DEMENTIA CARE IN NSW

1. BACKGROUND TO PROPOSAL

With the ageing of the population, dementia is now one of the major public health problems of the current century. In addition, caring for a relative with a dementia places demands on the carer that are impossible to meet without a range of health and support services specifically adapted to the needs of dementia. Without adequate resources for early diagnosis, carer support, education and community case management, people with dementia are being placed prematurely into residential aged care facilities adding to the shortage of residential aged care places and hence to hospital access block. In addition, the current resources for managing dementia and delirium in our acute hospitals is placing those patients at serious risk and placing stress on other patients, relatives and hospital staff.

It is incumbent upon Area Health Services to ensure that a full range of services for the diagnosis and management of dementia, including the support of carers, is available. Unfortunately, neither the Australian Government nor the NSW Government has accepted their responsibility for the provision of resources to Area Health Services to meet the needs of people with dementia. Pilot programs in individual Health Areas have been funded but these are sporadic and totally inadequate.

This is not the case in Victoria where the State Government has provided resources for both community assessment and for residential behavioural management to supplement those provided by the Australian Government for residential care and for Aged Care Assessment Teams. In addition, hospitals are being supported to develop special areas and expertise in the management of delirium.

In NSW, the Future Directions program provides a very limited range of resources while the Chronic Disease program does not include dementia.. The Australian Government has also failed to provide resources for the residential care management of people with dementia with major behavioural problems.

2. EPIDEMIOLOGY

- Data form Henderson and Jorm (1), suggest a prevalence of dementia of 2.1% for the age group 65-74 and 12.3% for the age group 75+, making a prevalence rate of 6-7% for the age group 65+. This means that in an Area, like the Hunter, with a total population of about 600,000, there are currently about 4,800 people with dementia, predicted to rise to 5,800 by 2011. These figures may be an underestimate of the need, however, as Jorm and Henderson is based on epidemiological studies carried out in the 1980's, and it is unlikely that many early dementias would have been recorded.

- The 'New South Wales Action Plan on Dementia' (2) estimates that the living situation of people with moderate or severe dementia is:

    - 51% at home
    - 37% in nursing homes
    - 9% in hostels
    - 4% in other institutions

. From the above, we can assume that approximately half of all people with moderate to severe

dementia will be living outside aged care facilities and the number of people with mild to moderate dementia living outside aged care facilities will be approximately equivalent to the estimated prevalence in the community.

Whether living in the community or in residential aged care facilities, people with dementia are accessing, and need to access, the full range of health services across the community-acute care spectrum. Aged Care and hospital services must be resourced adequately to allow people with dementia and their carers to receive appropriate levels of care.

3. ESSENTIAL RESOURCES REQUIRED BY ALL AREA HEALTH SERVICES

3.1. DIAGNOSIS AND ASSSESSMENT

An accurate diagnosis and comprehensive assessment, including physical, functional, psychological and social assessments, is essential to the provision of appropriate services for each person who has dementia as well as for their families and carers. The initial assessment is best carried out by the person's general practitioner (who makes the medical diagnosis and general medical assessment) supported by a Community Dementia Nurse (who carries out the psycho-social, cognitive and functional assessment). The assessment by the Dementia Nurse is ideally carried out in the patient's home so that carers and family can be involved and the home environment can be assessed. Many patients will need referral to a geriatrician while a small number of complex cases will require a multidisciplinary memory disorders clinic, involving a psychogeriatrician and neuro-psychologist.
The team of general practitioner and Dementia Nurse can then continue to case manage the person with dementia and to provide the necessary community supports and respite services.
The minimum level of resources required by all Area Health Services to meet these assessment needs are:
. one community dementia nurse per 5,000 people over age 70
. one social worker per 20,000 people over age 70
. one community geriatrician per 10,000 people over age 70
. one psychogeriatrician per 20,000 people over age 70
. one neuropsychologist per 30,000 people over age 70
These resources will cover services for dementia only and are not meant to cover all psychogeriatric services. There is clearly considerable overlap between the two areas but these resources are over, and above, the psychogeriatric resources required to meet the needs of older people with mental illness.

