

*Paper in Response to*  
*The Healthcare Reform Consultation Document*

*Your Health, Your Life*

**Responding Organizations:**

**Hong Kong Alzheimer's Disease Association**

10 June 2008

The Hong Kong Alzheimer's Disease Association (HKADA) wishes to respond to the "Healthcare Reform Consultation Document" (Document) entitled "Your Health, Your Life". The following comments and suggestions are based on discussions among executive committee members of both associations, and presentations and comments from participating audience at the Policy Seminar on "Let's put Dementia on the Agenda" hosted by the Center for Social Policy Studies, the Department of Applied Social Sciences of the Hong Kong Polytechnic University (PolyU), and co-organised with the Brain Health United, a joint venture between the Faculty of Health Sciences, PolyU, and the HKADA. The Seminar was held on April 21, 2008 at the PolyU and was well attended by 75 persons from the medical and social sectors, old age home operators, family caregivers and the lay public. Dr Leong Che Hung and Prof Nelson Wing Sun Chow were specially invited guests who have made remarks and attended the entire seminar.

1) Important crossroads-

Major challenges due to the ageing population and rising prevalence of dementia:

Dr York's Chow's opening message to the Document rightly points out Hong Kong's healthcare system to be at an important crossroads. This is made more true by the rising incidence and prevalence of persons with dementia consequential to the ageing of the population, and both rates with a six-fold increase from now to 2050. A study conducted by the Department of Health and the Chinese University of Hong Kong stated in 2006 that the prevalence of dementia in community dwelling elders aged 70 years and above was 9.3%, and among these individuals, 84.6% of them were suffering from dementia in the mild stage. The study also stated that up to 90% of affected persons were not aware they had the disease. These indicate on one hand the possibility of early diagnosis and an opportunity for subsequent medical intervention that is known to be beneficial in stabilizing and delaying symptoms; yet, on the other, insufficient awareness in the public and medical sectors towards early diagnosis and intervention.

Prof Nelson Chow indicated that while most media and public discussion have focused on the financing models in the second part of the Document, equal attention should be paid to the service model reform which places emphasis on enhancing primary care, promoting public-private partnership (PPP), strengthening the public safety net, offering different care options in conjunction with market reform, and a life course approach to health protection.

In this way, the healthcare system of Hong Kong has arrived at a crossroad brought about by the graying of population, highlighted by dementia and accentuated by the dependency ratio resulting from a declining birth rate. Prof Nelson Chow has also on another occasion cautioned the fact that the median age of the population in the past 10 years has risen by 5 years will indicate the issues of ageing will surface faster than we have expected. We are already at the crossroad where decisions and our Vision of the future care for our old folks especially families with demented members need to be shaped and established.

- 2) Driving interaction and collaboration between different service providers-  
Which will meet the needs of persons with dementia according to “Stratification of Care needs in different stages of illness”:

Dr YM Wu in the Seminar has proposed a Life Course Approach to Dementia Care ( Appendix 1) from primary prevention of the dementing illness and protection of brain health, to the different stages of dementia which reflect different medical and social needs and management approaches.

The Document endorse a Life Course Approach to maintaining health which is fully applicable to late life Alzheimer’s disease. Scientific and medical literature have identified modifiable risks for the disease. Good socioeconomic conditions in early childhood, educational opportunities for youth, cognitively stimulating careers, vascular risk reduction in mid-age, avoidance of significant life events which causes depression, cognitively stimulating leisure activities such as dancing and chess, social engagement in older age after retirement, have been associated to possible reduction in the prevalence of dementia in old age through enhancing brain and cognitive reserve. This message needs to be propagated to the wider lay public, educational, social and medical sectors.

- 3) Enhancement of the Primary care system-  
The importance of early detection:

We fully agree with the strategic positioning of primary care in providing access to lifelong, comprehensive and holistic care for persons with dementia and their families.

Literature revealed lack of confidence in family physicians in diagnosing dementia and especially managing behavioral and psychological problems of persons with dementia. On the one hand, the family physician’s office is in the best vantage point in opportunistic case finding of early dementia, particularly in at risk groups, i.e. the aged, heavy vascular burden etc. Also, the family physician plays a key role in providing support to the carer of the patient with dementia; in this way the family physician and the caregiver work as partners in the longer term management of the person with dementia.

