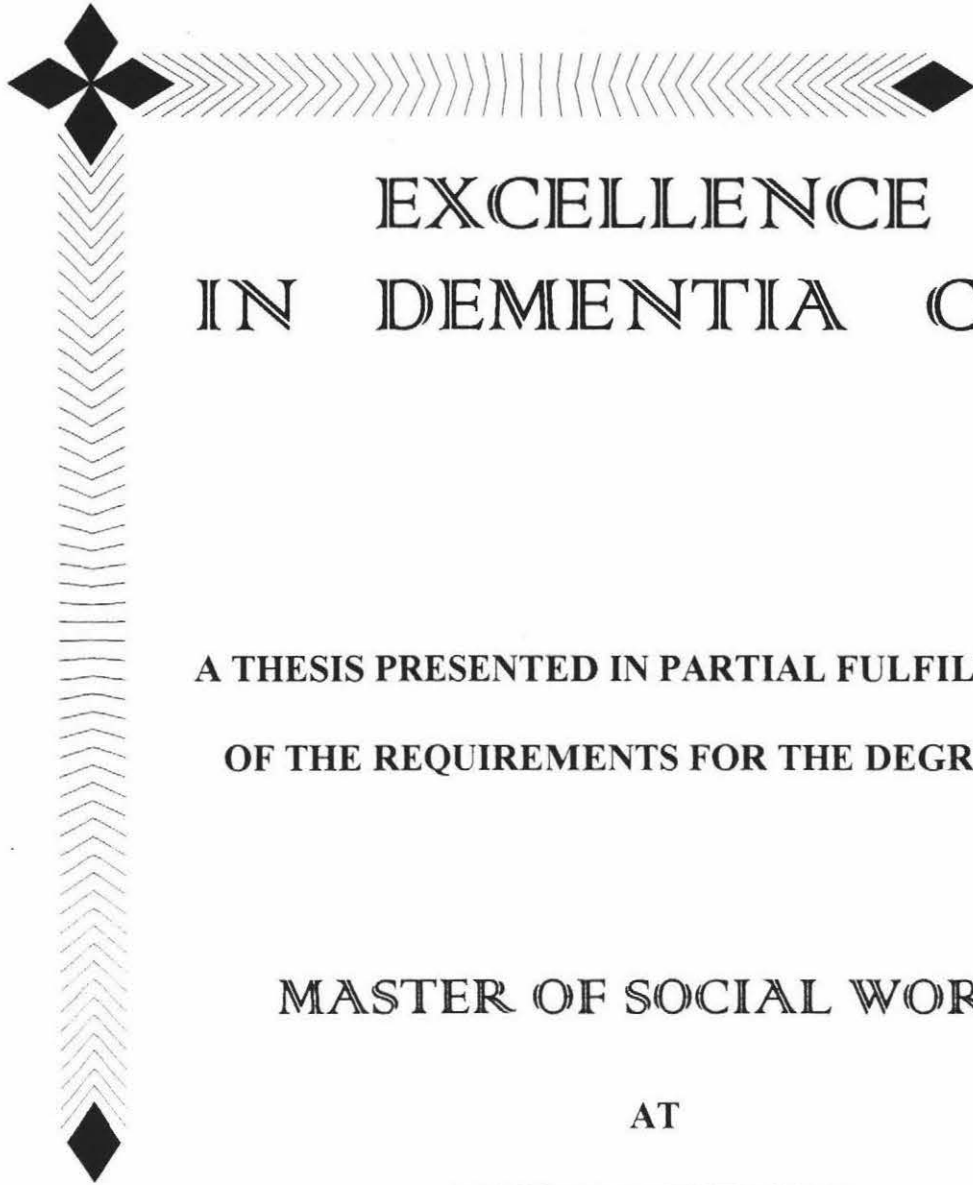


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EXCELLENCE
IN DEMENTIA CARE

A THESIS PRESENTED IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF SOCIAL WORK