3.2. CARER SUPPORT

It is important to understand the complex role of carers in maintaining a person with dementia in the community. This acknowledges the carer's distress when coping with the demands of the difficult behaviour, changes in personality, loss of companionship, social isolation, lack of sleep and continual strain on their lives and their psychological, emotional and physical health. Therefore, carers require on-going access to support to be able to carry out their role, which begins with the diagnosis and continues for up to ten to fifteen years. Even after admission to a nursing home, the carer will require support to cope with the guilt and grieving.
Their requirements include:
. information and education about dementia and the services available
. access to further information as needs change
. regular respite care – in-home, day centre and residential
. access to urgent respite

. community support services at home
. strategies to manage challenging behaviour
. counselling to assist with the demands of caring and with the accompanying guilt, grief and loss
. assistance with liaison with GPs and other services
. assistance to plan for the future – power of attorney, guardianship, placement issues
. carer support groups

To meet these needs, we require:

. a HACC system adequately funded to provide services to older people wishing to remain at home
. an increase in CACPs to reduce the waiting list to an acceptable level
. the roll-out of EACH packages throughout all Areas
. additional day centre places which can be most cost-effectively provided in existing aged care or health care facilities. These day care places should include the capacity to manage difficult behaviour.
. a system to provide for respite care for people with dementia, including the provision for urgent respite.

3.3. EDUCATION AND INFORMATION

The provision of a comprehensive range of information and education about dementia and its management is essential for the sufferer, for the carer and family and for all health professionals who care for people with dementia. The last group includes acute care staff in hospitals, community health staff, community support staff and residential and day care staff.

The programs required are:

3.1.1. Information for people in the early stage of dementia

This program has been promoted by the Alzheimers Association as "Living with Memory Loss".

3.1.2. Information and education for carers, families and community support staff, including:

. understanding of dementia
. community support services available
. respite options
. management of difficult behaviours
. legal aspects of dementia
. preparing for the later stages, including residential care and advanced care planning

3.1.3. Education for health professionals

All programs should be available at least annually and geographically accessible.

The resources required to coordinate such a program are:

. one Dementia Education Coordinator for every existing Health Area
. one clerical support position for each Dementia Education Coordinator

3.4. RESIDENTIAL CARE

The range of residential care options required in a community include:
. high care places, for which the Commonwealth Government sets a target of 40 places per 1000 population over age 70, some of which should be dementia-specific
. low care places, for which the Commonwealth Government sets a target of 50 places per 1000 people over age 70, some of which should be dementia-specific
. respite care at both high and low care levels, including both elective and urgent respite.
. transitional care beds for people people waiting for aged care placement
The current deficiencies, with regard to residential care for people with dementia are:
. a lack of respite care options, especially for urgent respite
. the absence of facilities, at either hig or low care level, suitably designed and staffed to care for people with more difficult behaviours such as aggression, disinhibition and severe vocalising.
Each currently existing Health Area requires at least one high care facility and one low care facility suitably designed and provided with supplementary staffing (over and above that available under the RCS system) to allow for the long-term care of people with dementia and the more difficult behaviours.

3.5. CASE MANAGEMENT

Once the diagnosis of dementia has been made, the person and their carers face an illness of up to 10 years duration. Much of this may be faced at home but, even after residential care placement, the carer continues a major physical and emotional involvement. On-going case management of dementia is necessary to cope with the fact that symptoms , behaviours and caring problems may continually change throughout the course of the illness.
The Community Dementia Nurses, requested in 3.1. above, supplemented by Case Managers for Community Options Programs, CACPs and other HACC programs, will meet these case management needs.