However, family physicians in Hong Kong often expressed lack of time and knowledge of social service support available. However, such deficiencies in primary care can be bridged. The Hong Kong Alzheimer’s Disease Association has since 2005 launched an early detection programme which provides detailed psychometric tests on persons suspected to have cognitive impairment. These tests are conducted by trained occupational therapists of the Association. Clients identified to have mild cognitive impairment or early dementia are discussed with volunteering specialists of the Association; and clients considered needing further medical evaluation will be referred to Evangel Hospital, a private hospital

which offers diagnostic and medical service to our referred clients at a discounted and affordable rate.

Regular case conferences are conducted with participation of doctors of Evangel Hospital, volunteering specialists of HKADA and our occupational therapists and social workers. These sessions promote mutual understanding, professional education, monitoring of progress of patients, case management and support for primary healthcare providers and their clients.

So far, 792 persons were assessed by our Early Detection Program. 72.6% were identified with different levels of cognitive impairment; and about 45% of them were suspected to be suffering from dementia. 135 of these clients were referred to receive further medical investigation in Evangel Hospital while the remain preferred waiting for follow up at hospitals under Hospital Authority. Among those who received investigation in Evangel Hospital, 88% had got diagnosis that agreed with results of our assessment. They were referred to appropriate services provided by HKADA, including day care service, in-home training and carer support group.

The Document mentioned the setting up of Centers of Excellence and collaboration between different service providers. The HKADA-Evangel programme may serve as a model of collaboration between a medical and a supportive facility in early detection and management of dementia.

Family physicians should start intensifying their training in early diagnosis and treatment of the disease. In this regard, the Hong Kong College of Family Physicians has coorganised with the Hong Kong Alzheimer's Disease Association in a 6 month certificate course in early diagnosis and management of dementia for family physicians (Programme attached in Appendix II).

Prof Nelson Chow has pointed out that early detection of dementia does not require radical changes on a policy level. Wider public education on the early symptoms of the disease so that family members are aware of possible illness in their older parents is crucial for early detection. At the same time, education of primary care doctors in the accurate diagnosis and management of the condition should parallel public education so that early detection can be matched with medical evaluation and treatment.

Dr YM Wu has estimated that 270 new cases of dementia has to be diagnosed per day in 2050, increased from 49 in 2005 in Hong Kong to catch up with the rising incidence of the disease in elders. At present, the small numbers of cases seen in specialist clinics of psychogeriatrics, geriatrics and neurology generates a waiting time of up to 12 months before the first consultation with no intervening supportive measures; and then diagnostic and management protocols are not standardized across specialties. Hence, the high prevalence and commonness of the dementing condition in elders necessitates a change of strategy towards early diagnosis and treatment in the family physician's setting.

- 4) Hong Kong is a caring and compassionate society; and no one should be denied adequate healthcare

through lack of means -

Better meeting of the social and care needs of persons with dementia and their family members:

Ms Elsie Chung has pointed out that there is no clear governmental policy for dementia care in Hong Kong. The Social Welfare Department has adopted an integrated approach to service provision based on empirical research dated more than 10 years ago.

However, increasing number of persons with dementia, raised awareness of the public and expectations, knowledge on the different care options in meeting the needs of clients, finer diagnostic and behavioral evaluation, and recognition of carer stress have led to development of dementia specific programmes for daycare, home care and residential care. Yet the availability of such specific programmes cannot at the moment be made available to all sufferers in need; being limited by awareness of family members to the scarce services, knowledge of healthcare providers of the existence of such services and referral mechanisms, and funding for the specialized input of existing services for elders.

There is a cogent need for expansion and funding support of existing and new dementia specific services to cater for rising needs.

During the Seminar, a service provider of a day center expressed that over 50% of her clients suffered from dementia, and the limited schedule of accommodation for a day center has prevented her from initiating proper dementia specific programmes for the demented such as for those who have wandering and pacing behaviour. Another provider voiced the lack of service for single living elders suffering from early and mild dementia, and suggested to provide cognitive programmes for them in district community centers. All these initiatives will require additional funding and specialized training and input.

A subvented home operator remarked that over 56 % of her residential clients suffered from dementia, yet only a small proportion of them qualified for dementia care supplement. The inadequate additional support had prevented proper management of her clients with care needs related to dementia.

A private home operator urged the government to provide dementia care supplement for their clients in need when the Document had also suggested more public-private partnership.

