

## CONSENSUS STATEMENT 2004

Endorsed by: the World Psychiatric Association, Section of Old Age Psychiatry, the International Psychogeriatric Association and the Pacific Rim College of Psychiatrists.

### **Improving the quality of life for Asian people with dementia**

#### **Introduction**

##### **The Demographic Driver**

In 2000, among the world's population of 6.08 billion, 57% is from Asia. Population aging in Asia is predicted to double from 4.2% to 8.8% for people aged 65 years or above between 1960 and 2020, with a consequent explosion of the number of people with dementia, as age is the major risk factor for dementia.

By 2025, it is estimated that the number of persons with dementia will increase to 34 million, with around 20 million in Asia.

Development of infrastructure and programs for dementia care, awareness of dementia as a disease and the expectations of policy-makers regarding dementia, however, do not match this growth of the population with dementia.

Some of the major problems identified by doctors in Asia include the following:

1. There is a policy vacuum in many countries in both health and welfare for people with dementia.
2. Human and financial resources are generally inadequate to respond to the rapidly increasing number of persons with dementia.
3. There is inadequate training for formal carers and a lack of support for informal carers.

4. Rapid urbanization and social changes in many countries have significantly restructured the family unit, leading to a decrease in support for the elderly and people with dementia.

### **The development of the consensus program on improving the quality of life for Asian people with dementia (QoLDEM)**

As a response to the demographic driver and acknowledging the very major problems associated with the impact of dementia in Asia, a program of consensus meetings of Asian leaders in dementia care was conceptualized.

This program received endorsement from three international organizations: the World Psychiatric Association, Section of Old Age Psychiatry, International Psychogeriatric Association and the Pacific Rim College of Psychiatrists.

Financial support was generously provided by Eisai Human Health Care Company, which sponsored the program.

The Jockey Club Centre for Positive Aging, a dementia centre funded by the Hong Kong Jockey Club and operated by the Chinese University of Hong Kong, accepted the role of host to this consensus project.

On 29 April 2004, the inaugural consensus meeting was held in the Shatin Jockey Club House, Shatin, Hong Kong, during which participants from China, Japan, Indonesia, South Korea, Singapore, Malaysia, Philippines and Thailand worked towards the development of a Consensus Statement (see appended list of the Advisory Board). Each country had prepared a brief for the group and then presented the issues verbally. The group considered the issues and decided on the first draft of the Statement, which received further amendments by electronic communication in May 2004. The final version was completed in July 2004.

This is a three-year program. It is anticipated that in 2005, the Consensus Meeting will work towards developing a set of detailed care guidelines. Such a set of care guidelines will have core elements common to the Region and will include country-specific items. Criteria for quality care will also be established to ensure that all levels of care contribute to the quality of life of persons with dementia.

In 2006, the QoLDEM Advisory Board members will meet to discuss and establish outcome measures in quality-of-life domains, as well as key performance indicators for the evaluation of dementia care services and performance.

### **Definition of quality of life (QOL) for persons with dementia**

The descriptions by Lawton (1994) and the WHO QOL group (1995) are accepted as the framework within which the QoLDEM group directed their thinking.

Lawton described four domains – behavioral competence, the environment, psychological well-being and perceived quality of life (QOL).

The WHO QOL working party defined QOL as individuals' perception of their position in life in the context of the culture and value systems in which they live, in relations to their goals, expectations, standards and concerns.

QOL is seen as a multidimensional concept which includes six domains: physical domain, psychological domain, level of independence, social relationships and environment, as well as spirituality/ religion/ personal beliefs.

### **Quality of life : domains of interest**

The “pathway of dementia” is used for staged descriptions of general and health-related QOL. This pathway commences with the stage of pre-dementia, moving to mild cognitive impairment (MCI), early dementia, moderate dementia, severe dementia, and concluding with end-of-life considerations.

Quality of care for persons with dementia underpins and contributes to the successful achievement of all QOL domains in all stages of dementia.

## **What can contribute to quality of life in the pathway of dementia?**

### **1. Pre-dementia**

The major contributors are healthy aging through living well, in the context of a healthy lifestyle, which includes a healthy and balanced diet, exercise, meaningful social activities and low stress. In achieving this, the possibility of reducing morbidity should make a major contribution to the quality of life of people who are growing older.

The strategies to achieve quality of life will include: reduction of poverty, improved education, financial security, healthy accommodation and environment. The role of health promotion, health maintenance, quality health care programs and accessible transport is also important. Further, the enhancement of spirituality (meaning of life) in this period, with resulting life satisfaction, supported by health-promoting family values, satisfying friendships and recreational pursuits are seen to be valuable. A sense of usefulness in old age, aided by the participation in lifelong learning will assist in the maintenance of cognitive capacities as well as enjoyment of life.

### **2. Stage of Mild Cognitive Impairment (MCI)**

Early detection with committed and assertive follow-up combined with appropriate and timely intervention is essential at this stage. Future availability of effective pharmacological and non-pharmacological treatment will probably play a significant role.

Non-pharmacological quality-of-life issues may include: optimizing intellectual activities — reading, playing games such as chess, cards and mahjong, calligraphy, bingo, drums and other recreational activities.

Where it is legally acceptable, the registration of people with MCI in a registry may enhance assertive follow-up. Public awareness programs in this area of MCI, providing a positive message to the community and health care professionals, will support this strategy.

