

Dementia in New Zealand: improving quality in residential care

A report to the Disability Issues Directorate

Ministry of Health

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Contents

Acknowledgements	2
Executive Summary	4
1 Background	10
1.1 Defining dementia	11
1.2 Prevalence of dementia	11
1.3 Services for people with dementia	12
2 Towards a service development plan for people with dementia	15
2.1 Access to services	15
2.11 Diagnosis	15
2.12 Needs assessment	16
2.13 Service co-ordination	18
2.2 Involving carers, families and communities	19
2.3 Pharmacotherapy	20
2.4 Younger people with dementia	22
2.5 Support for Māori with dementia	23
2.6 Support for Pacific people and other cultural groups	25
3 Models of residential care services	26
3.1 Type of facility	26
3.2 Physical environment	29
3.3 Process of care	30
3.4 Medication and restraint procedures	32
3.5 Management culture	33
3.6 Competence (including training)	36
4 Respite care and day care	39
5 From planning to action	42
Appendix 1 Definitions	45
Appendix 2 Dementia working group	47
Appendix 3 The pathway of dementia	48

Dementia in New Zealand: improving quality in residential care

Executive Summary

For some time, concerns have been expressed by advocates of people with dementia about the safety and quality of care delivered in residential settings. This led the Ministry of Health to commission work to explore these issues and advise the Minister of Health on ways to make improvements. A group representing a wide range of sector professionals and other experts, was brought together for a workshop to identify specific problems and where possible, advise on solutions. Two draft reports were circulated for comment. This report not only reflects the diverse range of opinions expressed by the working group and Ministry of Health staff, but places these in the context of evidence of best practice in dementia care.

The specific issues examined in the report include how to:

- optimise staff training, skills and competencies, and staff:resident ratios
- provide of a safe and quality environment in an appropriately configured unit
- involve family members, residents and carers in the planning and provision of care
- use medication and restraint (chemical as well as physical) appropriately and safely
- ensure access to services, including needs assessment and reassessment
- conduct regular audit of services and enforce compliance
- provide early identification, treatment and community based services, to support people with dementia and their carers

Dementia is defined as a syndrome caused by disease of the brain, which may be the result of a number of different illnesses. It is a progressive failure of most cerebral functions. People affected by dementia suffer social, material and personal losses; they lose self esteem, social skills and personhood, become depressed, and with severe neurological impairment may also develop physical illnesses. How such a decline manifests itself will depend on the social and cultural setting in which the person lives.

There are approximately 38,000 people with dementia living in New Zealand. At least 50 percent with mild dementia live in their own homes, supported by a wide range of community services. About 60-70 percent of people living in residential settings have some form of dementia. There are approximately 35,000 licensed residential care beds in New Zealand. Meeting the needs of people with dementia in both home and residential settings must take into account their different needs at different stages of the illness ie early onset, mild, moderate and severe forms.

Early recognition and prompt diagnosis are essential, not only to distinguish dementia from reversible forms of cognitive impairment, but also to assist families with planning for the future in terms of both care provision and personal arrangements. The quality of the assessment will depend on the clinical as well as social skills of professionals carrying out this work and are of paramount importance in advising about ongoing care needs. A thorough knowledge of dementia as well as of the social and cultural environment in which the person lives will contribute to good care outcomes and protect against abuse. Access to specialist advice to support initial diagnosis and ongoing follow-up is essential.

There is growing evidence of the effectiveness of various therapies and activities for people with dementia. This evidence challenges commonly held beliefs that no therapeutic intervention is of any value. Key to this approach is the recognition of the personhood of people with dementia. Recognising the social and emotional needs of people with dementia, is a critical success factor for good quality care.

Dementia presents a challenge for those with the condition as well as for their carers (whānau, family and friends). Carers play a vital role in providing direct care for people with dementia living at home and their absence or stress is a major predictor of early admission to residential care. To move towards a genuinely communicative, interpersonal model of care will require an active partnership between family carers and professionals.

It has been said that people with dementia living in residential care are unlikely to complain and unlikely to be heard if they do. This may partly reflect the nature of their illness, but is also a reflection of social attitudes. Society fails to tolerate people with dementia well. There is still the belief that people with dementia are unaware of the world around them and are unable to benefit from interaction with others. People with dementia however may communicate through a range of behaviours, yet the response of professionals is often to see this as a symptom to be suppressed.

Some providers of residential services are delivering good quality services while others are not. There is a need to clarify success factors and try to replicate these nationally.

Many providers of residential care are attempting to manage challenging behaviours in an environment not suited to this type of care. Appropriately trained staff to ameliorate distress and minimise behavioural problems would be useful. Alternatively, reassessment by specialists and transfer to a specialised facility better suited to the needs of the person with dementia may be more appropriate.

Facilities also face tensions between providing a custodial ‘institutional’ model of care with a focus on risk minimisation versus a ‘person-centred’ model that allows expression of normal risk taking behaviour. It is essential for providers to continually be aware of the needs of people with dementia, how these change over time, and what strategies can be implemented to achieve them. Involving whānau, families and carers in safe and acceptable practice of care will to some extent help with finding solutions to sometimes complex needs.

Quality of life for people with dementia has been defined as:

- ◆ competent cognitive functioning
- ◆ the ability to engage in meaningful time use and social behaviour
- ◆ the ability to independently perform activities of daily living
- ◆ the maintenance of a positive emotional state.

Components of good quality care for people with dementia include:

- ◆ good assessment and diagnostic facilities
- ◆ well trained, highly skilled staff, well supported by management
- ◆ the promotion of individual rights and choice
- ◆ the maintenance of relationships with carers, whānau, family, and friends
- ◆ flexible care routines and individualised care plans

- ◆ non-use of physical and chemical restraints
- ◆ appropriate living conditions, such as a small size facility providing a homely environment.

Meeting health and safety standards and implementing effective quality assurance systems are two foundations of good quality care in residential settings. Good management practices, such as leadership, recognition of staff needs and achievements and availability of support services for staff will also improve the quality of care. Ensuring that medical (including specialist support) is available for assessment (and reassessment) is essential in meeting the changing needs of people with dementia. Facilities that care for people with dementia need the highest levels of staffing skills, sustained by continuous training, where staff receive support, encouragement and recognition but can also move to easier work if they no longer have the passion required.

A major problem is that blame for poor quality is often attributed to resource limitations. However, models of good practice that do exist serve to illustrate what can be achieved within available resources. Quality does not need to cost more, but an initial investment must be made in order to bring some services up to standard. At the same time this does not deny that resources are often stretched to the limit in many areas of health and social services in New Zealand.

Staffing arrangements (numbers and skill mix) in a residential facility should be suited to the needs of residents and be updated in line with changing needs and circumstances. Staffing numbers and skill mix will depend on resident numbers, their dependency levels and needs, as set out in care plans, the size and layout of the facility, the type of care provided and time of the day. Multidisciplinary assessment (including specialist assessment) and care planning to meet changing needs must also be regularly reviewed to ensure the safety of residents in care. Analyses of appropriate staff ratios and skill mix tailored to meeting the needs of people with dementia is lacking for residential care settings in New Zealand.

Such information is particularly important for the Māori population, which is undergoing rapid ageing. An important dimension of Māori health and well-being is whānau- ora, the health and well-being of the immediate family. Older Māori stand to benefit from their whānau health services which support Māori families to achieve their maximum health and well-being. Equally important is cultural awareness when providing health services for Māori. By Māori, for Māori dementia services are one way of achieving this; however there is still a need a need for 'mainstream' services to be culturally safe.

Residential services cannot be considered in isolation from other settings of care for all ethnic groups. Respite care is the term used to describe an arrangement whereby older people normally cared for at home are placed temporarily in alternative accommodation to give their usual carer a break. The facility in which the respite service is available should also be appropriately designed to ensure the safety and comfort of residents. Day care services offer people with dementia carefully supervised social, recreational and health activities in a comfortable group setting which can help create a greatly improved quality of life. Some programmes offer transport to and from the centre. Both respite and day care should be locally based. Small scale centres in domestic settings with empathetic, trained staff appear best placed to provide good quality respite and day care for people with dementia.

Home care (such as help with personal care, household tasks, social problems and treatments) includes a wide range of health and social services that could assist a person with dementia to live independently at home. In New Zealand, home care services vary in availability and quality in different part of the country. Team approaches have been used effectively to achieve good outcomes for people with dementia living at home. There is however a lack of training, supervision and standards for careworkers supporting people with dementia and their carers at home.

Recommendations requiring urgent action:

It is recommended that the Ministry of Health:

Training

- 1 Works with CSSITO, Alzheimer's New Zealand and sector groups to ensure that training programmes in dementia residential and community care are nationally consistent, accessible, affordable and reflect the needs of people with dementia.
- 2 Liaises with professional organisations to ensure that training in assessment and the early recognition of dementia is included as part of continuing educational programmes.
- 3 Liaises with CSSITO to ensure that unit standards prescribed in contracts are regularly updated, and that providers are regularly monitored with regard to their contractual obligations for training.

Staffing

- 4 Requests advice regarding, and an in-depth analysis of, appropriate staffing levels, skill mix and accountabilities, for residential dementia services in New Zealand, from the Expert Advisory Panel currently working on Nursing specifications for Residential Aged Care. The Ministry will need to assess the policy and fiscal implications of this advice.

Use of medication and restraint

- 5 Requires residential facilities to meet the New Zealand Standard 814:2001. *Restraint Minimisation and Safe Practice*.
- 6 Requires residential facilities to inform carers if restraint is to be used; ensure carers are involved in the consent to restrain process, ensure residents have legal protection through the 3PR Act; and residents have access to independent advocacy services.
- 7 Audit restraint procedures and processes for remedial action when standards are not being met.

Recommendations requiring action over the next 12 months

It is recommended that the Ministry of Health:

Involvement of whānau, families and carers in planning

- 8 Through dementia service providers, involve whānau, families and carers in care (ie provide information, assist with support and placement decisions, include in care planning process, including reassessment and evaluation)
- 9 Develops an information brochure for subsidised residents and their whānau and families entering residential care, that outlines what they should expect from residential services.

Support for Māori with dementia

- 10 Ensure through contractual obligations that the care and treatment of Māori with dementia is responsive to their needs and cultural expectations, through contractual obligations. This includes consideration of culturally appropriate services in the community and residential settings, the role of whānau, special issues around carer support and the risk of isolation if placements are made in culturally inappropriate settings.

Support for Pacific people with dementia and other cultural groups

- 11 Ensure that providers of care for people with dementia from different cultural groups take into account the risk of isolation, the importance of culturally appropriate services and special issues that arise in providing carers support, through contractual obligations.

Access to services (including needs assessment and reassessment)

- 12 Develops, as part of the Ministry's current needs assessment project, an evidence based guideline (and training) for the assessment and reassessment of people with dementia.
- 13 Implements a review and auditing process for reassessments, through contracts with assessment services.

Audit of services and enforcement of compliance

- 14 In association with the sector, proceeds with the inclusion of new nationally consistent service specifications into contracts.
- 15 Progresses the inclusion of new provisions for holding providers accountable to their contractual requirements through strengthened audit clauses in contracts.
- 16 Develops a national complaints procedure to assist with auditing services and monitors the response to complaints.
- 17 Explores ways of improving performance, for example, publicly recognising improvements in quality through health and disability awards.

Recommendations requiring action over the next 12-24 months

It is recommended that the Ministry of Health:

Dementia specific standards

- 18 In association with Standards New Zealand, develops dementia specific residential standards which can be brought under the umbrella of the new Health and Disability Services (Safety) Act 2001.