A very important factor leading to a gap between prompt and appropriate meeting of healthcare needs of persons with dementia is the inherent deficit of the Standardized Care Need Assessment Mechanism which employed a tool (Minimal Data Set-Home Care [MDS-HC]) which is insensitive to the need assessment of persons with dementia because the cognitive dimension is not adequately addressed. This resulted in an inability of matching much needed services for persons with dementia in the early and moderate stages when physical disability is minimal; but behavioral and psychological needs may be prominent. Hence, persons with dementia will become qualified for service only when physical disability needs occur and are identified by the existing tool. In Alzheimer's disease, physical disability

occur late in the advanced stage of the disease, usually in the 6<sup>th</sup> to 8<sup>th</sup> year of the disease; and in this way, behavioral and psychological needs of dementia and constant care required to prevent getting lost and prevention of other household hazards may not be attended to. Even in the advanced stages, the waiting list for care and attention, nursing home or infirmary service is notably lengthy. Hence, another assessment tool sensitive to needs of early cognitive decline is needed and services to cater for the medical and supportive needs of these clients is cogently needed. Early intervention is established to stabilize symptoms and preserve function to allow the client to remain in community living.

Participants of the Policy Forum have also urged to provide more explicit criteria to allow disability allowance to be awarded to clients with cognitive disability.

The issues for younger persons presenting with early onset dementia even as early as 40-50 year old are emerging. These have fallen out of the existing safety network; medically, because of unawareness of the diagnosis or difficult diagnosing; and socially, because elder provisions do not apply to them. Yet they and their families may often be excessively burdened psychosocially.

5) Every member of the society is a stakeholder-

But the caregiver for the person with dementia has not been given due recognition

Prof Nelson Chow remarked on the inclination of community recognition towards medical academic contribution, but neglecting the informal family caregiver who has sacrificed the most in the care of a family member. He called for substantial support in the financial arrangements to assist these families.

Dr. Claudia Lai brought out the important concept of family in dementia care, and this is echoed by Dr CH Leong who now chairs the Family Council. This can become an opportune platform for an intergenerational exploration into the different issues of ageing and dementia; including brain health promotion across the life span and family caregiving within the family.

Dementia affects not only the individual sufferer but the accompanying family caregivers. The mean number of persons in a local household is 3. For every person with the disease, at least two other persons will be simultaneously affected and will also be in need of support, not to mention the extended family.

Mrs Teresa Tsien draw reference to overseas models which provide carers with financial allowances, tax exemptions, flexible job arrangements and paid leave for caregivers.

A local caregiver voiced the provision of transport for persons with dementia to day care center to be extremely helpful for families. Another requested expanded vocational training of home helpers who can provide overnight home stay services to families with a demented member. In our society, such services have been sacrificed to allow funds for other “acute” services. In this regard, Prof Nelson Chow remarked adamantly on the over segregation between the medical and social services. In dementia care, both needs are often mixed and interlaced.

To this end, we urge the Reform to provide better assistance to these unfortunate members of our society who have their means outstripped through having to shoulder the costly and emotionally exhausting burden of informal care.

6) Public-private partnership-

More than PPP in dementia care:

Mrs Tsien and Dr Claudia Lai have emphasized multipartite engagement in reforming and bettering care for persons with dementia. These involve deep collaboration between the government in policy and funding allocation; the community in providing cost-effective interventions; the private sector in lowering the cost in drug and treatment; academic institutions in training and education in all aspects of care and family caregivers in intergenerational engagement and advocacy.

The Document puts heavy emphasis on the PPP which encourages the shift of burden of care and healthcare allocation to the private system which will drive a concomitant market reform. These changes largely refer to the medical care. In the care of dementia, the interface between medical and social need are blurred; e.g. coping difficulties in the family can present in the accident and emergency department as dehydration and falls; elder abuse can be masquerade as depression and fractures; poorly attended medical issues lead to discharge problems and functional decline resulting in premature long term care. These are only a few of common but neglected issues. In such regard, PPP should also include consideration of the medical and social collaborative participation and become duly rewarded.

A concern on market driven care is the inclination toward the more profitable advanced diagnostics and procedures but neglecting the less glamorous and client attracting long term and palliative care in dementia. If these services are not appropriately and adequately be available in the “market”, a service gap will be occur inevitably and backfire on the acute public hospital system. Incentive should be created by the Reform for these services and require initiatives from the government. In Singapore, such services in the private system receives dollar to dollar subsidy from the government and availability in the community are ensured before PPP was launched.

