Appendix 5

Report of the Working Group on Dementia

July 1999

Chapter 1
The Disease and Its Care Needs

The Disease

Dementia is a pathological state characterised by gradual decline in intellectual function that occurs in clear consciousness. It is not a process of normal ageing. It is a disease.

2. There are many causes for dementia. The commonest cause is Alzheimer's disease, an irreversible degenerative disorder of the brain, followed by vascular dementia. Commonest reversible causes are drugs, depression and metabolic causes like hypothyroidism. Risk factors for Alzheimer's disease include ageing, family history of dementia and Down's syndrome. Other possible risk factors include head injury.

3. The typical clinical course in dementia is progressive decline in mental and physical functions, leading to total dependence on others and requiring multiple levels of services. The course is variable and can last up to 15 years. The average survival is 8-10 years. The clinical course of the disease can be divided into four stages and the associated care needs are outlined:

(a) Very early stage — mild memory impairment, subtle personality changes, diminished interest and skills, emotional distress. Services and programmes required would include early detection, management and training for the demented in memory. Public awareness and acceptance are also very important.

(b) Early stage — more severe memory impairment (especially short-term memory for recent events), and deterioration in self control. They need help with daily affairs such as shopping. It has been suggested that specific treatment for dementia at early stage could slow down deterioration.

(c) Middle stage — common problems include wandering, language impairment, disturbing behaviour, delusions and incontinence. Need constant supervision.

(d) Late stage — loss of physical agility, becomes bed bound.Constant nursing care needed.

4. Apart from the gradual cognitive decline, non-cognitive symptoms of dementia are common, occurring in up to 70% of cases. These include personality changes, delusions, hallucinations, depression and behavioural problems.

5. A demented person usually has multiple problems, including mental, behavioural, physical and social problems, and hence has multiple care needs and requires different services at different stages of the disease.

6. A recent survey conducted by the Psychogeriatric Department of Castle Peak Hospital identified the ten most difficult areas for care of dementia. They are in descending order: (i) restlessness at night; (ii) delusion, hallucination, paranoia; (iii) confusion; (iv) wandering; (v) screaming; (vi) suspiciousness; (vii) disorientation; (viii) communication

problem (ix) inappropriate sexual behaviour; and (x) agitation. These disturbing behaviours and psychotic symptoms are most substantial during the middle stage of the disease. The demented is still physically mobile at this stage, and managing the patient with such disturbing behaviours and psychotic symptoms is considered the most difficult and frustrating period for the carers.

Care Needs of Dementia

7. Since dementia is a complex problem, a multi-disciplinary approach is essential in the care of dementia. Services include medical, social, voluntary and legal. Medical service comprises outpatient service, domiciliary care, outreach service to aged homes and day care centres, day hospital, inpatient unit and long-term care. Social services include financial help, home help, day care centres, multi-service centres for the elderly, residential and respite services. Voluntary services also play an important part in service provision, e.g. Alzheimer's Association. Other services like legal advice may be needed at some stage as well.

8. Care needs of people with dementia can be summarised as follows –

(a) Prevention
Preventive strategies are useful especially for vascular dementia. Vascular dementia may be prevented by reducing risk factors of cerebrovascular accident. These include identification of those at high risk of cerebrovascular accident (screening for hypertension and atrial fibrillation, early identification and good control of diabetes), low-dose aspirin and encouragement towards healthy lifestyle (diet, exercise, non-smoking). With the advance of scientific knowledge, it is possible that certain preventive measures may be useful for Alzheimer's disease.

(b) Early identification
It is essential to treat the reversible causes of dementia. By recognising the problem, early identification also reduces stress both for the individual and the carers and enables them to develop a care plan at the early stage.

(c) Comprehensive medical and social assessment
Comprehensive assessment by multi-disciplinary professional staff will identify the various problems, resources and needs of the patient which is important for making a diagnosis and to generate an initial management plan.

(d) Management
Management is more than treatment in the medical sense. A comprehensive care plan should address the individual's physical, psychological, social and material needs. The aim of the management is to maintain or improve the quality of life of the demented and their carers while respecting their autonomy.

(e) Continuing care to the demented
Persons with dementia need considerable support in maintaining self-care and activities of daily living, sometimes with continuous supervision. The ability of informal carers to meet these needs, and burdens on carers need to be addressed. Practical and continued help with household and personal care

may considerably enhance quality of life of the demented and alleviate the pressure on the carers.

(f) Information, advice and counselling
Persons with dementia and their carers need easy access to readily understandable and accurate information regarding the disease, its management, prognosis and support services. Educating the individual and carers are important components in care planning.

