educational institutions for such inclusion should be actively pursued, supported and implemented.
5. In medical and allied health postgraduate training, curriculum should have advanced training in dementia care, where such courses/programs include the care of older persons as part of their training.
6. Attitude development, mentoring and modeling the best quality dementia care, and the instillation of the philosophy of "unconditional positive regard" for people with dementia should underline all such educational and training programs.

## **Consumer participation**

1. In light of the recognition of persons with dementia as central in quality care and their families as core manpower, these two groups, as consumers, should have a central place in consumer participation.
2. To facilitate their participation in quality care and to retain their caring role, family carers should be supported by all available means. These include: resolution of family conflicts and enhancement of positive relationships through analysis and positive deployment of family dynamics. Workers will assist in counseling and negotiation for the best outcome whenever family conflicts arise regarding quality care provision for persons with dementia. Respite care, especially in-home arrangements should be used effectively. All persons with dementia and their families should be involved in care-plan decisions and implementation. These strategies may recruit for, and enhance, consumer participation.
3. Consumers should be actively invited to participate in policy development, education programs and public education activities.

## **Guidelines for quality dementia care**

The Consensus group recognizes that best-practice guidelines have country-specific, culture-specific and health care system-specific characteristics. A “one size fits all” set of guidelines is seen to be inappropriate.

For those countries, which are developing their best-practice guidelines, these will be anticipated before the next Consensus Meeting to be held in 2006.

## **Other issues**

### **Media**

A positive, mutually respectful relationship in partnership with all levels and types of media is required for the development and maintenance of quality dementia care, especially through accurate and timely promulgation of information.

### **Training**

New, innovative and creative technologies will contribute to quality care. The use of such technologies as Global Positional System (GPS) electronic locators, mobility-assisting technology, electronic communications (especially for the younger generation of carers) are all worthy of encouragement and deployment.

### **Right to treatment**

The high cost of available beneficial medications is balanced by the right of people with dementia to have such treatments. The balance between economics and right to treatment should not disadvantage people with dementia. Innovative methodologies for making such treatment affordable should be employed.

### **End-of-life care**

Quality dementia care must include the best quality in the end-of-life stage of the person with dementia. Comfort, emotional support and quality relationships are necessary components of services. The spiritual life of each person should be attended to with care and concern. Bereavement counselling for those to be left behind should begin before the death of the person with dementia and continue thereafter.

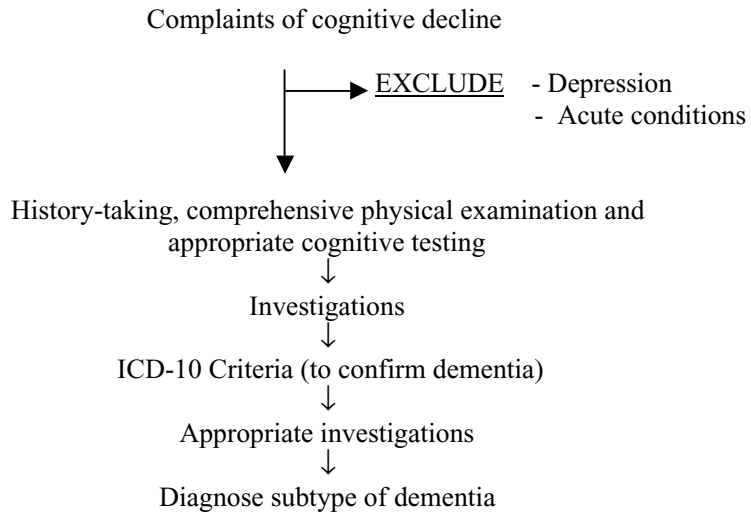
## **Acknowledgements**

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Eisai Health Care Company supported this program.

## [Appendix 1 Diagnosis Algorithm]

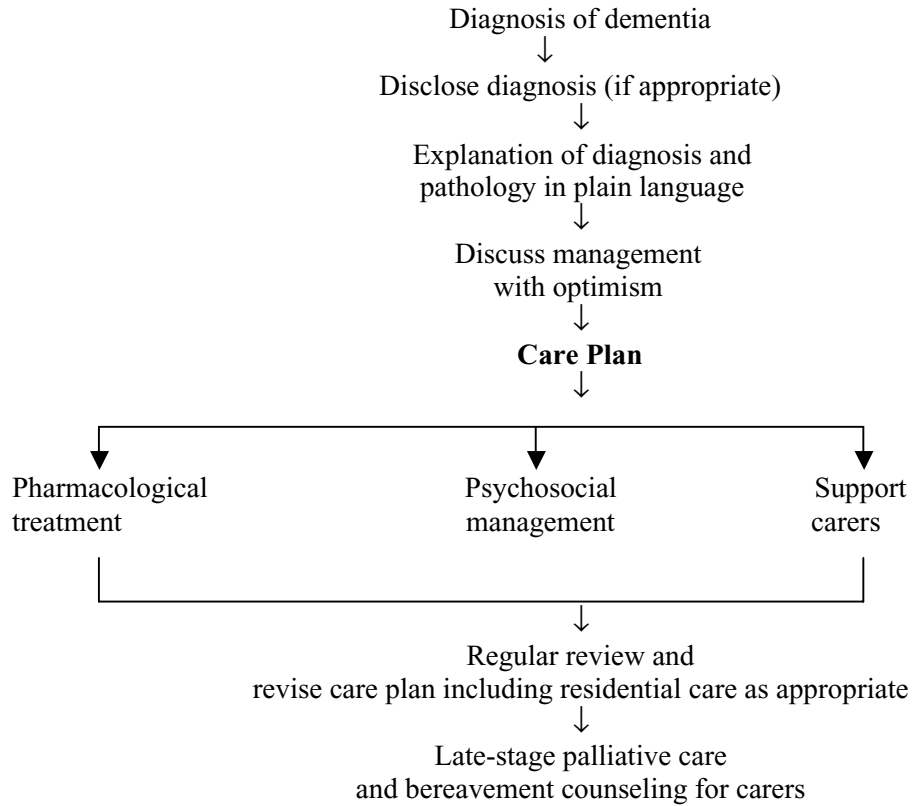
### Algorithm for diagnosis and management of dementia





**[Appendix 2 Management Algorithm]**

**Algorithm for diagnosis and management of dementia**



## **Appendix 3 List of Participants**

### **Attending participants**

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