7) Public Hospital Services at Risk-

And putting persons with dementia admitted to hospitals at risk

Dr Wu highlighted delirium and dementia were common among hospitalized elders, as prevalent as 30% in some studies and mortality associated could be as high as 32%. Studies have also shown that multifactorial intervention reduces duration of delirium, length of stay and mortality. Acute care settings are unfriendly to demented patients. A doctor among the audience remarked that specialization of care in the hospital has fragmented total care and paid attention to obvious medical problems according to specialties and lost sight of the accompanying presentations of the person with dementia admitted to the

hospital. This has resulted in unnecessary physical and chemical restraining which may further aggravate the general condition and cause further functional decline. Post discharge may also not be adequate in monitoring and supporting the client and family members. Delirious elders also need longer term follow up when definite symptoms of dementia may become established in 1 to 2 years time.

A nurse in the audience also echoed that manpower constraints have prevented a more effective and humane approach to delirious and demented patients in which restraints and complications arising may be reduced. She proposed specialized delirium programmes to be made available to patients.

A caregiver proposed simple measures such as more flexible visiting allowances such as permitting the close family member to stay in the ward to reassure the patient may already be very helpful.

Dr Wu concluded that validated tools, education of healthcare staff, prevention programmes and multi-disciplinary intervention to be practiced in the hospital, to make the hospital a safer place for demented elders.

#### 8) Human dignity:

Dr Wu remarked that Hong Kong as a socio-economically advanced city has surprisingly lagged behind others in establishing legislation in relation to the emerging challenges brought about by the graying of our society, such as elder abuse, enduring power of attorney for healthcare, and long-term care facility regulation.

Ethical and legal considerations are instrumental in ensuring the quality of living and care for vulnerable elders especially in long-term care. Japanese legislature, for example, recently enacted the Elder Abuse Prevention Law. Though Hong Kong as a common law jurisdiction has related legal provisions, they are not consolidated into a cohesive body of law. Arguably the magnitude of the problem of elder abuse has been overlooked, and has not received the same attention, treatment, and level of enforcement as child abuse for which there are existing legislations. It is submitted that legislation on elder abuse would provide a clearer guideline for aged care services providers, health care workers, social workers and the community at large.

Enduring power of attorney (EPA) should be extended in scope to include decisions on personal care. EPA enables a person of sound mind to appoint another to handle affairs related to finance and properties when the person has lost his/her mental capacity. This is useful for an early dementia person in anticipation of his eventual loss of capacity. However, currently the power of attorney does not encompass the power of decisions-making for personal care matters. Such personal care matters are in fact very relevant to the person with dementia and his/her family.

In relation to Advance Directive (AD), the UK Parliament has codified the common law position in the



Mental Capacity Act 2005. It clarified the uncertainties surrounding the issue. This should be noted as the discussion on AD has just begun in these few years, and the Law Reform Commission recommended the common law approach rather than the statutory approach. Medical professionals in Hong Kong should nevertheless promote the use of AD and participate in the AD decision making process during the course of the illness.

A large proportion of aged home residents suffer from dementia. Medical coverage to long term care setting is inadequate under the current situation. Doctors trained in community geriatrics are lacking. Remuneration for nursing home work is hardly rewarding enough to attract experienced doctors. To achieve quality medical care in the aged homes the government should consider a co-payment scheme whereby community geriatric services could be purchased directly or indirectly through the agency running the aged homes.

Another option is to use public money from tax income and/or social health public insurance to fund an all inclusive care for the elderly. Under a capitated funding model, the non-government organization has the obligation to provide community care, primary health and residential care, and reimburse hospital expenses, whenever the need arises. Since the managed care agency would bear the financial risk, there is enough incentive for focusing more on disease prevention and community geriatric care in lieu of tertiary care in hospitals.

Progressive dementias invariably lead to death. Emphasis should be put on improving quality of life rather than curative intent during the later stage of the illness. This principle underpins the importance of good end-of-life care and the concept of dying-in-place. Notwithstanding the fact that most would acknowledge these principles, they are not readily put into actual practice because of various obstacles and resistance. Paradigm shift, administrative support, staff training, medical input, environmental modification, government policy changes are all required to bring about good practices in end-of-life care and dying-in-place. A recent survey highlighted that a substantial proportion of elders preferred receiving end-of-life care and eventually dying in their own residential place over being admitted to a hospital for their final journey of life.