The reduction of risk factors for dementia should be more energetically pursued at this time. These include the vascular factors of hypertension, hypercholesterolemia, smoking, diabetes, obesity, vascular diseases, heavy alcohol use; also, the taking of antioxidants and the treatment of psychiatric morbidity (e.g. depression) should be part of this strategy.

Research into possible interventions and the development of dietary and supplement guidelines is necessary.

Working with consumer group(s) will provide a collaborative platform. Where there is no consumer group for people with MCI, the formation of such a group should be actively pursued.

### **3. Early dementia**

The most important activity for QOL in the early stage of dementia is early identification, diagnosis and treatment. To this end, the education of primary care physicians as well as specialists is crucial.

All countries represented have validated instruments for cognitive assessment (e.g. the Mini-mental State Examination), which should be used routinely by all physicians working with the elderly.

The physician who makes the diagnosis of dementia should provide patient and carers with appropriate counselling and explanations of the diagnosis, course and prognosis of dementia.

Early planning for the future of the person with dementia in all areas of life will be facilitated. These areas include financial and legal arrangements, driving competence, lifestyle change, relationship with family members and psychological well-being. Support for carers should be planned and implemented at this early stage.

Ready access to affordable medications at this stage is essential and energetic management of medical co-morbidity can have a significant positive impact on the person with dementia.

Home-based support, elderly day care, pursuing voluntary work and trans-generational activities with younger members of family and community will add to quality of life at this stage.

As Asians are very conscious of and frequently enquire about the hereditary implications of all diseases and their medical and social impact on progeny, accurate information and supportive counseling for the whole family is also necessary.

#### **4. Moderate dementia**

In this stage of dementia, quality-of-life activities are particularly important and relevant.

Medical treatment for the cognitive and non-cognitive behavioral and psychological symptoms of dementia (BPSD) must be energetically pursued. Medical co-morbidity must be identified as early as possible and treated as effectively as possible. Socially related illness such as under-nutrition, infections or infestation from unhealthy environments must be addressed.

Safety issues for the person with dementia should be high priority.

Environmental contributions to safety include non-slip floor surfaces, adequate lighting, appropriate color of rooms, avoiding dangerous exposure of electricity outlets, safe storage of toxic materials such as domestic cleaning fluids, level footpaths, safe preparation of good quality food, seasonally appropriate dressing, and continuing financial security.

The education of non-health-related professions such as the police, staff of shops, banks and restaurants should be engaged to provide a more accepting, tolerant and supportive out-of-home environment.

Technology, such as the application of Global Positioning System (GPS) guided locators, alarms and other yet-to-be-invented systems should be actively explored and applied as appropriate.

Education of family members not to overprotect the individual but to work through a process of balanced autonomy should enhance quality of life. Reduction in carer stress must be part of service delivery at this important stage.

Driving assessment, support for transport needs, and encouraging participation in meaningful social and spiritual activities is essential.

The physical well-being of persons with dementia may be negatively impacted upon by major surgery or anesthesia, which should allow for the aging process. In addition, dental care, hearing and visual impairment, medication education and compliance, as well as self-initiated medication (herbal or over-the-counter (OTC)) and, for older women, addressing gynecological needs, are all relevant matters for attention.

Sudden, unexpected changes to familiar environments should be avoided; relocation of persons with dementia should be undertaken in planned stages accompanied by a program of familiarization.

## **5. Severe dementia**

In this, the late stage of dementia, the effective management of all morbidities, active mobility and ambulation in the residential setting or at home is important. The use of restraint should be deleted as a care option. Prevention of physical, psychological and financial abuse is exercised by constant vigilance. The establishment of guardianship legislation provides a firm and powerful basis for abuse prevention.

Healthy and attractive cuisine for quality of life is of particular importance in Asian culture. Food should be provided not only for nutrition , but also for personal enjoyment.

The privacy, dignity and autonomy of persons with dementia must be constantly respected.

Quality nursing and personal care in quality places cannot be ignored in policy or practice, as with the appropriate use of medication, avoiding both over- and under-use.

The concept and the practice of “Comfort and Peace” should envelop the person with dementia.

### **End-of-life issues**

Before this stage of dementia, the matters of a Living Will and associated decisions regarding resuscitation should have been made. The matter of inheritance distribution should also be settled before this stage. The principle of quality palliative care at the end of life should underpin all care at this stage. The key practice of “Comfort and Peace” should be seen as essential and pervasive.

While the Region is not at the point of seeing euthanasia as a social or legal issue, it should be considered before this becomes a matter of concern in each country.



The necessity for timely and effective bereavement counselling of family and staff members in care facilities should be established routinely, together with the need of culturally and religiously appropriate rituals before and after the death of the person with dementia.

## **Conclusion**

This consensus statement is by no means exhaustive. It attempts to reflect the dominant concerns of this Consensus Group from the countries in the Region.

Workers in the field can add other quality-of-life issues as appropriate. This document serves to highlight quality-of-life issues, stimulate thought, debate and discussion, and prompt all health-care professionals in the field of dementia care to think seriously and deeply, and review their policy and practice to provide the best quality of life to persons with dementia and their families.

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This Consensus Statement is endorsed by: the World Psychiatric Association, Section of Old Age Psychiatry, the International Psychogeriatric Association and the Pacific Rim College of Psychiatrists.

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