AT

MASSEY UNIVERSITY

PATRICIA MARY MELLING

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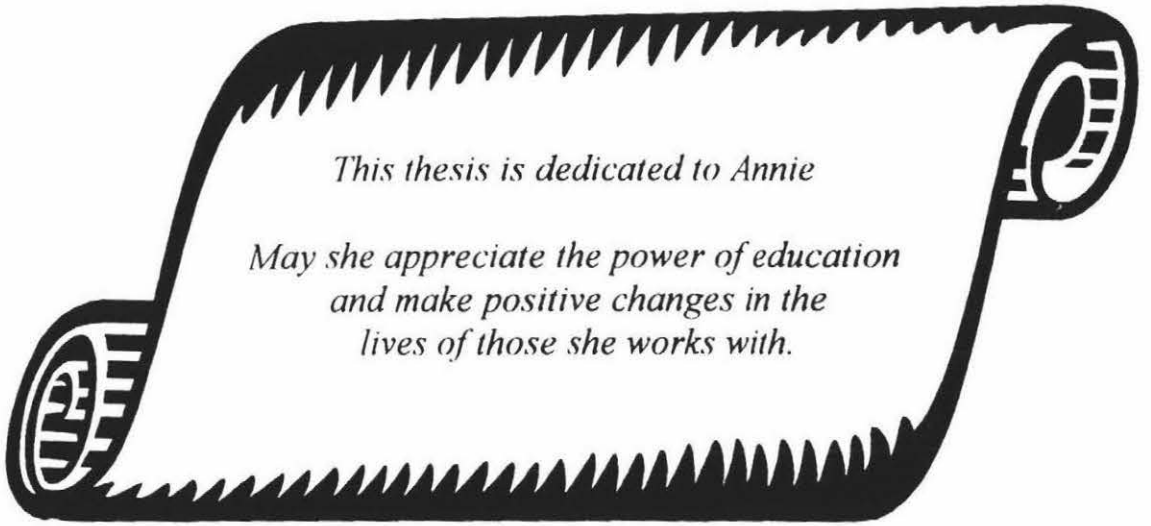
It has been a long journey over the past five years as I hopefully approach the completion of my thesis. There have been many people along the way who have helped and encouraged me. My driving force has been my youngest daughter Annie who has just completed her Bachelor of Social Work Degree. It has been our goal to graduate together hence the final burst on my part as she has just finished her final year and taken up employment.

My thanks go to my employers, Good Health Wanganui for funding my fees and the Alzheimer's Society Manawatu Inc. who have provided me with all the necessary resources, supervision time and support. The support of my peer workers, their assistance collecting material for me and keeping me informed of the latest policy changes in the health and welfare areas, is very much appreciated. There have been so many changes during my time of writing that I have constantly had to update my data.

This thesis necessitated the purchase of another computer and I extend my grateful thanks to Roy who has spent countless hours programming my machine and rescuing my work on many occasions. His patience seems unlimited.

My thanks to my supervisors Mary Ann Baskerville and Mike Garland who have always made themselves available to direct, suggest and edit my work. Thank-you for your positive encouragement and your vision for completion.

Finally to my partner Ian, thank-you for putting up with me in my times of stress when fitting in writing this thesis around a busy lifestyle. I hope I can continue to advocate for all people with dementia and add quality of life to the lives I touch.



ABSTRACT

This thesis is based on the belief that the functioning and quality of life of persons with dementia has the potential to improve in an environment where autonomy and independence are fostered within the abilities of the individual and the limitations of their disability. The thesis draws on critical theory to formulate a comprehensive framework aimed at empowering workers and caregivers to improve the quality of life for people with dementia living in residential facilities or at home. The thesis then shows how this critical approach can be applied in practice.

Two surveys were conducted. The first, examined whether workers were able to implement changes in residential facilities following an educational programme. The second evaluated the usefulness of a booklet produced for family caregivers on choosing residential care for their loved ones.

The thesis examines the policy implications and concludes with recommendations directed at policy makers and managers, which, if adopted, would provide the best quality of care for people with dementia.

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INTRODUCTION

Providing responsive institutional care for the increasing numbers of persons with progressive dementia challenges service providers, families and politicians. Alzheimer's disease is the fourth leading cause of death of older persons (Ministry of Health 1993). With an estimated developmental course of eight years plus, beginning with the onset of the symptoms, the disease exhausts the physical and fiscal resources of families in its progressively advancing stages. Families frequently turn to resthomes and hospitals to provide the care that they are unable to provide during the later stages of the disease.