(g) Residential care services
While the demented should best be cared for at home for as long as possible, it is recognised that residential care services may be inevitable to cater for the demented's needs effectively or avoiding disproportionate burden on the carer.

Care Needs of Carers

9. As the conditions of the demented deteriorate, the patients would suffer disorientation and memory loss. To reduce the trauma of the patients, it would be best if they can reside in a familiar environment. However, this in turn may mean that the carers would need to shoulder significant responsibilities and pressure in caring for the demented. Therefore, in planning service provision for the demented, it is important to realise that there are, in fact, two groups that warrant our attention, namely the demented elderly and their carers. Caring for a dependent family member is a demanding job and often generates high level of stress. Indeed, both local and overseas studies have shown that care-giving responsibilities have negative effect on the carers. Most stress comes from the following four aspects: physical deterioration, financial strain, negative emotional response and frustrated social life.

10. To address the above-mentioned common stresses, the needs of carers by types of services can be summarised as follows -

(a) Need for information on dementia and community resources
Such information will empower the carers to take care of their elderly dependants with the help of community support resources. In most instances, the carer role comes in sudden and they are caught unprepared. Availability of such information is crucial to help them get acquainted to the caring role and to perform the caring tasks more competently.

(b) Physical care assistance
Taking care of someone with impairments involves considerable amount of physical labour. Carers may need assistance in lifting the demented from bed, in and out of the bath, etc. This is particularly significant for the aged carers who are weak in physical strength. Carers often report injuries as a result of lifting and transferring the frailed and such physical stresses may also exacerbate their already existing chronic illness, such as arthritis and hypertension.

(c) Training on skills of taking care of the demented
To deal with the cognitive and physical impairments of the demented, training to carers on methods to deal with the problems of memory loss, disorientation, bedding, dressing, etc. are thus essential.

(d) Respite service
It is widely recognised that both day and residential respite care can relieve burden of the care-giving role and allow the family to continue care for the demented at home, who would otherwise have been placed in an elderly residential institution.

(e) Emotional support
Since the caring role brings about various kinds of stress, carers may experience burn-out and eventually become incapacitated to take care of their dependants. Counselling and emotional support for carers thus play a crucial role to help them through.

(f) Recognition
Studies have shown that carers can easily burn-out because of two factors: care without support and care without appreciation. Considering their contribution to the community and their commitment to care, they deserve a wider public recognition.

(g) Financial assistance
As the conditions of the frail elderly deteriorate, they need adaptations to their living environment or purchase special equipment or facilities. All these require money or other material resources. The low-income aged families are the most vulnerable and they should be covered by the social safety net.

11. As outlined above, in drawing up a strategy to provide services for the demented, it is important that the needs of their carers are also taken into account, to enable the demented and their carers to cope with the disease together.

Chapter 2
Dementia in Hong Kong

12. There are various studies on dementia in Hong Kong conducted in community or selected groups of elderly in residential care homes. They are either clinically diagnosed by psychiatrists or based on cognitive impairment by assessment tools such as the Mini-Mental State Examination or the Short Portable Mental Status Questionnaire.

Clinically-diagnosed Dementia

13. In late 1995, the Department of Psychiatry of the Chinese University of Hong Kong conducted a community-based study on 1 034 Chinese elderly in Shatin aged 70 years and above. The prevalence of dementia in Hong Kong was found to be 4% for those 65 or above, i.e. about 25 000 persons. It was also found that the rate of dementia increased with age and approximately doubled for every five years until around 90 years. In the 70 to 74 year old age group, less than two people in 100 develop dementia, while in the 90+ age group, more than one in four people develop the disease.

14. The same study also revealed that about 45% of the demented subjects were living in residential care homes. As for the prevalence of dementia in residential care services, the prevalence in Old Aged Homes/Care and Attention Homes was estimated to be 17%. Another study conducted by the Psychogeriatric Department of the Castle Peak Hospital in 1996 showed that the prevalence of those living in subsidised and private Care and Attention Homes were 12% and 36% respectively. The prevalence of dementia in a Nursing Home, which provides higher level of care, was as high as 94% in a survey. The Hong Kong Council of Social Service conducted another survey at 92 subsidised residential care homes for the elderly in 1998. Out of the 15 622 residents, 1 305 (about 8%) were confirmed to have dementia by medical professionals.

Cognitive Impairment

15. According to the Community Survey of the Study of the Needs of Elderly People in Hong Kong for Residential Care and Community Support Services conducted by Deloitte and Touche Consulting Group in 1997, 25% of the elderly population aged 60 and above having some degree of cognitive impairment, including 5% having moderate or severe cognitive impairment. Based on the assumption that cognitive impairment is a relevant indicator of dementia, the proportion of demented people aged 60 or more in Hong Kong is estimated at 5%.