Respite Care, Day Care and Home Care

- 19 Develops a policy on respite, day care and home care services for people with dementia and their carers, to guide the provision of these services.
- 20 In association with Standards New Zealand develops standards for respite, day care and home care services for people with dementia.

Information and education

- 21 Assesses the needs of consumers for information about dementia, and evaluates access to existing dementia educational resources.

Environmental design

22 Develops a policy based on best practice in the design of dementia, facilities, ie small scale units with features that help to orientate, maximise independence and dignity, and promote functional abilities.

Pharmacotherapy for dementia

23 (Pharmac) keeps under review, criteria for funding pharmaceuticals suitable for the treatment of dementia.

Younger people with dementia

24 Ensures that providers caring for younger people with dementia are able to fully meet their special needs with appropriate care packages. This will be part of a wider project which will examine age appropriate residential care.

Population data on dementia

25 Explores ways of collecting population-based data on dementia in New Zealand in order to better assess needs and plan more effectively for future service provision.

Research

26 Support NZ research proposals on dementia including operational needs assessment and evaluation of existing services.

1 Background

Advocates for people with dementia have for some time been raising concerns about the safety and quality of care¹ in residential services. The Ministry of Health is committed to improving the quality of services for people with dementia and has already begun addressing these concerns through a range of initiatives including:

- the Health of Older People Strategy.² This proposes that by 1 July 2002 there will be a service development plan for people with dementia. This is to include the development of dementia specific standards for residential care services and the strengthening of audit processes relating to these services.
- strengthening the capability of the Ministry of Health to hold providers accountable for both their statutory and contractual obligations through improved auditing provisions. Currently providers are audited both by the Ministry's Licensing Section as well as by the Disability Issues Directorate (DID). Licensing inspectors measure compliance with regulatory requirements and quality auditors measure compliance with contractual requirements of the DID. The Ministry plans to combine these dual audit processes so as to rationalise the number of audit events which providers are subjected to.
- the passing of the Health and Disability Service (Safety) Act. This will introduce a new certification regime for providers, from October 2002, replacing the old licensing requirements with the new Health and Disability Sector Standards.³ These were developed in partnership with the sector.
- restraint minimisation and safe practice standards.⁴ (covering all forms of restraint). These have been written to ensure residents in care are relatively safe from harm, from both themselves and others.
- the development of new service specifications for residential services. These include specifications for specialist dementia services, developed in consultation with the aged-care provider sector. Once a new contracting mechanism has been agreed with the sector, these new service specifications will be implemented. The Ministry plans to move towards nationally consistent service specifications and standards.

Against this background, a working group was established in August 2001 to advise the Disability Issues Directorate of the Ministry of Health on ways to improve the safety and quality of care for people with dementia in residential, respite and daycare services.

The group was made up of service providers, health professionals and other representatives from the aged care sector. Members are listed in the Appendix 1 of this report. The group met on 19 September 2001 to consider:

¹ See appendix 1 for definitions of terms

² Ministry of Health. September 2001. Health of older people strategy. Health sector action to 2010 to support positive ageing. Draft for consultation.

³ Ministry of Health, Standards New Zealand. 2001. Health and disability sector standards. NZS 8134:2001.

⁴ Ministry of Health, Standards New Zealand. 2001. Restraint minimisation and safe practice. NZS 8141:2001.

- optimal staff training, skills and competencies, and appropriate staff:resident ratios for residential dementia care facilities
- provision of a safe and high quality environment in appropriately configured residential dementia care units
- involvement of family members, carers and residents themselves in the planning and provision of residents' care
- use of medication and restraint (chemical as well as physical)
- access to services, including needs assessment and reassessment
- audit of services and enforcement of compliance.
- the need to improve early identification, treatment and community based services as a priority.

The group identified a wide range of issues in relation to the above dimensions of care⁵ as well as realistic strategies for addressing them. This report examines these issues in relation to best practice, based on available evidence, and identifies options for improvement in residential services for people with dementia.

1.1 Defining dementia

The World Health Organisation⁶ defines dementia as

... a syndrome due to disease of the brain, usually of a chronic progressive nature in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied and occasionally preceded by deterioration in emotional control, social behaviour or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease and in other conditions primarily or secondarily affecting the brain.

The most common form of dementia is Alzheimer's disease, (50-70 percent) followed by dementia of the Lewy Body type (20 percent) then vascular dementia (10-20 percent). Other diseases that may be associated with dementia include Parkinson's disease, alcohol related dementia, AIDS related dementia, dementia following certain types of head injury, multiple sclerosis, brain tumours, and infections of the brain.

1.2 Prevalence of dementia

Planning for the needs of people with dementia requires baseline information about the number of people affected, their present and likely future circumstances, what health needs they have, and how effective different service options are in meeting these needs.

Dementia predominantly affects people aged over 65 years and becomes more common with advancing age. There is wide variation in prevalence rates reported by different studies. Some of this variation reflects different levels of impairment, some

⁵ This included the need to recognise that dementia is a major health (rather than disability) issue.

⁶ WHO, 1992. ICD-10, International statistical classification of diseases and related health problems, tenth revision, Geneva.

levels being so mild that they do not markedly interfere with normal daily functioning but nevertheless are detected by the cognitive tests used in some surveys. There is less disagreement about severe forms of dementia. Low cognitive scores can also be caused by poor education, impaired physical health, other psychiatric illness, deafness, language difficulties or other factors affecting performance on tests.⁷ There has been only one published study on the prevalence of dementia in New Zealand,⁸ which has shown prevalence rates similar to other countries.

Estimates of the prevalence of dementia range from 1 percent for those aged 60-64 years, rising at a rate of about 1 to 2 percent per year of age, to around 30 percent of those aged 85 years and older. The overall prevalence among older people (65+) is therefore typically around 8 percent, ie there are about 38,000 people with dementia in New Zealand at present.

Estimates from the United States (1995 data) suggest that approximately 7 percent of all deaths are attributable to Alzheimer's disease, (although not necessarily reported as such on death certificates) placing it close to stroke as the fourth leading cause of death.⁹

It is important to remember that people with dementia are not the only ones affected by this syndrome - families, friends and neighbours are also affected, and their needs must also be included in service planning.

1.3 Services for people with dementia

There are a wide range of services for people with dementia and their carers in New Zealand, ranging from primary medical care, social work, counselling, day care and other domiciliary support services, to residential and long term specialised hospital services. These services are provided by a diverse range of providers with varied funding arrangements, including public sector organisations, for-profit private companies, not-for-profit religious and welfare organisations and advocacy groups such as the Alzheimer's Society. However, access to these services often varies from region to region. Availability of information for consumers and their families about dementia and dementia care services, and support services for carers and families (including respite care) is also inconsistent around New Zealand, yet these services are key to improving the quality of care for people with dementia, whether they live in their own homes or in residential facilities. People with dementia often require more services in the early stages of the syndrome, when there are significant difficulties with activities of daily living.

In New Zealand, the majority of people (at least 50 percent¹⁰) with mild dementia (ie minimal functional and cognitive limitations) are cared for in the community, some

⁷ Brayne C, Galloway P. 1990. The association of education and socio-economic status with the mini-mental state examination and the clinical diagnosis of dementia in elderly people. *Age and Ageing* 19:91-96.

⁸ Campbell AJ, McCosh LM, Reinken J et al. 1983. Dementia in old age and the need for services. *Age and Ageing* 12:11-16.

⁹ Ewbank DC. 1999. Deaths attributable to Alzheimer's disease in the United States. *Am J Public Health* 89:90-92.

¹⁰ Butler R, Fonseka S, Barklay L et al. 1998. The mental health of nursing home residents; a New Zealand study. *Ageing Mental Health* 2(1):49-52.

with good support systems, although this is by no means uniform across the country. Care in the community is frequently provided predominantly by one family member.¹¹ The ability of people with dementia to remain in their own homes is determined by a number of different factors including:

- availability of family/other carer support
- availability and accessibility of relevant community services
- extent of disability and functional impairment
- behavioural complications
- psychotic symptoms.

The stress associated with caring for a person with dementia can have a considerable negative impact on carers. Carers taking on this role need information about dementia and the support services available, including day care, respite care, and social work services, and how to locate and evaluate residential care options.

The proportion of people with dementia resident in long-term care varies by age and dependency levels. In New Zealand there are 530 licensed rest homes and 235 hospitals for aged care. Residential care includes stage 2 rest homes, stage 3 specialist dementia units, continuing care hospitals and high dependency, psychogeriatric hospitals.¹² Residential facilities are generally privately owned. Prospective residents are income and asset tested and government subsidies are paid if the resident's income and assets are below the threshold. Currently, the Ministry of Health contracts approximately 100 providers of specialist dementia services.¹³ The number of licensed residential aged care bed numbers for rest homes and hospitals are provided in the table below.

Table 1: Licensed Residential Aged Care Bed Numbers

Type	Premises	Bed Numbers	Total rest home beds	Total geriatric hospital beds
1. Rest home	526	15,788	15,788	
2. Rest home and hospital wing	232	15,845	9,097	6,748
3. Hospitals offering geriatric care	72	3,336		3,336
Total	830	34,969	24,885	10,084

Note: Dementia level care may be provided in rows 1 and 2. Hospital care may be provided in rows 2 and 3. High dependency psychogeriatric continuing hospital care may be provided in rows 2 or 3.

Planning of services for people with dementia must take into account the needs of all groups: those with early onset, mild, moderate or severe forms of dementia; people living in rural areas, and people who are socially isolated despite living in the community. The fact that the onset of dementia is difficult to diagnose, and that disease usually progresses slowly over a long period, must also be taken into account. Support services need to be tailored to meet the specific needs of individuals.

¹¹ Opie A. 1992. *There's nobody there*. Auckland. Oxford University Press.

¹² Ministry of Health 2001, personal communication

¹³ Ministry of Health 2001, personal communication

In summary, while many of the changing needs of people with dementia and their carers could be met by primary and community services, people with severe loss of cognition leading to major functional impairment, or those who develop behavioural or psychological problems, will require specialised services. It is often the behavioural manifestations that precipitate residential placement, largely because of carer stress. Multidisciplinary teamwork and effective communication between families and professionals, between primary and secondary services, and between specialities, is the key to high quality care for people with dementia and their families and other carers.

2 Towards a service development plan for people with dementia

In developing a service plan for people with dementia, it is important to recognise the complexity and range of services required. People with dementia are a heterogeneous group which means there is no single solution to the challenges they face. The effects of dementia are experienced differently by different people. These differences must be taken into account when planning services to meet the needs of people with dementia and their carers. One size does not fit all.

2.1 Access to services

Access to dementia services includes access to a pathway of care, from early recognition at the primary level (medical, education, home-based and community support services) to residential and hospital-based care at the secondary level.

In 1997 the National Health Committee and ADARDS developed guidelines for the support and management of people with dementia.¹⁴ These guidelines highlight service gaps and suggest ways in which these might be addressed. The NHC report recommended that *every NZ citizen should have access when necessary to expert specialist advice in dementia from a publicly funded service.*

2.11 Diagnosis

It is often assumed that the majority of people with dementia are known to services. However, one survey¹⁵ in the UK found that of those people living with dementia in the community, only about half were known to services. No one service or agency provides the key to identifying people with dementia. General practice is possibly the most important source (on average, older New Zealanders visit their GP approximately four times a year) although it is not known to what extent general practitioners recognise dementia in their patients. Early diagnosis is important, to distinguish dementia from reversible causes of cognitive dysfunction. Some GPs may not be comfortable dealing with social, cognitive and behavioural problems or they may be reluctant to label someone with the diagnosis of dementia because of negative attitudes and stigma associated with this condition. Others may not have had the training to detect early signs of dementia.