As the aging population increases there are going to be increasing numbers of elderly suffering from dementia. This will have increasing policy ramifications and create even greater economic costs to the country. Victims in the advanced stage of dementia, be it Alzheimer's or a related disease, may become completely dependent on others for years or even decades. This can cause serious disruption to families and huge financial burdens. The number of persons affected by Alzheimer's Disease is expected to double in the next decade. The primary reason for this being that more and more people are living into their seventies and eighties, the age range in which dementia strikes. The likelihood of developing dementia of some type is estimated at twenty to thirty percent for persons aged eighty-five and over (Cross & Gurland 1987). At a time when there is an increasing need for long-term caregiving, social changes have undermined traditional, largely informal care mechanisms for the elderly.

Some reasons for this are :

- the decline of the extended family
- increased mobility
- trends towards more women working and having fewer children
- single parent families

These factors have reduced the willingness and ability of families to care for the elderly. As a result the demand for formal long-term care services will intensify

and these services will depend increasingly on public funds which are becoming scarce in the present economic climate.

Changes in the health/welfare interface and the introduction of Neo-liberal (or New Right) policies of 'user pays' have opened up the way for competition between private and public providers. The result of this is evident in the move away from providing long-term care for the elderly in public hospitals. Traditionally public hospitals or publicly funded 'Old Peoples Homes' provided long-term care for people assessed as needing twenty-four hour nursing care. Funding for services for the elderly and disabled previously provided by Income Support Services (formally the Department of Social Welfare), is now administered by the Regional Health Authorities (RHAs). This body distributes funds through contracts for services. These contracts are being taken up largely by resthomes and private hospitals.

Legal Resthome requirements for staff / patient ratio and staff qualifications are lower under Regulation 36 of 'Old Peoples Home Regulations 1987', as compared with the 'Hospital Act 1957'. This allows resthomes to employ caregivers (or careworkers) with no qualifications and no previous experience of caring for elderly who suffer from dementia. Financial constraints in the workplace hinder caregivers from receiving training and the specialized knowledge required to care for residents with dementia.

This thesis examines the outcomes of education and training for caregivers working in residential facilities and how they affect the quality of care, which ultimately affects residents' quality of life. Using critical theory, this thesis examines how education can empower caregivers either at home or in a residential facility to improve the quality of life for this client group.

The present environment is influenced by structural changes to the health system as part of the restructuring of the New Zealand economy which was begun under the

Labour Government of 1984. In 1991, the National Government announced a further and more radical restructuring of the health system based on Neo-liberal (or New Right) concepts. These Neo-liberal ideologies are a constant source of concern and debate throughout New Zealand at this time.

FOOTNOTE:

The ideology of the New Right is derived from the nineteenth - century *laissez-faire* philosophy which is labeled *neo-liberalism*, and also from conservative thinking, *neo-conservatism*, which places more emphasis on maintaining authority, morality and law and order through a strong state. The *New Right* believes the welfare state inhibits individual freedom, is inefficient and wasteful and morally disruptive. It argues that individual freedom is limited through the imposed burden of taxation necessary to fund state welfare. Their policies include the encouragement of the private sector to provide alternative privately based welfare, the contracting-out to the private sector of parts of the welfare services, and the application of private market principles within state welfare provision. They also encourage the family rather than the state to exercise greater responsibility for the care of its young and old dependents (Williams 1992).

CHAPTER 1

Statement of Research

AIM:

This study explores the relationship between education and empowerment. The concept of empowerment refers to the enabling of people to achieve a creative sense of power through enhanced self-respect, confidence, knowledge and skills. The study aims to show that education is the key to empower caregivers to improve the quality of life for people with dementia. The caregivers in this study include both those at home caring for a person with dementia and those working in residential facilities, such as resthomes or hospitals.

Because of recent changes in the health sector, private rest homes are now contracted by the Regional Health Authorities to provide residential as well as long-term hospital care for elderly people who can no longer be supported in their own homes. The Government's neo-liberal rationale, is the belief that the private sector can provide this care cheaper than the public health system.

The Wanganui 'Chronicle' dated 3 May 1995 published three articles in relation to staff labour costs being cut at Jubilee long-term care hospital for the elderly. Staff were told they would have to accept pay cuts in line with wages paid by the private sector or the hospital would close. This resulted a reduction in staff numbers and in staff skill ratios. I believe that unless there is a commitment by managers to provide education and training for unqualified staff the quality of care for elderly people with dementia will be adversely affected. Educational institutions have responded to these changes by providing more flexible training courses for the increasing number of unqualified workers. The majority of residential facilities have contracts with the RHA which specify the training required by staff to meet the service description.