16. The Hong Kong Council of Social Service conducted another survey at 57 Care and Attention Homes in 1997. Out of the 6 116 residents, 2 261 (about 37%) were found to have cognitive impairment. In 1998, the same organisation conducted another survey conducted in 25 Day Care Centres for the Elderly and revealed that out of the 1 111 clients, 251 (about 22.6%) had cognitive impairment.

Observations

17. The above results showed that the overall prevalence of moderate to severe dementia in those aged 65 and above was 4%. This is very similar to rates in other countries. In general, overseas studies show that moderate to severe dementia affects about 5% of people over 65. At the moment, it is estimated that more than half of the demented live in the community with a combination of support from informal carers (family and friends) and formal services. The remainder lives in residential care facilities such as Care and Attention

Homes and Nursing Homes. It is estimated that 37% of Nursing Home residents have substantial cognitive or behavioural characteristics associated with dementia.

18. Hong Kong has a rapidly ageing population. In 1981, the population of elderly aged 65 or above was 334 000. By 1998, the elderly has increased to 690 000, i.e. 11% of the total population. This rising trend is expected to continue. By 2016, it is projected that the elderly population will reach 1 090 000, which will approximate 13% of the total population. In absolute terms, there are approximately 27 600 people over the age of 65 with dementia in 1998. By 2016, this is expected to increase to 43 600, representing an increase of 60%. Apart from the increase in proportion of elderly people, the increase is also attributed to the fact that the average life span is lengthening and the chances of developing dementia increases with age.

19. Further large-scale epidemiological studies may be needed to examine the prevalence of dementia. Nevertheless, the findings of the above studies suggest that the prevalence of these problems in Chinese elderly in Hong Kong is comparable with the figures in western countries.

Chapter 3
Existing Services for the Demented

20. A range of existing services is currently available for the elderly. Elderly people with dementia, like any other elderly in need, are accessible to these services. A few services with special reference to the demented and their carers are highlighted below.

Raising Community Awareness and Knowledge

21. The Department of Health and other organisations provide health education pamphlets and activities for the general public to enhance understanding of dementia and promote a positive and caring attitude towards the sufferers.

Prevention

22. Health promotional activities on prevention of risk factors of cerebrovascular accident such as healthy living provided by various organisations help prevent vascular dementia.

Early Identification

23. It is important to diagnose and manage dementia at the early stage as early detection may help to defer deterioration. In this respect, primary medical practitioners in both public and private sectors are playing the role of identifying early traits of dementia. In particular, Elderly Health Centres of the Department of Health provide health screening including cognitive function for their members.

Medical Care Services

24. Psychiatrists and geriatricians of the Hospital Authority are providing specialist medical care services to the demented such as cognitive rehabilitation and behavioural modification. The memory clinics are specialised at early detection and management of dementia. There are also medications that may improve the cognitive function as well as control the non-cognitive symptoms in dementia.

25. Both Psychogeriatric and Geriatric Teams provide outreaching medical services for the demented at the community and residential care homes.

26. When the demented elderly deteriorate to a stage where constant and intensive professional medical and/or nursing care are required, Infirmary Service under the Hospital Authority provides services for them.

Welfare Services

27. Various community services such as counselling, home help and day care services are available for demented elderly and their carers to enable the elderly to remain in the community as far as possible.

28. Besides accommodation, residential care homes also provide general personal and nursing care. The commissioning of Nursing Home places, serve to provide higher level of nursing care to the elderly, including for the demented. It was estimated that 94% of the residents suffered from dementia of different degrees. In addition, long stay care homes also provide care to people suffering from mental illness, including dementia.

29. A Dementia Supplement at about $41 000 per elderly per year has been provided to subvented residential care homes since November 1998 to employ therapist, social worker and nurse to provide better care and training for the demented elderly.

30. To cater for the special needs of elderly with dementia, the Social Welfare Department will be conducting pilot schemes on setting up of dementia units in subvented residential care homes and day care centres in 1999 to provide enhanced and dedicated services for the demented.

Support to Carers

31. Health education programmes are provided by the Elderly Health Services of the Department of Health to enhance the ability of carers in delivering care to demented people. These programmes are conducted both at Elderly Health Centres and community settings such as social and multi-service centres for the elderly, day care centres and residential care homes.