Māori and minority ethnic groups may be particularly disadvantaged because of barriers preventing access to primary health care, such as cost and cultural insensitivity of some services.

Early recognition of cognitive loss allows for better planning in terms of both care provision and personal arrangements. However, health professionals need to be aware

¹⁴ National Health Committee, ADARDS. 1997. Guidelines for the support and management of people with dementia. Wellington. New Zealand.

¹⁵ In *Dementia: challenges and new Directions*. 1997. Research Highlights. Edited by Susan Hunter.

of the stigma associated with a diagnosis of dementia and the impact this can have on a person's self-identity.¹⁶ GPs can assist by linking individuals to specific community based care, financial and legal services. Training in early detection of dementia should be provided to GPs, nurses and health care workers employed in primary care settings, to enable them to facilitate access to effective care and support services. Regular public information campaigns designed to raise awareness of dementia among the general public would support general practitioner competence/effectiveness and facilitate access to health care and social support services.

A mechanism that has been developed overseas to assist with the diagnosis of dementia, is the memory assessment centre. These centres are staffed by an appropriate mix of professionals and are particularly useful in assisting people who may be unnecessarily concerned that they have dementia, as well as coordinating treatment for people with reversible causes of cognitive dysfunction and dementia. The centre brings together a range of providers with expertise in this area and also functions as a resource centre for dementia.

Although appropriately trained GPs are able to detect early signs of dementia and provide appropriate referral, they often face difficulties finding available support services in the local community for the people they see. Improving the availability of these services in all communities would build confidence in the diagnosis and management of dementia at the primary level.

Changes required for quality improvement

- ◆ Training in the early recognition of dementia for all primary care providers, to advise people of their condition at the earliest time, and provide information, modify risk factors, identify treatable problems, address carer issues and future planning. A memory assessment centre, training tools such as resource directories and flow charts could also assist with these tasks.
- ◆ Regular links need to be maintained with people with dementia after diagnosis.
- ◆ Public awareness campaign aimed at reducing the stigma presently associated with a diagnosis of dementia.
- ◆ Reduction of barriers to access to primary health care for Māori and disadvantaged groups
- ◆ Support (education and home services) for whānau who care for people with dementia.
- ◆ Internet information on dementia (and other sources) should be available for people with early dementia as well as for families, whānau and other carers.

2.12 Needs assessment services

Assessment services are the principle gatekeeper for accessing some primary and almost all secondary level services. Over recent years there has been growing dissatisfaction about the quality of needs assessment services in New Zealand. Concern has been expressed that the model of needs assessment (ie the separation of needs assessment from service provision) has major limitations, particularly for

¹⁶ Burgener S, Dickenson-Putnam J. 1999. Assessing patients in the early stages of irreversible dementia: the relevance of patient perspectives. *Journal of Gerontological Nursing* 25(2), 33-41.

dementia.¹⁷ There is also concern that the assessment tools in use (eg the support needs assessment forms) have not been validated. The Ministry of Health is currently undertaking evaluation of these services.

It is essential that providers of assessment services are well trained in and have a good understanding of dementia and its effects on people and their carers. They also require good nursing and/or social assessment skills and a good knowledge of the complexity of memory impairment to enable appropriate care decisions to be made. The quality of the assessment process is crucial for ensuring that people access appropriate services matched to their particular needs. For example, need for care is not solely determined by cognitive impairment but more by functional capacity and social support availability. In the majority of cases, cognitive impairment is a good proxy for functional level, but not in all cases. Assessment services must ensure that there are safe and independent opportunities for people with dementia and their carers to provide feedback on the quality of these assessments and if necessary to have their assessments reviewed.

Planning services for people with dementia requires a broad understanding of needs including different types and levels of need. Dementia is often described in terms of a number of stages. This is useful to gain insight into the nature, progression and impact of dementia. It is important to note however, that a person with dementia may not necessarily move sequentially from one stage to the next. As the disease progresses, the level of disability increases, the demand on carers increases and the demand for social and medical support increases. Stages may be classified as:

- early difficulties
- the emergence of significant difficulties in daily living
- reduced capacity for independence
- incapacity and a high dependence on care
- terminal phase

Planning to strengthen and expand services for people with dementia, their carers, whānau, and families, needs to consider the continuum of care represented by the above stages. The objective of planning for services is to achieve a more intensive, comprehensive and co-ordinated approach to service delivery.

A very important component of needs assessment and one which is often overlooked, is the burden placed on carers. There can be rewards as well as burdens from caring, but it is the burdens for which services must plan. Support for carers who wish to continue is essential. But so too is the recognition that some relationships cannot sustain trials of caring. Over time the burden of caring can become too great even for the most committed carer, with many dementia sufferers ultimately needing professional provision of 24 hour care. This should not be viewed as a failure by the carer or family, since it is often unavoidable.

Access to comprehensive home support services for carers of people with dementia could ease their stress to some extent. There is considerable variation in the level of these services around the country yet they are essential in allowing people with

¹⁷ National Health Committee 2000. www.nhc.govt.nz

dementia to continue living in their own homes for as long as possible. There is no doubt that for Māori, community care or home care is more culturally acceptable than residential care.

Changes required for quality improvement

- ◆ Training of health professionals in the specialised area of assessing needs of people with dementia, to ensure access to appropriate and timely services. Assessment of these specialised needs should not be carried out by 'generic' assessors through the needs assessment service co-ordination service.
- ◆ Development of appropriate services in areas where gaps exist. Specialist resources available in psychogeriatric teams must be utilised in assessment of people with difficult problems.
- ◆ An independent complaints system for needs assessment services, responsive to people with dementia and their carers. An appropriate corrective process that responds to complaints must be in place. It is a necessary component of this.

2.13 Service co-ordination

People with dementia and their carers not only need ready access to appropriate services, but effective coordination of their care. There is currently fragmentation of care for people with dementia in New Zealand, particularly when people are moved to another geographical area with a different service co-ordinator. One way to achieve improvements in service co-ordination is through a case management model. In this model, the person with dementia and their carer play a major role in developing a care plan that suits their preferences and circumstances, often assisted by a case manager, who may or may not also be involved with their needs assessment.

Carers currently provide the majority of care to people with dementia living at home. They would like greater acknowledgement of their contribution to the care process and to be given access to information and support. They also want major input into the decision to use respite care services or to move to residential care, and continued involvement in care decisions, after the person with dementia has been placed in a residential facility.

Changes required for quality improvement

- ◆ Better co-ordination of services to ensure greater responsiveness to the needs of people with dementia, their carers and their families. These services include early diagnosis, advice, and support, at the primary level and referred specialist services (with continued advice and support) for people with cognitive difficulties to enable them to access appropriate care at the secondary level. People with dementia need more support in early and moderate stages than in advanced states. Assessment and diagnosis needs to be done early.
- ◆ Consideration of a case management model, including a Māori case management workforce to improve service co-ordination.
- ◆ People with dementia and carers should have their voices heard regarding placement decisions and service delivery. Carers should be comfortable with the environment when visiting. It should be accessible to them by their current means of transport and they should have input into daily care.

- ◆ Consumer information about dementia and availability of services needs to be regularly updated and made freely available to assist people with dementia and their carers to access appropriate services.
- ◆ Public information campaigns designed to raise awareness, reduce stigma and improve understanding of dementia. Such campaigns should clearly indicate sources of further information and will require repetition at regular intervals.

2.2 Involving carers, whānau, families and communities

Dementia presents a challenge for those with the condition and those caring for them. The ability to manage dementia and maximise quality of life can be enhanced if the appropriate information and support is available to carers, families and the community at large. Carers play a vital role in providing direct care for people with dementia in the community and their absence or stress is a major predictor of early admission to residential care. Carers who are required to relinquish wage earning positions in order to become a carer, e.g a daughter to care for a parent, also face financial hardships, which adds to their stress.

Up to 50 percent of carers experience significant anxiety and depressive symptoms during the course of their caregiving.¹⁸ However, despite this, many carers also report a sense of satisfaction with their role and a sense of accomplishment in keeping their relatives at home. A programme of support for carers, assisting them with management of behavioural problems and intermittent illnesses, and facilitating referral to appropriate services when necessary (such as respite and day care) has been shown to delay admission of people with dementia to residential care.¹⁹

A major contributor to carer stress is behavioural disturbance. Carers and families could be supported through group based educational programmes with other carers and service providers. These support programmes should be offered in the community as well as in residential care settings. They offer carers an opportunity for socialising, learning how to manage behaviours, when to visit and how to get the most out of visiting relatives/others in residential care. In addition, professional assistance with behavioural support and other practical care issues discussed are of great benefit to carers.

High quality, accurate, up-to-date information across a range of topics, from the availability of services in local areas to practical information about the progression of the illness, is crucial to support good quality care. Information can empower carers, allowing then a sense of ownership of and involvement in the care process, which helps to validate their role.

Nurses, psychogeriatricians, occupational therapists, diversional therapists, physiotherapists, speech language therapists, social workers and Māori community health workers are some of the professionals that have an important contribution to make to the care of people with dementia in the community. They focus on the

¹⁸ Schultz R, O'Brien AT, Brookwala J et al. 1995. Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates and causes. *Gerontologist*. 35:771-9.

¹⁹ Mittleman MS, Ferris SH, Shulman E, et al. 1996. A family intervention to delay nursing home placement of patients with Alzheimer's disease. A randomised controlled trial. *JAMA* 276:1725-31.

treatment of the whole person and aim to restore, maintain or slow decline in the person with dementia's functional capacity.

There needs to be a high level of co-ordination between the family carers and professional providers of services in the community in order to maintain overall good quality care. An ideal care plan is one which respects the competency of the carer and minimises professional involvement, while at the same time maximising the effectiveness of services and enhancing the overall quality of life of the person with dementia.

Changes required for quality improvement

- ◆ Service providers must acknowledge the important role of carers in dementia care and be prepared to work with them and families on an ongoing basis. People with dementia and their whānau and families need information about the disease and how to cope with its manifestations. This includes learning to communicate and interact with the person with dementia.
- ◆ Family carers must have input into the writing of the care plan for people with dementia, in community as well as residential care settings.
- ◆ Professionals need to evaluate a carer's coping strategies and encourage carers to care for themselves, using health promotion and stress reduction strategies. Carers may need help to gain support for themselves from appropriate family members and friends. Use of community services for dementia care needs to be encouraged and services developed where there are currently gaps, such as services for Māori
- ◆ Carers should be encouraged to use as well as to seek advice and support from appropriate community services for people with dementia (eg day care, respite care), and not see such requests for advice or assistance as 'failure'.

2.3 Pharmacotherapy

While a number of cognitive enhancing drugs have recently become available for the management of dementia, adaptation of the physical and social environment, behaviour modification, education and support for carers is still the mainstay of therapy.^{20,21} Neuroleptic agents (such as risperidone) appear moderately effective in controlling behaviours.^{22,23} No medication will control wandering.

Acetylcholine deficits are the most prominent chemical disturbance in people with Alzheimer's disease and are thought to contribute to the deterioration in memory and other cognitive functions. Acetylcholine is a neuronal transmitter. It is metabolised by the enzyme acetylcholinesterase (AChE). Several pharmacological approaches have been used to correct acetylcholine deficits including:

²⁰ Duijnste MSH. 1994. Relatives of persons suffering from dementia: differences in the burden. *Ageing and Society*. 14:499-519.