The New Zealand Qualification Authority has provided a framework for qualifications at all levels. Educational institutions, especially Polytechnics, have responded to changes in workforce training and offer a wide range of courses from introductory certificates to advanced diplomas. Obviously there needs to be communication between industry and education to meet the training needs of workers in a changing environment. Often the content of training courses is unrealistic. Educational institutions are unaware of time restraints placed on staff in their work place. The course emphasis is placed on spending quality time interacting with each resident, but in reality staff time in the evening for example, is taken up with toileting, serving supper, cleaning up, and then assisting all residents into bed. Management and policy makers must be committed to the training and education of staff and to a realistic staff to resident ratio.

From my experience of working in the area of health, and especially health and welfare of the elderly, it appears to be the managers of the residential facilities who are reluctant to finance appropriate training for staff. People suffering from dementia in residential care require carers who are trained to understand dementia and use appropriate knowledge and skills to cope with their behaviour. Often this behaviour is aggressive and disruptive and if not handled and responded to appropriately, it can result in the unwarranted use of chemical or physical restraints.

As an advocate for people who suffer from dementia I have a mission to improve their quality of life. Because people with dementia are often unable to verbalize their feelings, I believe that the education of caregivers will empower them to bring about change in the home/workplace which will improve the quality of life for people who suffer from dementia.

In this thesis I proposed to test my hypothesis in two ways. The first part involved surveying two classes of polytechnic students who had completed a six week course on 'Dealing with Dementia'. My purpose was to gauge if the

knowledge they derived from the course had firstly empowered them to make changes in their workplace to improve the quality of life for residents with dementia and secondly, to gauge the attitude of managers to change. For the second part of my study, I produced a booklet for caregivers to assist them when choosing residential care for their person with dementia who can no longer be cared for in their own home. The aim of this booklet was to educate caregivers to encourage them to ask the right questions when selecting a rest home or hospital care for their loved one.

It is hoped that by empowering caregivers to ask the right questions, managers will be pressed to provide the quality of care expected and employ trained staff specialized in the care of people with dementia. Competition between rest homes should also put pressure on service providers to improve the quality of care they provide. In some districts where caregivers have little or no choice of a suitable facility, knowing what constitutes quality care should, I hope, put pressure on service providers to improve their care in line with what caregivers expect.

CHAPTER 2

PERSPECTIVE / CONTEXT

I locate myself in the study in a number of ways. I am a Social Worker by profession, working 20 hours for Good Health Wanganui, as a rural Social Worker based in Marton, and 20 hours a week as Manager of the Marion Kennedy Centre, a day-care service provided by Alzheimer's Society Manawatu Incorporated (ADARDS). I am also a full-time caregiver to my mother who is herself an Alzheimer sufferer and living with my partner and I. I am a member of the New Zealand Social Workers Association and the New Zealand Society of Diversional Therapists. My interest in dementia began about nine years ago when my mother started making irrational decisions. Since then I have been involved in the establishment of the Marion Kennedy Centre in 1991 and was a founding member of the New Zealand Society of Diversional Therapists, serving as an executive member and being involved in the development of a national training programme for Diversional Therapists.

My work and my family life bring me in constant contact with elderly people suffering from dementia. I can understand how the lives of caregivers are affected and what it is like living with a person who has become totally dependent on you for their personal care. As a social worker I am part of a multi-disciplinary team who assesses elderly persons for support services and residential care. I come into contact with many caregivers and rest homes. I am appalled at the lack of stimulation some of these people receive in residential care and by stories caregivers often relate to me; such as, going to visit their father and finding he was strapped to a chair.

I often advocate on behalf of members who attend our day care services, regarding medical concerns or over medication given by health professionals and rest homes. People with dementia are often denied access to quality care because they are unable to express their individual needs due to their dementia. My knowledge

has come from experience of living and working with this group and networking with other professionals, diversional therapists and recreation workers. I have experienced the positive results of using therapeutic approaches which are grounded on various theories.

My work with this group is based on the 'Critical Theory' of Fay (1975,1987). Because it is difficult to assist people with dementia to understand themselves, to empower themselves and thereby liberate themselves, I propose to achieve emancipation for people with dementia by empowering their caregivers to make changes that will improve their quality of life.