32. Carers' Support Centres, Community Rehabilitation Network and voluntary agencies such as the Alzheimer's Association are also providing counselling, advice, knowledge and practical skills in care delivery and information on the available community resources to cater for the need of carers. In addition, self-support groups are also run by these organisations to carers with moral and emotional support in times of need.

33. Various community support services such as the home help service provide tangible and physical care assistance to help lessen burden on carers especially who are elderly people themselves.

34. To cater for the need of relief for carers, the Social Welfare Department will be conducting another pilot scheme on setting up of day respite service for the elderly in day care centres in 1999-2000. Together with the existing 16 respite places in residential care homes, residential respite places are also available in the piloted dementia units at subvented residential care homes to provide temporary relief for carers.

Legal Aspect

35. The Mental Health (Amendment) Ordinance 1997 empowers the Guardianship Board to better protect the well-being of mentally disordered/handicapped persons, including the demented.

36. The Amendment Ordinance also enhances provisions in Part II of the Mental Health Ordinance, Cap. 136 which empowers the Court to, inter alia, appoint a committee of the estate of a mentally disordered/handicapped person who is incapable of managing his/her property and affairs. Demented persons are also covered under the Ordinance.

37. Enduring Powers of Attorney Ordinance (Cap.501), enacted since June 1997, provides the creation of enduring powers of attorney to manage the property and financial affairs of a person in the event of subsequent mental incapacity.

Staff Training

38. The Department of Social Welfare provides in-service training for personal care workers and home helpers on Gerontology. The training comprises structured basic and refresher courses. In addition, the Visiting Health Teams of the Department of Health

organises health education programmes specifically on dementia for formal and informal carers at community settings, such as social and multi-service centres, day care centres and residential care homes.

39. With the funding of $10 million from the Chief Executive's Community Project List 1999, the University of Hong Kong will develop and conduct a series of structured training courses for formal and informal carers. These training courses will be multi-disciplinary in approaches to equip carers with comprehensive gerontological knowledge and skills. The training package comprises courses offered at various levels, each building on the previous level to cover various topics on care for the elderly including behavioural and cognitive problems which are considered the most difficult areas for care of dementia.

Observations

40. As outlined above, a range of services are currently available for the demented and their carers to meet their needs. Nevertheless, with an ageing population, it is expected that service demands would increase correspondingly. There is still room for improvement to these services for the demented both in terms of quantity and quality. Furthermore, a more integrated approach in the delivery of service is recommended so that demented elderly and their carers can have easy access to a comprehensive and well co-ordinated care service.

Chapter 4
Principles for Care of Dementia

41. Adopted from the WHO and World Psychiatric Association guidelines in 1997, good quality care of older people with mental health problem comprises the following elements:

Comprehensive
A comprehensive service should be patient-centred, taking into account all aspects of the patient's physical, psychological and social needs and wishes.

Accessible
An accessible service is user-friendly and readily available.

Responsive
A responsive service is one that acts promptly and appropriately to problems and referrals.

Individualised
An individualised service focuses on each patient and his/her family. The planning of care must be tailored for and acceptable to the individual and family, and should aim wherever possible to maintain and support the person within her/his home environment.

Trans-disciplinary
A transdisciplinary approach goes beyond traditional professional boundaries to optimise the contributions of people with a range of personal and professional skills. Such an approach also facilitates collaboration with voluntary and other agencies to provide a comprehensive range of community orientated services.

Accountable
An accountable service is one that accepts responsibility for assuring the quality of the service it delivers.

Systemic
A systemic approach flexibly integrates all available services to ensure continuity of care and co-ordinates all levels of service providers.

42. On the basis of the above-mentioned premises, the Working Sub-group on dementia considered the following principles as pivotal to the future provision and assessment of services for care of dementia.

(a) Community care approach
Community care of dementia should be emphasised as studies have shown that admission of the demented to hospitals or residential care homes may hasten deterioration because the demented are prone to be more confused in new and unfamiliar environments. The aim of care for dementia is thus to help the demented stay at home as far as possible.

(b) Multi-disciplinary approach
Dementia is a complex problem. It causes disabilities in physical, mental, behavioural and social functioning. Effective intervention should aim at a holistic improvement and management of all these aspects.

(c) Preservation of dignity and quality of life
An individual suffers significant cognitive and physical impairments when the disease progresses to its late stage, leading to a state of total dependence on others. Respect of the individual as a human being is one of the major principles in care of dementia. We should also aim at maintaining the quality of life by maximising residual functions of the individual.

(d) Early detection and intervention of people with dementia
They are the key to recognise the problem, facilitate access to service and effective management as well as to reduce stress both for the individual and the carers.