²¹ Kitwood TM. 1989. Brain, mind and dementia. With particular reference to Alzheimer's disease. *Ageing and Society*. 9:9-15.

²² Schneider LS, Pollock VE, Lyness SA. 1990. A meta-analysis of controlled trials of neuroleptic treatment in the control of dementia. *J Am Geriatr Soc* 38:553-63.

²³ Katz IR, Jeste DV, Mintzer JE et al. 1999. Comparison of risperidone and placebo for psychosis and behavioural disturbances associated with dementia.; a randomised double blind trial. *J Clin Psychiatry*. 60(2):107-15.

- increasing the synthesis of acetylcholine
- activation of nicotinic acetylcholine receptors
- inhibition of acetylcholinesterase. (AChE)

Of these strategies, the inhibition of AChE is currently the most successful treatment for Alzheimer's disease.

Three AChE drugs are currently available: donepezil, rivastigmine and galantamine. By inhibiting the action of AChE, they raise the concentration of acetylcholine at sites of neurotransmission. Galantamine also enhances the action of acetylcholine on nicotinic receptors.

At the beginning of treatment, cognition for the average person with Alzheimer's disease increases from its immediate pre-treatment level. However, as the disease progresses, the amount of acetylcholine being produced in the brain decreases again and the amount available for neurotransmission will eventually fall to pre-treatment levels. Accordingly, cognitive function will again decline, and in time, when the disease process is more severely advanced, the drug is likely to have little significant clinical effect. For the person with dementia, treatment with these drugs thus temporarily postpones the onset of more severe disability without affecting the eventual outcome of the process of cognitive decline.

Not all people with dementia (and not all types of dementia), benefit from an AChE inhibitor. Those who do not show an improvement in the first few months, are unlikely to show later benefit. Evidence to date shows that responders may gain up to one year of improved function on average.^{24,25} Long term studies still need to be carried out.

Once dementia has become severe, (ie Mini Mental State Examination score below 10) clinical effectiveness of these drugs has not been demonstrated.

A systematic review of published literature^{26,27} on the three drugs has shown some benefit on global outcome measures. However, not everyone treated appears to benefit and no analysis has been able to identify who will benefit before treatment is commenced. Yet many people with Alzheimer's disease and carers report functional benefits and improvement in behavioural symptoms such as agitation and aggression, as well as in motivation, concentration, control and independence. This is a substantial benefit as it reduces some of the impact on carers. Adverse effects of all three drugs include nausea, vomiting, diarrhoea and abdominal pain. These effects are reversible on stopping treatment.

²⁴ Cummings JL. 2000. Cholinesterase inhibitors: a new class of psychotropic compounds. *Am J Psychiatry*. 157:1-15.

²⁵ Mayeux R, Sano M. 1999. Treatment of Alzheimer's disease. *N Eng J Med*. 341:1670-1679.

²⁶ National institute for Clinical Excellence. 2001. *Guidance on the use of donepezil, rivastigmine and galantamine for the treatment of Alzheimer's disease*. Technology appraisal number guidance number 19. January 2001. London, England.

²⁷ Lovestone S, Graham N, Howard R. 1997. Guidelines on the drug treatments for Alzheimer's disease. *Lancet* 350:232-3.

From a health economics perspective, the main benefit of these drugs is temporary improvement in cognitive function (for some people with mild to moderate dementia) which potentially can delay admission to residential care, reduce the use of respite services and produce savings in use of other health services. Cost savings are not easily measured from existing trial data. The current lack of subsidisation of these drugs in New Zealand results in inequity of access for economically disadvantaged groups.

Changes required for quality improvement

- ◆ Discussions between Pharmac and relevant stakeholders to measure the viability of funding donepezil, rivastigmine and galantamine for the management of some people with Alzheimer's disease, within the current funding framework, should be facilitated.
- ◆ If these drugs can be subsidised they should be administered to people with dementia under the supervision of specialist psychogeriatricians, and general practitioners working within multidisciplinary dementia teams, using relevant clinical guidelines.
- ◆ Indications for the use of these drugs and costs associated with their prescription should be made transparent to people with dementia, their families and carers to assist in their decision making regarding treatment options.

2.4 Younger people with dementia

Younger people with dementia do not fit easily into the services designed for their older counterparts. It may sometimes be that carers have to choose from facilities or services established for older age groups.

Younger people with dementia may react differently to older people. They tend to be more physically fit and active and tend to have more responsibilities in terms of employment and families. There may be delays in diagnosis, sometimes related to general practitioners having little experience with early onset dementia. Public awareness of early onset dementia is also low, leading to potentially more stigma being attached to the condition in younger people. Younger people with dementia have service needs which are distinct from their older counterparts. They require different care solutions because of the emotional and psychological phase of life their age represents. Care packages must reflect all the needs of a 40-60 year old person and that of their significant others.

There are a number of diseases associated with dementia that may affect younger people, the commonest being Alzheimer's disease, followed by multi-infarct dementia and multiple sclerosis. Others include Parkinson's disease, AIDS, Huntington's disease, Creutzfeldt-Jacob disease, Down's syndrome and alcoholism. Early diagnosis of dementia is very important, to distinguish true dementia from reversible causes of cognitive impairment. Diagnosis may be difficult because symptoms may be confused with other problems, such as depression or migraine.

Younger people with dementia will need to retire early from work while carers may also have to give up employment in order to care for them, leading to a double loss of income at a critical stage in family life. The diagnosis will come as a shock to the family with considerable need for counselling and information. People with dementia

in the early stage will be partially aware of their disability and prognosis, and may become very depressed and anxious. Genetic implications associated with some of the causes of early onset dementia may also affect the ability of families to cope.

There may also be heightened safety issues with younger people as they are likely to be physically fitter and more active than older people. This can cause huge strains on families. Personal relationships and friendships may deteriorate. There may be much less tolerance for the same challenging behaviour in younger people than in older people. Legal and financial affairs may have to be dealt with sooner given that younger people may have a more rapid deterioration in functioning.

The best way of meeting the needs of younger people with dementia is through community services (until placement in residential care becomes unavoidable). While this is also desirable for older people with dementia, the special needs of younger people should be fully recognised in the delivery of services, with special emphasis on family counselling, emotional support, clinical management and innovative day and respite care planning.

Changes required for quality improvement

- ◆ The special needs of younger people with dementia must be given particular attention. This must involve appropriate care packages developed to reflect their needs and those of their carers, in the community as well as in residential care.
- ◆ Innovative programmes for younger people with dementia need to be explored.

2.5 Support for Māori with dementia

Practitioners and the health sector generally should be aware of the impact of population trends for Māori and the consequences for rates of dementia among Māori.

- The Māori population is increasing as a proportion of New Zealand's population
- The proportion of older Māori is growing.
- Māori are less likely to remain healthy in later years and have a lower life expectancy.
- Māori are culturally, socially and economically diverse.
- Māori have a range of relationships with whānau—not all follow the more conservative, extended model—yet many whānau relationships are reciprocal.

While Māori currently make up only 4 percent of New Zealand's older population projections suggest that by 2051 Māori will make up 11 percent of the total older population.²⁸ This implies that health services for older Māori must become more accessible in terms of cost, cultural appropriateness and location. Although older Māori report greater health care needs, their use of health services is at a lower rate than non- Māori.²⁹ In addition, the Treaty of Waitangi is a fundamental consideration

²⁸ Statistics New Zealand. 1998. *New Zealand now – 65 Plus*, Wellington New Zealand.

²⁹ Hirini PR, Flett RA, Long NR et al. 1999. Health care needs of older Maori: a study of kaumatua and kuia. *Social Policy Journal of New Zealand*. 13, 136-153.

in the development of health services in New Zealand and of critical importance in the face of significant health disparities between Māori and non Māori.³⁰

An important dimension of Māori health and well-being is whānau ora, the health and well-being of the immediate and wider family. Older Māori stand to benefit from their whānau health services, which support Māori families to achieve their maximum health and well-being. Equally important is cultural awareness when providing health services to Māori through mainstream rather than by Māori for Māori providers

In making a diagnosis of dementia, cultural differences relating to the concepts of physical and mental well-being must be considered. In particular, the validity of commonly used mental status instruments for Māori is an issue of current concern. Work is currently being undertaken by researchers developing Māori specific measuring instruments for mental health.^{31,32} Standard testing instruments may contain items that are biased for educational attainment or culture.^{33,34} It can also be difficult to assess people whose primary language is different to that of the examiner, although this seldom applies to Māori. Decisions about care may be affected by cultural differences, for example, in willingness to seek institutional care. It is important that Māori needs and expectations are well understood.³⁵

There appear to be few culturally acceptable options for residential services for Māori as well as other groups such as Pacific people.³⁶ Successful services for people with dementia require flexible practices and structures which have the capacity to adapt to the specific needs of the people requiring care.³⁷ It is important to ensure that mainstream services are culturally appropriate. In particular, it is important to ensure that whānau are made welcome in residential facilities and given opportunities to participate in the care of their relatives. There is also a concern that family members are not aware of the state financial support available and may not always receive assistance to which they are entitled.

At present, ‘by Māori, for Māori’ dementia service providers are few in number, and the development of such services may not be considered a priority given the many more pressing health and social disparities.³⁸

³⁰ Te Puni Kokiri. 2000. Progress towards closing social and economic gaps between Maori and non Maori. Wellington. New Zealand

³¹ Durie MH, Kingi TK. 1997. *A framework for measuring Maori mental health outcomes. A report to the Ministry of Health.* Department of Maori Studies. Massey University, Palmerston North.

³² Kingi TKR, Durie MH. 2000. *Hua oranga – a Maori measure of mental health outcome.* Te Pumanawa Hauora, School of Maori studies. Massey University. Palmerston North.

³³ Jacques A. 1992. *Understanding dementia.* Second edition. Churchill Livingstone. United kingdom.

³⁴ Uhlmann RF, Larson EB. 1991. Effect of education on the mini mental state examination by age and educational level. *J Am Geriatr Soc* 39(9):876-80.

³⁵ Ministry of Health. 1995. *He Taura Tieke – measuring health service effectiveness for Maori.* Population Health Services Section. Wellington.

³⁶ Ministry of Health. 1997. *The health and well-being of older people and kaumatua: the public health issues.* Wellington. New Zealand.

³⁷ Richmond D, Baskett R, Bonita R et al 1995. *Care for older people in New Zealand.* Wellington. New Zealand.

³⁸ King A. 2000. *The New Zealand Health Strategy.* Wellington. Ministry of Health.

The needs of Māori people with dementia as well as the support needs and preferences of whānau are a high priority in future primary health care, community support services, respite and residential care development.

Changes required for quality improvement

- ◆ The care and treatment of Māori people with dementia should be responsive to their needs and cultural expectations. This includes consideration of culturally appropriate services both in the community and residential care settings, the role of whānau, special issues that arise in providing carer support and the risk of isolation if placements are made in culturally inappropriate settings.
- ◆ Targeted funding to develop services for Māori, eg to support set up costs such as capital investment, education, workforce development and research is needed.

2.6 Support for Pacific people and other ethnic groups with dementia

Older Pacific people are a small but growing part of the Pacific population and of the older population in New Zealand. It has been projected that the older Pacific population will increase to 11 times its present size in the next 50 years.³⁹ There is wide ethnic diversity among Pacific people, including among others people from Samoa, Raratonga, Tonga, Niue, Tokelau and Fiji.

In the 1996 census there were more than 200 other ethnic groups identified in New Zealand, including over 180,000 New Zealanders of Asian origin.