#### 9) Our Vision for the Healthcare System-

To achieve a comprehensive community model that improves the state of health and quality of life of persons with dementia and their families, and provides brain health protection for every member of the community

We propose a Comprehensive Community Model of Dementia Care 2008 (Appendix 3) and identified the inadequate provisions in the respective services and the linking interfaces. A Community Model for Dementia Care should encompass screening for cognitive impairment after age 75 yrs, clinical

evaluation and follow up in primary care, specialist input for difficult clinical issues, daycare and respite, later long term care, and appropriate medical care in the repeated hospitalizations. This continuum of care will need standardization, short waiting time for various services, coordination between the medical and social sectors, empowering and support for primary care, and public and professional training in all aspects of dementia and ageing issues.

10) “Putting Dementia on the Agenda”-

The Promise to “Get the Job Done” :

The Agenda is not only for Governmental consideration, although recognition of “Dementia Care” by Government as a healthcare priority is crucial for driving changes and appropriate funding.

The Agenda also extends to every one in the community if a Life Course Approach is taken toward Brain Health. This will need to engage education of the young, offering of job opportunities, promotion of positive and fruitful leisure, mid life vascular risk reduction, comprehensive preparation of retirement financially and psychologically, providing opportunities for elders for continuous learning and social engagement and prompt and appropriate care options. It will become thus a Personal Agenda to preserve and enhance our brain health through healthy and cognitively active life style.

Dr Leong has pointed out the setting of Health related targets to any healthcare reform and agenda; we propose the following in relation to the above:

- 1) Establish protocols and standard formats in screening for early dementia in elders aged 75ys and above in medical and social services for elders;
- 2) Increase places for dementia specific programmes in daycare and respite so that matching of needs can be appropriate and timely;
- 3) All persons with dementia with accurate diagnosis and in the early and moderate stages should receive specific medical treatment with a cholinesterase and memantine;
- 4) Family physicians should be trained in early diagnosis and treatment and be made aware of social supportive facilities in the locality; all family physicians to complete a 6 sessions training within 3 years;
- 5) Reduce waiting time for specialist evaluation for difficult problems to within 8 weeks in 3 years when family physicians become more engaged in dementia care;
- 6) Enhance medical and social coordination through a district based coordinating platform which need to be deliberated on;
- 7) Enhance geriatric and psychogeriatric input and teaching for long term care in early detection and management of BPSD in residential clients avoiding unnecessary chemical and physical restraints e.g. reduction in 50% in 2 years;
- 8) Enhance care and appropriate management of “delirium” and “delirium on dementia” for

hospitalized elder clients largely in medical and orthopedic wards and the rehabilitative settings; reduction in duration of stay by 10% and reduction in chemical and physical restraints by 1 day in 1 year time, together with standard protocols and training to all nurses and front line medical doctors in 1 year time in the Hospital Authority;

- 9) Increase dementia specific daycare centre and respite service so that urgent needs can be met initially with 1 week; e.g. patients on verge of discharge or at the AED can be arranged respite immediately to avoid unnecessary hospitalisation of social care needs presenting as medically problems.
- 10) Life course approach to be promoted to lay public within 2 years through media, education and healthcare channels.
- 11) Dementia issues to be on the agenda of all public committees engaged in elder care, even involving education and youth establishments at suitable occasions within 2 years.

Referring back to the Healthcare Reform in question, the HKADA would like to pose the following questions:

- 1) Will the Reform provide the comprehensive care depicted above?
- 2) Will the Reform and financial arrangements proposed in the Document provide timely and appropriate care for all, in the public as well as private sectors?
- 3) Will long-term care be addressed, including medical and palliative aspects?
- 4) Will the supply of various service modules be made ready and in the right mix; because a market driven service will necessarily be inclined towards the more profitable diagnostics and procedures, and marginalize low technology and long term care?
- 5) Will PPP include the medical and social interface and partnership in dementia care? and;
- 6) Will the life course approach to brain health be made applicable to all?

Only in such light will “Your Health, Your Life” become meaningful, because it matters for “Our Health, Our Life”.

~ End ~

## **Introduction of the Responding Organization**

### **Hong Kong Alzheimer's Disease Association**

A non-profit making charitable organization, found in 1995 by a group of medical and para-medical professionals, university educators, social workers and carers. It is committed to promote dementia care in Hong Kong by running 2 integrated day centres, 2 early detection centres and an in-home training service, organizing training in all aspects of dementia care and advocating appropriate management of the condition in the community. The objectives of the association are: to promote early detection of the dementing illness; to offer persons with dementia an opportunity to live at home; to facilitate access to multidisciplinary assessment and care plan; to arrange for continuing and appropriate care; to enhance the quality of life of the affected and their family members; and to promote public awareness of the disease and community education on brain health.

### **Members of Responding Document Task Group:**

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Date