3.6. ASSESSMENT AND MANAGEMENT OF DIFFICULT BEHAVIOURS

This is both the most challenging and the most contentious aspect of the care of dementia in the community. For carers and for staff and other residents of residential care facilities, behaviours such as constant calling out, aggression, intrusiveness and inappropriate sexual behaviour, can be the cause of excessive stress to the point where life can be seen as intolerable. Part of this difficult behaviour is related to psychiatric comorbidity, including personality disorders, depression and psychoses. On the other hand, there is a strongly held view by some dementia workers that some of the difficulty in managing this behaviour is due to our attitude towards people with dementia and our inability to understand their communication.
What is clear is that the resources available to assess and manage these people are totally inadequate, both in the community and in aged care facilities. The resources required include the community dementia nurses, geriatricians, psychogeriatricians and neuropshychologists listed in 3.1. above plus:

. one Dementia Specialist Worker (nurse or clinical psychologist with appropriate training and expertise) for the assessment and management of difficult behaviour in the community per 20,000 people over age 70
. one Dementia Specialist Worker (nurse or clinical psychologist with appropriate training and expertise) for the assessment and management of difficult behaviour in residential aged care facilities per 1000 RACF beds
. one in-patient facility in each Health Area of 12-24 beds (depending on the size of the Area) for the short-medium term assessment and management of difficult behaviours
. at least one high care facility and one low care facility suitably designed and provided with supplementary staffing (over and above that available under the RCS system) to allow for the long-term care of people with dementia and the more difficult behaviours.
. one facility in Northern NSW and one in Southern NSW for the long-term management of the small number of very violent people with dementia.

3.7. ACUTE IN-PATIENT CARE OF CONFUSED PATIENTS

People over 65 years of age account for almost 50% of hospital days and up to 30-40% of older people will suffer from delirium during their hospital stay. The consequences of this delirium include prolonged hospital stay, adverse events such as falls injuries and an increased risk of death or nursing home placement. People with dementia or delirium admitted to public hospitals need special care to ensure that their acute medical or surgical needs are met and that they do not suffer an iatrogenic problem or an increased risk of nursing home placement. The precautions that need to be taken for the optimal care of confused patients include:
. the provision of a special area for nursing that allows direct vision of the patients, controlled lighting and freedom from noise.
. some degree of security for patients who are likely to wander
. adequate staffing levels and skills
All major public hospitals need a purpose designed area for the management of confused older patients and trained staff to provide care for these patients.

4. SUMMARY OF MINIMUM REQUIREMENTS FOR ALL AREA HEALTH SERVICES

These resources will cover only services for people with dementia and are over, and above, other community aged care services, such as ACAT, or centre based services, such as day therapy or day hospital..
4.1. Community Dementia Nurses at a rate of one per 5,000 people over age 70
4.2. One Social Worker per 30,000 people over age 70
4.3 Community geriatricians at a rate of one per 10,000 people over age 70
4.4. Psychogeriatricians at a rate of one per 20,000 people over age 70
4.5. Neuropsychologists at a rate of one per 30,000 people over age 70
4.6. One Dementia Education Coordinator and one clerical support position for every existing Area Health Service

4.7. At least one high care facility and one low care facility in each Area Health Service suitably designed and provided with supplementary staffing (over and above that available under the RCS system) to allow for the long-term care of people with dementia and the more difficult behaviours.

4.8. Dementia Specialist Workers (nurse, social worker, psychologist) trained in the assessment and management of difficult behaviour, at the rate of one per 30,000 people over age 70

4.9. Dementia Specialist Workers (nurse, social worker, psychologist) trained in the assessment and management of difficult behaviour, at the rate of one per 2000 RACF beds

4.10. One in-patient facility in each Health Area of 12-24 beds (depending on the size of the Area) for the short-medium term assessment and management of difficult behaviours

4.11. One facility in Northern NSW and one in Southern NSW for the long-term management of the small number of very violent people with dementia.

4.12. All major public hospitals need a purpose designed area for the management of confused older patients and trained staff to provide care for these patients.

5. REFERENCES

1. A.S. Henderson and A.F. Jorm, 1998, *Dementia in Australia*, AGPS, Canberra, p12

2. Office on Ageing, Social Policy Directorate, 1995, Being There, The NSW Government's Action Plan on Dementia 1995-1999, Sydney