Understanding the needs of these ethnic groups is complex. However what is clear is that ethnic communities traditionally place great value on older people and emphasise obligations to care for older family members. Inadequate resettlement assistance and English language competency present challenges for some ethnic communities, and providers of services need to be sensitive to such cultural diversity.

Changes required for quality improvement

- ◆ The care and treatment of people with dementia from other ethnic groups such as Pacific People, Asian New Zealanders needs addressing in culturally sensitive ways.

³⁹ Statistics New Zealand 1999. *Demographic Trends. 1999*. Wellington.

3 Models of residential care

People with dementia are assessed as needing residential care for a variety of reasons, usually when the burden of care becomes too great for the carer in the community, or when there are inadequate support services available - particularly for the person living alone.

There are a number of models and philosophies of residential care for people with dementia. In more recent residential developments, the focus seems to be on design (emphasising small-scale units, home-like environments) linked to consumer preference and empowerment (recognising that some people require units tailored to meet their particular needs, as illustrated in appendix 3).

Key issues for general residential facilities include managing challenging behaviours (such as wandering, intrusiveness, aggression) in an environment not suited to this type of care. Re-assessment is generally required when a person's behaviour becomes unsafe or unmanageable, but such assessment is dependent on the residential home making the referral. Frequently, referrals are made following a crisis, making preventive strategies difficult to implement. The issue of reassessment of residents in general residential facilities has been a concern for some time in New Zealand as this could result in the resident being transferred out of the facility. However, the needs of a person with dementia will change over time and they may well benefit from being placed in a specialised facility where their behaviours are more appropriately managed.

Managers of residential facilities for people with dementia are responsible for balancing the safety of residents (implementing appropriate risk management strategies to achieve this) with provision of homely domestic style living arrangements. There are tensions between providing a custodial 'institutional' model of care with a focus on security and risk minimisation versus a 'person-centred' model of care that allows expression of normal risk taking behaviour. It is important for all providers to continually be alert to the changing needs of people with dementia and implement appropriate strategies to meet these needs. This includes recognition of the range of dependencies that people with dementia have over time as well as supporting existing abilities. On the one hand, the limiting of risk taking could be seen as justification for using restraint practices, yet where normal risk taking is permitted and resident's quality of life is improved, providers may be questioned about safety. Involving family and carers in balancing safety and quality of life will assist with finding solutions to these difficult issues in the practice of residential dementia care.

This section discusses best practice models of residential care for people with dementia, with a focus on the type of facility, physical environment, process of care, restraint procedures and management culture.

3.1 Type of facility

A growing trend in some countries has been the development of special care units (SCUs) for people with dementia, either stand alone or attached to general residential

facilities.⁴⁰ These units recognise that people with dementia require care geared to their particular needs. There is no standard definition of a SCU, although experts agree on the following five characteristics:⁴¹

- admission of residents with cognitive impairment
- staff specification, selection and training
- activity programming for the cognitively impaired
- family programming and involvement
- segregated and modified physical and social environment.

SCUs are usually small in size and are designed and fitted to resemble a home setting, offering appropriate activities, a spatial layout responsive to wandering and attention to colour and sound.⁴² They differ in size, structure, philosophy of care, staffing levels, acuity and organisation.

Internationally^{43,44,45} there appears to be evidence for the benefits of small scale units providing domestic-like homely care, on the quality of life of people with dementia. In the United States, SCUs tend to be designed with the needs of the mid-stage dementia resident in mind.⁴⁶ In Sweden, group homes (ie suitably adapted ordinary housing) have been developed as an alternative to traditional residential care. In the UK, the Domus project facilitates group living, where people with dementia largely fend for themselves with support from appropriate care services. The results are positive; there is more interaction between residents, less depression and a lower rate of general decline, than for people living in conventional residential settings.⁴⁷

The following five components of care were identified from an independent literature review as being most closely related to improved care outcomes:⁴⁸

- assessment and diagnostic procedures
- staff specialisation and ongoing education
- non-use of physical and chemical restraints
- flexible care routines and individualised care plans
- specialised environmental design and adaptation.

⁴⁰ Woods B. 1995. Dementia care; progress and prospects. *Journal of Mental Health* 4:115-124.

⁴¹ Mentis JC, Buckwater KC. 1998. Dementia special care units; programming and staffing issues. *Journal of Gerontological Nursing*.

⁴² Lefroy RB. 1997. A special dementia unit: review of the first eleven years of operation. *Australian Journal of Ageing* 16 (1):16-19.

⁴³ Dean R, Briggs K, Lindsay J. 1993. The Domus philosophy; A prospective philosophy: a prospective evaluation of two residential units for the elderly mentally ill. *International Journal of Geriatric Psychiatry*. 8, 807-817.

⁴⁴ Carr J, Marshall M. 1993. Innovations in long-stay care for people with dementia. *Reviews in Clinical Gerontology*. 3, 157-167.

⁴⁵ Bellelli G, Frisoni GB, Bianchetti A., et al. 1998. Special care units for demented patients: a multicentre study. *The Gerontologist*. 38 (4):456-462.

⁴⁶ Kovach CR. 1996. Alzheimer's disease: long-term care issues. *Issues in Law and Medicine*. 12(1)47-56.

⁴⁷ Dean R, Briggs J, Lindsay J. 1993. The Domus philosophy; a prospective evaluation of two residential units for the elderly mentally ill. *International Journal of Geriatric Psychiatry*. 8, 807-817.

⁴⁸ Chappell NL, Reid C. 1999. *Institutional care for dementia sufferers*. Centre on Ageing, University of Victoria, British Columbia, Canada.

Six standard outcomes identified as important were:

- activities of daily living
- cognitive functioning
- agitation
- social skills
- mood or affect
- expressive language skills⁴⁹

Both SCUs and integrated units were found to be implementing some of these dimensions of care successfully but few were implementing all dimensions well. The implications of this review are that many dimensions of care fit together to constitute good quality care. This implies that performance measures restricted to a single dimension are inadequate. When facilities implement best practice in one dimension of care, this does not necessarily imply best practice in all dimensions. Therefore, auditors of facilities should focus on ensuring that high quality of care is achieved across all dimensions of care, and expressed in a range of outcomes.

Anecdotal information on ‘special care’ type units in New Zealand suggest that these facilities (ie small sized units backed by skilled, appropriately trained staff, a supportive environment and an extended range of appropriate activities) work well. While people with dementia can be cared for in general settings, there is often little support for them from other residents, which sometimes creates a whole range of other problems. In addition, many people with dementia in general residential facilities do not have access to specialist services and treatments (such as various therapies). There is also very little ongoing dementia training for staff in general facilities.

The general consensus from the literature is however, that people with dementia can be cared for in mainstream facilities provided there is recognition that they have special needs and require access to specialist services. If this is to be the case, then residential facilities must embrace a ‘person-centred’ model of care, recognise the importance of autonomy and dignity of residents, provide social and recreational activities and abolish the use of restraints. This may also mean some modification to the design of existing facilities to provide safe wandering areas.

Changes required for quality improvement

- | |
|---|
| <ul style="list-style-type: none">◆ A focus on implementing all five of the dimensions of care well, namely, assessment and diagnostic procedures, staff selection and training, non use of restraints, flexible care routines, family involvement and specialised environmental design.◆ Aim to achieve positive results across a number of care outcomes, including reduction in challenging behaviours, facilitation of social skills, stabilisation of mood, maintenance of independence of activities of daily living, and preservation of cognitive skills including expressive language skills. |
|---|

⁴⁹ ibid

3.2 Physical Environment

Models of environmental design for residential facilities for people with dementia emphasise smallness, normal domestic facilities, appropriate décor linked to memory of residents, appropriate stimulation, easy access and opportunities to observe the daily life of the unit, as well as safe outside space.

The importance of the environment for people with dementia is well documented in the literature.^{50,51} Cohen and Weisman provide a useful checklist of nine therapeutic design goals:

- ensure safety and security
- support functional activity through meaningful activity
- maximise awareness and orientation
- provide opportunities for stimulation and change
- adapt to changing needs
- establish links to the healthy and familiar
- provide opportunities for socialisation
- protect the need for privacy.⁵²

Lawton emphasises the need for planning to involve architects, administrators, health professionals and users. He suggests that architects should spend time with users to gain an understanding of their needs.⁵³ In the New Zealand context this would particularly include consultation with Māori and Pacific peoples.

However, people with dementia are not one homogenous group and vary with respect to care needs. People with challenging behaviours for example may need a building where they can see and be seen by staff, whereas people who are confused but retain social skills may need smaller, more private areas in addition to larger common spaces for socialisation to incorporate extended family or whānau. Many of these design features can be incorporated into existing buildings at reasonable cost.

In summary, there is general consensus in the literature about the optimal physical design features for residential environments for people with dementia.^{54,55,56,57} Such features include the need for small, homely units with many characteristics that are as familiar as possible, given the strangeness of unfamiliar living arrangements for the

⁵⁰ Lawton MP, Fulcomer M, Kleban M. 1984. Architecture for the mentally impaired elderly. *Environment and Behaviour*. 16;16:730-757.

⁵¹ Calkins MP. 1988. *Design for dementia planning: environments for the elderly and confused*. Maryland; National Health Publishing.

⁵² Cohen DH, Weison GD, 1991. *Holding onto home: designing for people with dementia*. Maryland, The John Hopkins University Press.

⁵³ Lawton MP. 1987. Strategies in planning environments for the elderly. *Journal of Independent Living* Fall. 1-14.

⁵⁴ Calkins MP, Arch M. 1988. *Design for dementia. Planning environments for the elderly and the confused*. National Health Publishing, Maryland, United States.

⁵⁵ Cohen U, Weisman GD. 1991. *Holding on to home: Designing environments for people with dementia*. Maryland: The John Hopkins University Press.

⁵⁶ Peppard NR. 1991. *Special needs dementia units: design, development and operations*. New York: Springer Publishing Company

⁵⁷ Netten A. 1993. *A positive environment*. Aldershot; Ashgate Publishing.

person with dementia. For example, age and culture appropriate furniture and fittings can be of help. Buildings need to be designed to make location of essential places as obvious as possible. Use of colour and signs can be useful in helping people to move around with ease. Good lighting is very important to maximise visibility as well create appropriate atmosphere. Being able to see staff and see where to go will minimise stress. Thoughtfully designed bathrooms can provide a warm comfortable place for relaxation. Designs which provide opportunities for normal domestic activities such as cooking, cleaning, gardening and hanging out the washing will assist staff as well as residents.

Staff also need space to escape, to hold meetings, and training programmes or even to have a shower. Facilities for staff reflect the esteem in which they are held by managers and may be a worthwhile investment for staff morale. Poor design increases accidents and limits staff ability to observe residents as well as disorientating and confusing residents.

In spite of the evidence of benefit for good design features, there is still some resistance to investment, either in new buildings or in retrofitting existing facilities. While further research is always helpful, the evidence base is now sufficient to support such investment.

Changes required for quality improvement

- ◆ A move towards small-scale homely, domestic style environments (along with age appropriate furniture and décor) designed to maximise awareness and facilitate healthy living for people with dementia. Privacy as well as safety issues must be taken into consideration.
- ◆ Social, psychological, artistic, and communication needs should be given equal weighting to physical needs.
- ◆ Planning to achieve optimal environmental arrangements will require co-operation among all providers of care, including carers, whānau, family and health professionals. Better co-ordination of non residential and residential services will also be required. Planning will also need to take into account the range of dependencies of people over time ie assessment and reassessment of needs.