(e) Support to carers
Caring for a dependent family member with dementia is a demanding task and requires both physical assistance and emotional support.

43. The Working Group proposed that the care for dementia should serve two groups of clients: the demented and their carers and that the model would be guided by the principles mentioned above.

Prevention and Early Identification

44. There are several specific circumstances within the care of dementia where preventive strategies may be useful. Vascular dementia may be prevented by reducing risk factors of cerebrovascular accident. These include identification of those at high risk of cerebrovascular accident through screening for hypertension and atrial fibrillation, early detection and good control of diabetes mellitus, and promotion towards healthy lifestyle. General practitioners are in a good position to educate patients and their family members about the importance of maintaining a healthy lifestyle. Early detection is paramount in dementia care and treatment. **The Working Group recommended that health promotional activities and health screening service currently conducted by the Elderly Health Services of the Department of Health should be strengthened with a view to reducing the preventable causes of dementia.**

Comprehensive Medical and Social Assessment

45. Dementia is a complex problem. It causes disabilities in physical, mental, behavioural and social functioning. Effective intervention should aim at a holistic improvement and management of all these aspects. A more integrated approach in the delivery of service should be adopted and specialised programmes and facilities should be developed to improve the functioning and mental health of the demented. These, among others, include cognitive rehabilitation, behavioural modification, reminiscence and validation therapies. The medications that may improve the cognitive function, control the non-cognitive symptoms as well as slow down the deterioration process should be used judiciously. **The Working Group recommended that psychogeriatric day hospital is an area to be considered.**

46. Existing community support services such as home help, day care and residential respite services should be further strengthened to enable the elderly including the demented to remain living at home as far as possible. **The Working Group recommended that feasibility of setting up more special dementia units in residential care homes and day care centres as well as day respite service for the elderly should be examined upon the completion of evaluation of the pilot schemes conducted by the Social Welfare Department.**

Support to Carers

47. Some demented persons exhibit behavioural problems, such as wandering, delusion, verbal and physical aggression that can be very disturbing to others, and demands intensive care efforts from the carers. Adequate tangible support such as home help, day care, day and residential respite services and other related services should be available to help carers cope with the demented family member.

48. Training on knowledge and skills of care as well as emotional support provided by the various existing organisations should also be encouraged and supported. **The Working Group recommended that there should be publicity campaigns to promote community recognition to the invaluable contributions of carers.**

Public Education

49. To enhance public education on care and respect for elderly with dementia as well as to facilitate prevention and early identification of the disease, we need to provide adequate and accurate information on the disease. **The Working Group recommended that there should be publicity campaigns through mass media to increase awareness and acceptance towards dementia. The Working Group also recommended that information on dementia and its support network should be available in the form of pamphlets for distribution to the public.** In addition, more targeted educational programmes conducted in groups currently provided by the Departments of Health and Social Welfare, non-government organisations and voluntary agencies such as Alzheimer's Association and the Hong Kong Psychogeriatric Association should be further encouraged and supported.

Staff Training

50. Apart from raising awareness on dementia, increased emphasis on the disease should be included in pre-service and in-service training for front-line welfare and health workers to enhance their knowledge and awareness to recognise the symptoms of dementia for early detection as well as for provision of care for people with dementia. **The Working Group recommended that there should be improved training on dementia for front-line welfare and health workers.**

51. Similarly, medical and health professionals should always be vigilant of the early symptoms and signs of dementia. They should also keep themselves updated with knowledge in managing the disease through continued medical education and other in-service training. **The Working Group recommended that in-service training provided for medical professionals of public sector by the Hospital Authority and the Department of Health should be enhanced.** As for private medical practitioners, their awareness and knowledge on management of the disease can be enhanced through professional colleges and associations.

Research

52. The Working Group recognised that further researches may be required to look into both the care needs of dementia and understanding of the disease. **The Working Group recommended that further researches should be conducted with regard to the prevalence of dementia on the local scene and to acquire foreign experience on updated understanding of the disease.**

Legal Aspects

53. Apart from guardianship and Enduring Power of Attorney, issues on Advance Directives, in particular decisions on medical treatment in the very late stage of dementia, need to be addressed. **The Working Group recommended promotion of Enduring Power of Attorney and guardianship. In the longer term, the concept of Advance Directives, its application in other countries and its implication of application in the context of Hong Kong should be further examined.**

Continued Efforts for Care of Dementia

54. Relevant bureaux and departments should continue to work together to implement these recommendations and provide services as a targeted approach for the demented. **To maintain the momentum, the Working Group recommended that regular progress reports on care of dementia should be submitted to the Elderly Commission.**

Working Group on Dementia
July 1999