3.3 Process of care

There is growing evidence in support of the effectiveness of various therapies and activities for people with dementia within the context of a ‘person-centred’ model of care. This evidence challenges commonly held beliefs that no therapeutic intervention is of any value.

Reality orientation was the first attempt to recognise the personhood of people with dementia and to deal with orientation problems.⁵⁸ This was followed by *validation therapy*⁵⁹ and *resolution therapy*,⁶⁰ both of which focus on feelings and emotions of people with dementia. *Reminiscence therapy* has also been found to be very

⁵⁸ Holden U, Woods R. 1995. *Positive approaches to dementia care*. Edinburgh;Churchill Livingstone.

⁵⁹ Feil N. 1993. *The validation breakthrough*. Baltimore; Health Promotion Press.

⁶⁰ Woodrow P. 1998. Interventions for confusion and dementia - alternative approaches. *British Journal of Nursing*. 7(20), 1247-1250.

reassuring for some and facilitates communication within groups. Other strategies which seek to provide stimulation as well as relaxation include music therapy, art, drama, dance, use of pets and various religious activities. Each intervention recognises the social and emotional needs of people with dementia, a critical success factor for good quality care. There are positive effects for both residents and staff through participation in these activities and improvements in general spatial orientation, independent functioning and the use of initiative have been noted.⁶¹

To facilitate a more person-centred approach to care, management and organisational structures will have to become more flexible. The recognition of people with dementia as 'people' is often overlooked by care providers,⁶² who merely attend to basic physical needs⁶³ when workloads become excessive. People with dementia deserve to be treated with respect and dignity, as mature adults.

To move towards a genuinely communicative, interpersonal model of care, will require a more active partnership role for carers and families in the assessment and planning of services and a more co-operative working relationship among agencies. It will be important to know more about existing relationships among health professionals, family carers and people with dementia.

Information about the person with dementia, obtained while they were attending day care or community services, needs to be transferred to the residential care setting where the person will live so that staff can learn to treat them as unique individuals. However, this information needs to be managed sensitively and in accordance with confidentiality guidelines and privacy laws.

Changes required for quality improvement

- ◆ A person-centred model of care for people with dementia, based on need, should be adopted. Dispel a 'task-orientation' mentality and replace with a 'passion for empowering people'. Treat people with dementia as 'valued people'.
- ◆ Facilitate dignity and allow a certain amount of risk taking.
- ◆ Engage family and whānau in the process of caring for people with dementia (education, assessment, reassessment, planning, ongoing care) as part of continuous quality improvement.
- ◆ Provide families with opportunities to learn about their caregiving role, including their rights and responsibilities so that their involvement is maximised. This may be through assistance from residential facility staff, family meetings at the facility, and through an education programme, such as Partners in Caregiving.⁶⁴
- ◆ Education programmes designed to facilitate a person-centred approach should be implemented for all staff working in residential facilities. The key change needed is an attitudinal change on the part of staff. This can only be achieved through the greater awareness and confidence that results from relevant and high quality educational experiences.

⁶¹ Kitwood TM. 1995. Building up the mosaic of good practice: introducing a new series in person-centred care. *Journal of Dementia Care*. 3,5,12-13.

⁶² Downs M, Marshall M. 1997. *Scottish needs assessment programme. Priority Services Network: Dementia*. Glasgow; Scottish Forum for Public Health Medicine.

⁶³ Liukkonen A. 1992. Basic care of demnted patients living in institutions. *Journal of Clinical Nursing I*: 345-350.

⁶⁴ Pillemer K, Hegeman MS, Albright B et al. 1998. Building bridges between families and nursing home staff: the Partners in Caregiving Program. *The Gerontologist*. 38; 4, 1-5.

- ◆ Such education must be ongoing, with particular attention to changes required in behaviour management as the person's level of dementia changes.

3.4 Medication and restraint procedures

Challenging behaviours are common as well as serious problems affecting people with dementia. Such behaviours impact on the quality of life of both the person with dementia and their carers. At some point during the course of their illness at least 90 percent of people with dementia will exhibit challenging behaviours.⁶⁵

Assessment should include review of particular triggers (eg pain, illness, medications). Behaviours should be carefully documented. It is important to look for causative factors such as bathing, mealtimes, company or loneliness. Consequences of the behaviour should also be recorded. The act of observing and documenting these behaviours can, in itself, reduce the number of incidents by learning to recognise, anticipate and avoid provocation.⁶⁶ Gibson and Potts discriminate between patients' aggressive behaviours and their resistance to care. This approach encourages staff to address tensions in relationships and environmental factors influencing behaviour rather than exclusively focusing on preventing the overt behaviours.^{67,68}

Nonpharmacologic interventions are generally tried first and may involve environmental modifications (eg therapy with music, pets or activity) as well as specific behavioural techniques.⁶⁹ While evidence from randomised controlled trials for the general use of psychotropic medication for behaviour problems is limited, there is some evidence from other studies for specific tailored use of such drugs. Trials are usually small or inconclusive for several of the antidepressive agents. No medication will control wandering, which is best managed with behavioural and environmental modifications. It is also important to allow 'risk taking' within the bounds of safety.

A new standard for restraint minimisation and safe practice has recently been developed in New Zealand. (NZS 8141:2001). This document reflects current best practice, which is to move away from the use of restraint in all its forms, but when such use cannot be avoided, ensure that this happens in a safe and respectful manner. The use of restraint is a clinical decision. It is not a treatment but is used as one of a number of strategies at a particular time with a particular goal in mind.

The New Zealand Committee set up this year to review restraint practices recommended that:⁷⁰

⁶⁵ Teri L, Larson FB, Reifler BV. Behavioural disturbances in dementia of the Alzheimer's type. *J Am Geriatr Soc* 1988;36:1-6.

⁶⁶ Canadian Medical Association. Supplement to *CMAJ* 1999; 160 (12 Suppl). Managing of dementing disorders. Conclusions from the Canadian Consensus Conference on Dementia.

⁶⁷ Gibson M. 1997. Differentiating aggressive and resistive behaviours in long-term care. *Journal of Gerontological Nursing*. 23(4), 21-28.

⁶⁸ Potts. HW. Richie MF, Kaas MJ 1996. Resistance to care. *Journal of gerontological nursing* 22(11)11-16.

⁶⁹ Beck CK, Shue VM. Interventions for treating disruptive behaviour in demented elderly people. *Nurs Clin North Am* 1994;29;143-55.

⁷⁰ Standards New Zealand, Ministry of Health 2001. *New Zealand Standard. Restraint Minimisation and Safe Practice*. NZS 8141:2001.

- service providers ensure that a patient receives the best possible care available and that the patient is safe from harm, both from themselves and others.
- seclusion is a specific type of restraint, only used in acute psychiatry and should not be considered in residential settings. If a resident needs this type of restraint, they should be in an acute hospital.
- organisations develop clear policies and procedures to guide service providers and seek legal advice to ascertain if the practice they are specifying is lawful
- basic approved techniques should be consistent throughout the country with agreed standards of practice and it would be desirable to have a national approval and monitoring body overseeing all restraint use.
- organisations subject their use of restraint to rigorous internal and external review by consumers, professionals and other relevant bodies until services are managed without the use of restraint.

Changes required for quality improvement

- ◆ Challenging behaviours should always be thoroughly evaluated clinically when they first occur, to rule out treatable or contributory causes. Environmental (eg changes in light or sound stimulation) and behavioural modifications should be attempted in the first instance to modify these behaviours before considering medication to control them.
- ◆ If medications are required these must be reviewed regularly and withdrawal considered accompanied by close monitoring of response. Medication should always be seen as temporary treatment for behavioural management and a plan of discontinuation put in place at the same time as commencement of the drug treatment.
- ◆ Promote restraint minimisation.
- ◆ The recommendations made by the New Zealand Committee on the use of restraint must be implemented by all residential facilities. These should be clearly defined in service specifications.
- ◆ Restraint use is a human rights issue. Legal protection of residents (3PR Act) must be adhered to and carers informed. People with dementia must be given access to independent advocates if they so choose.
- ◆ Family members/advocates must be made aware when restraint is being used and be offered an opportunity to challenge this.
- ◆ Seclusion should never be used in a residential facility.

3.5 Management culture

Studies on nurses' attitudes and satisfaction with working in residential settings with people with dementia have shown these to be strongly correlated with organisational and management practices.⁷¹ These studies support other work on burnout and stress which indicate a shift in emphasis away from blaming individual inadequacies to dysfunctional organisational culture. In relation to work satisfaction among nursing staff, several studies have identified the important role of trained staff at all levels, as well as the importance of communicating to staff that their work is valued and respected. This means that good leadership skills, as well as economic resources are required to achieve a high level of job satisfaction. Important too is the finding that

⁷¹ Gilloran A, Robertson A, McGlew T, et al 1995. Improving work satisfaction among nursing staff and quality of care for elderly patients with dementia: some policy implications. *Ageing and Society*. 15, 375-391.

factors located in both management and the organisational structure, are influential in improving the quality of care.⁷²

Low levels of work satisfaction have important consequences for management in that absenteeism and turnover may be adversely affected, and for staff, feelings of self worth and commitment to the job may suffer. This in turn is likely to have an effect on people with dementia; studies show an association between work satisfaction and the quality of care provided by staff.⁷³ In settings where job satisfaction levels are higher, residents are offered more choice, independence, information and privacy, as well as a greater degree of conversation during activities such as meal times, bathing and being helped to the toilet. Studies consistently highlight the following as key aspects of good management practice for residential services for people with dementia:

- leadership
- recognition of staff needs and achievements
- availability of support services for staff.

Good leadership includes setting clear and attainable goals for staff, as well as acting as advocate and ambassador for people with dementia. Researchers argue that innovation, imagination and risk-taking should be incorporated into any successful leadership strategy. Not only may such an approach benefit the people with dementia but also the staff who work with them.⁷⁴ The quality of leadership is an integral part of the relationship between staff work satisfaction and the quality of care received by people with dementia, in that if staff can be made to feel good about their work then they are more likely to deliver high quality care. This reaffirms their perceptions of self-worth and commitment to the job.

Specific policies and programmes for the care of people with dementia should be put into practice with the knowledge, consent and backing of the majority of front line staff. The feeling of ownership of policies and procedures is integral to maintaining and enhancing job satisfaction. If management attempts to implement policy decisions without involvement of front-line staff, this is likely to foster suspicion, doubt or cynicism which may alienate and demoralise staff with consequential negative impacts on residents. If staff, residents or family or whānau do not agree with management practice there must be in place appropriate complaints procedures.

In-service training has also been identified as contributing to overall high levels of staff morale. Not only are such sessions personally satisfying and informative but they also crucially demonstrate a supportive management culture.

Staffing arrangements (numbers and skill mix) in a residential facility should be suited to the needs of the residents and must be updated in line with changing needs and circumstances. Numbers and skill mix of staff will depend on resident numbers, their dependency levels and needs as set out in care plans, the size and layout of the facility, the type of care provided and time of day. There must be multidisciplinary assessment

⁷² Holden U, Woods B. 1995. *Positive approaches to dementia care*. Edinburgh: Churchill Livingstone.

⁷³ Robertson A, Gilloran A, McGlew T et al. 1995. Nurses job satisfaction and the quality of care received by patients in psychogeriatric wards. *International journal of geriatric psychiatry* 10:575-584.

⁷⁴ Gilloran A, Robertson A, McGlew T et al. 1995. Improving work satisfaction amongst nursing staff and quality of care for elderly patients with dementia; some policy implications. *Ageing and Society* 15:375-391.

and care planning to meet the changing needs of residents. Management must employ appropriately competent staff (and provide in service training) to ensure the well-being of residents by day and by night.

The role of the general practitioner in residential facilities varies in different areas of New Zealand. Some facilities employ general practitioners as medical directors, who provide advice on policies and procedures as well as individual resident medical care, whereas in other facilities, different general practitioners provide care for individual residents. In general, medical services are limited by available resources, which impacts on the potential for implementing preventive care.

There has been some criticism of the staffing numbers required for dementia services, stipulated in contractual arrangements between providers and the Ministry of Health. A brief review of available literature on standards in residential care⁷⁵ showed that staffing:resident ratios vary internationally and there does not appear to be good evidence to support one ratio over another. In fact, there is some evidence that merely increasing staff numbers does not improve quality of care, as staff may then spend more time on paperwork and administrative tasks, often required because of increasing scrutiny.⁷⁶ Emphasis appears to be shifting to improving quality by focusing on the resident's needs, staff training and support for the continuity of care provided by carers and whānau or family in community settings. An in depth analysis of an appropriate standard for staff:resident ratios appropriate for New Zealand settings may need further exploration.

There are two ministerial groups currently examining workforce issues in New Zealand, the Workforce Advisory Committee and the Expert Advisory Panel on Nursing Specifications for Residential Aged Care. The latter group has recently been requested to examine and report on appropriate nursing staff levels for dementia residential care.

In summary, studies on management culture, in relation to the attainment of high quality care for people with dementia in residential settings, show that the establishment and maintenance of a 'person-centred' philosophy of care within a supportive and innovative management culture is critical for success. For this culture to develop and flourish, a combination of good governance, sound management and dynamic leadership have been identified as important.

Changes required for quality improvement

- ◆ A combination of good governance, dynamic leadership and a supportive management culture is required to improve the quality of services.
- ◆ Management culture with a focus on the person with dementia and their carers/family/whānau, that is sensitive to and accommodates cultural practices and quality of life issues will build confidence with staff and alleviate stress.
- ◆ Facilitate staff involvement in decision making.
- ◆ Performance reviews with staff should include goals that are attainable.
- ◆ In-service training supported by management is essential for quality improvement.

⁷⁵ Department of Health. 1998. *Fit for the future? National required standards for residential and nursing homes for older people*. Consultation document.

⁷⁶ Sixsmith, Copeland 1993. *Int Ger Psych*

- ◆ Develop standard requirements for medical advice in facilities (including health promotion and disease prevention).
- ◆ Introduce appropriate complaints procedures for staff and family members/whānau.
- ◆ An in-depth analysis of appropriate staffing roles and ratios for residential dementia services in New Zealand should be included in the brief of the Expert Advisory Panel on Nursing Specifications for Residential Aged Care.
- ◆ Develop a strategic approach to implementing quality improvement in residential settings: This could include developing:
 - a continuous quality improvement framework
 - a 'centre of excellence' for dementia, ie a unit that conducts and collates research and provides up to date advice on best practice
 - development of 'best practice' design features for dementia facilities
 - encourage provider buy-in to compliance with the Ministry of Health's contractual requirements through involvement in developing the measurement criteria, tools and methodology used during audits
 - helping practitioners, families and society at large recognise 'quality' so the wider community can contribute to raising standards
 - guidelines for facilities to achieve CQI
 - national consistency on dementia training
 - quality checks ie random audits to check improvements
 - transparent, meaningful, best practice focused audit/accountability processes
 - seamless co-ordination between physical and mental health services
 - co-ordinated care with multidisciplinary approach
 - celebrate, praise, publicly recognise and reward good quality services
 - sanctions against poor performance (eg penalties, restrictions on practice, revocation of licence)

3.6 Competence (including training)

Ongoing training of staff who provide both residential and community services will contribute to the delivery of quality services. Both on site in-service training as well as formal educational programmes offered by training and education organisations are essential to maintain competence in the care of people with dementia.

In New Zealand, Industry Training Organisations (ITOs) are set up by their industries to develop skill standards and national qualifications. ITOs arrange training for employees in their industries and oversee the quality of training requirements. The board of Skill New Zealand administers the industry training fund which subsidises industry training.

The Community Support Services Industry Training Organisation (CSSITO) facilitates nationally recognised training for older people's health and diversional therapy. It is one of over 50 ITOs that serve industry sectors. ITOs are not training providers. They manage the development of training in an industry and ensure employers have choices about training. They also fund training in the industry, on behalf of government.

There are four unit standards against which staff directly involved in caring for people within a dementia unit should demonstrate competence: They are:

- Unit number 17029: assist a person who is affected by dementia to meet daily living activities
- Unit number 5012: lift and position people safely

- Unit number 5019: assist an older person to meet their physical needs
- Unit number 5020: support an older person to maintain their rights and responsibilities.⁷⁷

The Aged Care Education (ACE) training programme in New Zealand covers the above four standards through a series of videos and work books. In addition, these unit standards can also be achieved through polytechnics and other private training providers.

While a number of training packages for dementia have been developed and accredited in New Zealand, access to these may be limited in some parts of the country – and for some categories of workers. There is also concern that there is little training support for caregivers undertaking these training programmes. Many caregivers either have not been able to cope with the training because of poor reading skills or because English is not their first language. There may also be limited employer support for further education. The development of on-line education or training programmes could improve accessibility for some carerworkers.

Nevertheless, the providers of services for people with dementia (such as volunteers in day care centres, nurses, enrolled nurses and others in residential settings as well as specialist geriatricians in acute care hospitals) have a wide range of skills and qualifications. The current move to develop advanced nurse practice provides an opportunity to create nurse practitioner roles that are client focused and work across settings. The training and education of dementia workers in different settings and at different levels is vital to ensure high quality care.

Carers in the community also need access to educational programmes, even after the people for whom they care enter residential facilities. This would enable carers to understand the importance of their role in providing ongoing social and emotional care.

Complaints about quality of care generally relate to staff, who do not have an appropriate level of knowledge and understanding of dementia. Staff turnover presents further challenges to efforts to improve skill levels and requires service providers to be able to access education and training programmes on an ongoing basis. A good understanding of dementia by staff and carers at all levels will assist in better facility management and lessen breakdown in relationships.

The ongoing availability of educational resources for dementia care is also critical to meeting educational and training needs of carers. A commitment to workforce education and training includes provision of appropriate educational material at prices workers and organisations can afford.

⁷⁷ <http://www.cssito.org.nz>

Changes required for quality improvement

<ul style="list-style-type: none">◆ More attention to education and training needs. A working group should be established to advise on the following training needs in relation to development of the dementia workforce:
<ul style="list-style-type: none">○ a review of training organisations and their dementia programmes in relation to best practice models of care○ dissemination of updated information on best practice models of service delivery and high quality educational material○ the content of specific training modules for staff at all levels○ a fixed percentage of income allocated to training○ a monitoring system for meeting initial training requirements and assessment of maintenance of competency.
<ul style="list-style-type: none">◆ Inclusion of dementia-specific education and training in the undergraduate and postgraduate curricula of all trainee health professionals should be promoted to the universities and polytechnics.◆ Management of residential facilities must be committed to staff training and ensure all staff have access to appropriate in-service training in dementia care, including regular update/refresher courses.◆ Training programmes should be designed to facilitate a person-centred approach to care and service delivery, which recognises the uniqueness of the person with dementia. More attention should be focused on the social, psychological and communication needs of residents such as reminiscence therapy, validation therapy and reality orientation.◆ Empowering families to enable them to ask appropriate questions relating to the care provided is also a responsibility of management and staff in residential facilities.

4 Respite, day care and home care

Respite care

Respite care is the term used to describe a service whereby people with dementia normally cared for at home by relatives, are placed temporarily in alternative accommodation to give their usual carer a break.

Respite services can refer to short-term placement in some form of residential setting or to in-home provision of the service. Respite in the home of the person with dementia can be valuable but is rarely provided. Respite care outside the home allows the carer a complete break from the caring process. While respite care is of benefit to the carer, it is important that the needs of the person with dementia are not overlooked. It can sometimes lead to disorientation and behavioural problems particularly if respite is provided for only a short period of time. The challenge in providing respite care lies in ensuring that the service is adequately resourced and adopts standards of practice that permit flexibility to meet individual requirements of clients.

Continuity is important for people using respite care. Family carers and whānau should be able to provide information about care to staff in the residential facility and need reassurance that this information will be used appropriately. Families are most able to fully relinquish responsibility for care when they are confident their relative is receiving comparable care to that provided in the home environment. They also need information about the experience of respite care to help them make informed choices about the most suitable support services required. Using respite care can cause added stress initially because of conflicting feelings experienced by family/whānau and the reactions of the person receiving care.⁷⁸

The facility in which the respite service is available should also be appropriately designed to ensure the safety and comfort of residents. It must also have a high level of appropriately trained staff. Ideally respite services should be locally based in a small-scale homely environment and available when they are needed.

It is often difficult to find appropriate respite facilities for people with behavioural problems, yet these are precisely the people for whom respite care is most needed.

Day care

Day care services offer people with dementia carefully supervised social, recreational and health activities in a comfortable group setting which can help to create a greatly improved quality of life. Day care is as important for people living alone as it is for people supported by carers. Day care can:

- help to maintain or improve a person's levels of functioning
- offer participants the opportunity to socialise, enjoy peer support and receive health and social services in a supportive environment
- reduce depression

⁷⁸ Gilmour J. 2001. *On the margins: nurses and the intermittent care of people with dementia - a discourse analysis*. Unpublished PhD thesis. Massey University, Palmerston North

- increase self esteem and dignity
- stabilise medical conditions
- improve communication skills
- enhance sleep at night
- relieve loneliness and boredom
- increase contentment
- help families and carers who have responsibilities for a person with dementia who cannot be left alone during the day.

Some programmes offer transportation to and from the centre.

Day care may occur in day hospitals, day centres or in residential facilities. In general people in the early stages of dementia can be accommodated within a generic day centre. However, as their dementia progresses, attendance at a dementia specific or dementia focused centre may be more appropriate. Regardless of the type of day centre the person with dementia attends, it is very important that their needs are met by the service. Opening times should also be flexible in keeping with the emphasis on individualised provision of care for people with dementia.⁷⁹

There is a need to establish national standards for both respite and day care for people with dementia. Standard quality of care issues need to be formalised. Small scale centres in domestic settings with empathetic, trained staff appear best placed to provide good quality day care for people with dementia. Respite care and day care centres should be locally based. This will help to promote contact between staff and carers, promoting a sense of partnership and continuity of care.

Home Care

Home care includes the wide range of health and social services that could assist a person with dementia and their carer to live independently at home. Services may include help with personal care, household tasks, social needs or treatments. In New Zealand home care services vary in availability and quality in different parts of the country. In some regions, these services are provided by careworkers who have had minimal training, while in other regions, highly skilled nursing and medical providers deliver appropriate care. Home care provides power sharing, support and often greater effectiveness of care for the person and their carers. Providing home care to people with dementia can present significant challenges. Emotional problems, challenging behaviours and hostile attitudes test the skills of home care workers. Care providers who can cope with and not be overwhelmed by the person's challenging behaviours are essential for home care to be successful. Team approaches have been used effectively to achieve good outcomes for people with dementia living at home.

It is beyond the scope of this report to cover home care services for people with dementia. However, there was one major concern that arose from the working group meeting and consultation on the draft report that requires urgent attention. This was the lack of training, supervision and standards for careworkers supporting people with dementia and their carers at home. Accordingly, a recommendation to this effect is included in this report, despite its focus on residential services

⁷⁹ Curran J.S.M. 1995. Current provision and effectiveness of day care services for people with dementia. *Reviews in Clinical Gerontology* 5:313-320.

Changes required for quality improvement

- ◆ A range of different respite and day care services should be available to meet the diversity of needs of people with dementia and their carers. This includes the availability of home-based respite in addition to residential options.
- ◆ Better information about availability of respite care should be distributed through primary care providers and community services.
- ◆ National standards for respite care, day care and home care services for people with dementia should be developed and implemented.
- ◆ Training of staff who work in respite, day care and home care needs to be given priority attention, as does supervision and professional support for careworkers.

5 From Planning to Action

The working group on dementia was established to consider ways to improve the quality of services provided in residential care. This paper reviews evidence for effective service provision in residential facilities, in order to provide advice on these issues, based on best practice. However, the paper also covers some issues in community care, as it is recognised that these may impact on residential services. A number of changes that will improve quality of care have been suggested throughout the text. Recommendations are made in this section for immediate action, as well as action required in the longer term, ie over the next 12-24 months, for continuous quality improvement.

The priority issues identified by the working group were:

- optimal staff training, skills and competencies, and staff:resident ratios
- provision of a safe and quality environment in an appropriately configured unit
- involvement of family members, residents and carers in the planning and provision of care
- appropriate and safe use of medication and restraint (chemical as well as physical)
- access to services, including needs assessment and reassessment
- audit of services and enforcement of compliance
- early identification, treatment and community based services, to support people with dementia and their carers

Recommendations requiring urgent action:

It is recommended that the Ministry of Health:

Training

- 1 Works with CSSITO, Alzheimer's New Zealand and sector groups to ensure that training programmes in dementia residential and community care are nationally consistent, accessible, affordable and reflect the needs of people with dementia.
- 2 Liaises with professional organisations to ensure that training in assessment and the early recognition of dementia is included as part of continuing educational programmes.
- 3 Liaises with CSSITO to ensure that unit standards prescribed in contracts are regularly updated, and that providers are regularly monitored with regard to their contractual obligations for training.

Staffing

- 4 Requests advice regarding, and an in-depth analysis of, appropriate staffing levels, skill mix and accountabilities, for residential dementia services in New Zealand, from the Expert Advisory Panel currently working on Nursing specifications for Residential Aged Care. The Ministry will need to assess the policy and fiscal implications of this advice.

Use of medication and restraint

- 5 Requires residential facilities to meet the New Zealand Standard 814:2001. *Restraint Minimisation and Safe Practice*.
- 6 Requires residential facilities to inform carers if restraint is to be used; ensure carers are involved in the consent to restrain process, ensure residents have legal protection through the 3PR Act; and residents have access to independent advocacy services.
- 7 Audit restraint procedures and processes for remedial action when standards are not being met.

Recommendations requiring action over the next 12 months

It is recommended that the Ministry of Health:

Involvement of whānau, families and carers in planning

- 8 Through dementia service providers, involve whānau, families and carers in care (ie provide information, assist with support and placement decisions, include in care planning process, including reassessment and evaluation)
- 9 Develops an information brochure for subsidised residents and their whānau and families entering residential care, that outlines what they should expect from residential services.

Support for Māori with dementia

- 10 Ensure through contractual obligations that the care and treatment of Māori with dementia is responsive to their needs and cultural expectations, through contractual obligations. This includes consideration of culturally appropriate services in the community and residential settings, the role of whānau, special issues around carer support and the risk of isolation if placements are made in culturally inappropriate settings.

Support for Pacific people with dementia and other cultural groups

- 11 Ensure that providers of care for people with dementia from different cultural groups take into account the risk of isolation, the importance of culturally appropriate services and special issues that arise in providing carers support, through contractual obligations.

Access to services (including needs assessment and reassessment)

- 12 Develops, as part of the Ministry's current needs assessment project, an evidence based guideline (and training) for the assessment and reassessment of people with dementia.
- 13 Implements a review and auditing process for reassessments, through contracts with assessment services.

Audit of services and enforcement of compliance

- 14 In association with the sector, proceeds with the inclusion of new nationally consistent service specifications into contracts.
- 15 Progresses the inclusion of new provisions for holding providers accountable to their contractual requirements through strengthened audit clauses in contracts.
- 16 Develops a national complaints procedure to assist with auditing services and monitors the response to complaints.

- 17 Explores ways of improving performance, for example, publicly recognising improvements in quality through health and disability awards.

Recommendations requiring action over the next 12-24 months

It is recommended that the Ministry of Health:

Dementia specific standards

- 18 In association with Standards New Zealand, develops dementia specific residential standards which can be brought under the umbrella of the new Health and Disability Services (Safety) Act 2001.

Respite Care, Day Care and Home Care

- 19 Develops a policy on respite, day care and home care services for people with dementia and their carers, to guide the provision of these services.
- 20 In association with Standards New Zealand develops standards for respite, day care and home care services for people with dementia.

Information and education

- 21 Assesses the needs of consumers for information about dementia, and evaluates access to existing dementia educational resources.

Environmental design

- 22 Develops a policy based on best practice in the design of dementia, facilities, ie small scale units with features that help to orientate, maximise independence and dignity, and promote functional abilities.

Pharmacotherapy for dementia

- 23 (Pharmac) keeps under review, criteria for funding pharmaceuticals suitable for the treatment of dementia.

Younger people with dementia

- 24 Ensures that providers caring for younger people with dementia are able to fully meet their special needs with appropriate care packages. This will be part of a wider project which will examine age appropriate residential care.

Population data on dementia

- 25 Explores ways of collecting population-based data on dementia in New Zealand in order to better assess needs and plan more effectively for future service provision.

Research

- 26 Support NZ research proposals on dementia including operational needs assessment and evaluation of existing services.

Appendix 1

Definitions

Dementia Care

This is a residential service incorporating 24 hour provision of hotel and personal care for older people, who because of an age related dementia and the need for greater supervision have care needs which are beyond the resources of rest home services. This service also provides a home for each resident and must meet their social, spiritual and recreational needs.

High dependency psychogeriatric continuing hospital care

This is hospital level care which incorporates personal care, clinical support and hotel services for residents whose needs are such that 24 hour management and supervision of care by registered nursing staff is essential. This service also provides a home for each resident which must meet their social spiritual and recreational needs together with their need for ongoing professional and personal support. Typically these patients will have high dependency needs and exhibit challenging and/or antisocial behaviour as a result of the aging process and their psychiatric disorder, such as aggression, wandering, potential for self harm and inappropriate interpersonal relationships. These behaviours require staff skilled in psychogeriatric care and a secure environment.

Hospital care

This is hospital level care which incorporates personal care, clinical support and hotel services for residents whose needs are such that 24 hour management and supervision of care by registered nursing staff is essential. This service also provides a home for each resident which must meet their social, spiritual and recreational needs together with their need for ongoing professional and personal support.

Quality assessment and improvement

The measurement of the technical and interpersonal aspects of health care and the services and outcomes of that care and service. Quality assessment provides information that may be used in quality improvement activities. Quality improvement refers to the activities designed to objectively and systematically evaluate the quality of patient/client care and services, pursue opportunities to improve patient care/service and resolve identified problems.

Quality of care

The degree to which the patient/client care services increase the likelihood of desired outcomes, reduce the likelihood of undesired outcomes, and are consistent with current professional practice. Potential components of quality include accessibility of care, appropriateness of care, continuity of care, effectiveness of care, efficiency of care, patient/client perspective issues, safety of the care environment and timeliness of care. These elements can be incorporated into Donabedian's classic triad for assessing quality in terms of structure, process and outcome.

Quality of life

An individual's perception of their position in life in the context of the culture in which they live, and in relation to their goals, expectations and standards. The term incorporates concepts of physical and psychological well-being, levels of independence and autonomy, social relationships, support and spirituality. 'Health-related' quality of life emphasises the domains of physical and psychological well-being.

Lawton⁸⁰ defines four quality of life components for people with dementia:

- competent cognitive functioning
- the ability to engage in meaningful time use and social behaviour
- the ability to perform activities of daily living
- the maintenance of a favourable balance between positive emotion and the absence of negative emotion.

Quality of life is an outcome of quality of care.

Rest Home

This is a residential service incorporating 24 hour provision of hotel and personal care for older people. This service provides a home for each resident and must meet their social, spiritual and recreational needs.

⁸⁰ Lawton *Alz Dis Assoc Disord* 8 Suppl 138-50.

Appendix 2

Dementia Care Working Group

Age Concern: Imelda King
Alzheimers NZ: Liz Chesterman, Judy Cooper
Alzheimers advocate: Jennie Michel
Association of Residential Care Homes: Victoria Brown
Carers NZ: Laurie Hilsgen
Consumer: John Corboy
Deputy Director General of Mental Health, Ministry of Health: Anthony Duncan
Dementia researcher: Verna Schofield
Faculty of Psychiatry in Old Age: Pam Melding
Geriatrician: Nigel Millar
Grey Power: Dennis Paget
Hospitals Association: Estelle Robinson
Māori representation: Keita Dawson, Chris Cunningham
NZ Council of Trade Unions: Angela Harris, Ngaire Valster
NZ Council of Christian Social Services: Liz Andrews
NZ Nurses Organisation: Jan Hide
Residential Care NZ: Brenda McIver, Petrina Turner
Royal NZ College of General Practitioners: Claire Austin
Younger people with dementia: Gaynor Nairn

Appendix 3

In considering how best to meet the needs of a person with dementia, their whānau, family and carers, the concept of a pathway of dementia is described below. This describes difficulties experienced by the person with dementia, their networks (whānau, family, social, community), and the service providers who support them. Dementia has an insidious onset and gradually progresses. The rate of progression varies between individuals. Signs and symptoms tend to progress in stages and may vary with types of dementia. People with dementia will have various combinations of symptoms and possibly other complications as well. This makes it clear that there is no one solution to the provision of care. The following pathway provides an indication of levels of need for a person with dementia.

The Pathway of Dementia

Stage 1: Early difficulties (pre-diagnostic phase)	Stage 2: The emergence of significant difficulties in daily living	Stage 3: Reduced capacity for independence	Stage 4: Incapacity and high dependence on care	Stage 5: Final stage
The person may: Forget what they were just asked to do	The person may: Have problems recognising close family and friends	The person may: Have difficulty finding the right words in conversation	The person may: Need complete assistance with eating, toileting and often all personal care.	The person may: Lose most if not all ability to communicate
Be confused about where they are	Confabulate stories to fill blanks or account for errors	Have ideas (fixed or temporary) that are not real.	No longer recognise close family	Not be able to speak for themselves
Become lost on a familiar route (such as the way to the local shops)	Have memories that are false Increased disorientation and forgetfulness	Exhibit uncharacteristic mood swings or occasional outbursts of abusive language or violence	Lose ability to make decisions	Not be able to make decisions about medications
Have a reduced attention span	Have poor judgement and difficulty in thinking logically	Wander around their home or away from their home at random	No longer talk	Require palliative care, responsive to their needs
Become repetitive in conversation	Have trouble handling money	Become upset when faced with having to make choices	Suffers from medical complications of dementia.	
Be anxious or suspicious about possessions or the spouse/carer's behaviour	Experience difficulty in driving a motor vehicle. Forget the layout of their home	Increase disorientation of time and place Have uncharacteristic mood swings and outbursts		[Carers need a lot of emotional support]

Source: Department of Human Service 1997, Dementia care in Victoria; building a pathway to excellence, Melbourne.