HYPOTHESIS

My hypothesis is that education and training empowers caregivers to bring about change in their home or workplace and in the attitude of managers and peer workers which then enhances the quality of life for residents with dementia. I will give a brief overview of the concepts contained in the hypothesis.

DEMENTIA - AN OVERVIEW

Dementia has been defined as a global impairment of higher cortical functions including memory, the capacity to solve problems of day-to-day living, the performance of learned percepto-motor skills, the correct use of social skills and control of emotional reactions, in the gross clouding of consciousness. The condition is often irreversible and progressive (The Royal College of Physicians, 1981).

Alzheimer's Disease is the most common cause of dementing illness in persons of all ages. Current estimates by Alzheimer's Society New Zealand (ADARDS), state that approximately fifty percent of people with dementia have Alzheimer's Disease, another twenty percent have multi-infarct dementia and about ten percent have a mixture of both. Other causes of dementia account for the remainder; the

most common of these being Parkinson's disease, alcohol related dementia, Pick's disease, Huntington disease and AIDS related dementias.

Alzheimer's Disease is devastating for both those who have it and for their families. It has been called "The Silent Epidemic" (Mace & Rabins 1985), as carers looking after a family member refer to their daily care as being a "36 Hour Day" as the disease eventually renders the victim totally incapable of caring for themselves. At some stage people with Alzheimer's Disease require residential care in either a Stage II rest home, a Stage III special dementia unit, or hospital care.

WHO ARE THE ELDERLY?

Government policies have defined elderly as being those over the age of sixty five or those that suffer from an age related illness. This generally includes those who suffer from Alzheimer's Disease before the age of sixty five years. I acknowledge that psychological and physiological characteristics may be as diverse within age groups as between age groups, but when a person requires health services, funding for residential care which is presently provided by the RHA, is defined as those over the age of sixty five. The standards and grading of residential care are set by the New Zealand Rest Home Association, the Ministry for Health, the New Zealand Council on Health Care Standards and the RHA. A person cannot enter residential care until they have been assessed as requiring this level of care by a Senior Assessment Team generally attached to each local Crown Health Enterprise (CHE).

EMPOWERMENT

Empowerment theory offers a way of working which meets the needs of oppressed people and avoids making the oppression worse. Elderly people with dementia are considered oppressed because they are vulnerable to being exploited by politics and power. In the context of this thesis empowerment addresses two related objectives: the achievement of more equitable distribution of resources

and non-exploitative relationships between people and the enabling of people to achieve a creative sense of power through enhanced self-respect, confidence, knowledge and skills. The specific goals of empowerment are positive duties for workers to improve the quality of the lives of those for whom they have special responsibilities. De Bono (1979 p. 131) says conveying respect and treating people with dignity can create the happiness which an individual feels, if even for a moment, because they are not totally dependent on others. This feeling gives people control over some temporary feature of their lives, a self-space which can provide for dignity if that space enables a person to be at ease with him/herself and his/her circumstances. Rees (1991) believes that if empowerment is achieved it can have significant effects on people's physical and mental health and on their attitude towards powerful people and institutions. The process of achieving these goals involves an improvement in people's image of themselves, the acquisition of tangible resources such as food or shelter and intangible resources such as information and the creation of supportive social networks.

QUALITY OF LIFE - AN OVERVIEW

Older people perceive quality of life in terms of the influence of their culture, education, previous lifestyle, family strength, health care benefits, and community life, integral to their lives (George & Bearon, 1980). People should not assume that because a person has dementia that this should reduce their quality of life. The majority of people who suffer from dementia have lived normal lives and have held responsible positions in the community. It is important that they continue to be treated with dignity, and as an individual with specific needs. People with dementia are often unable to express their dislikes or concerns and sometimes behave inappropriately. This is often misunderstood and treated with either physical or chemical restraints. Whilst science has extended our life expectancy, it has at the same time failed to provide guaranteed social quality of life for these extended years.

CHAPTER 3

LITERATURE REVIEW

In recent years there has been an increasing volume of literature available on all aspects of dementia and dementia care. The literature which informs this thesis examines available research on the special care approach and the benefits of providing special care units specifically for those who suffer from dementia. There appear to be wide variations in philosophies, therapeutic approaches, protocols for behavioral management, staff education and environmental design. The diversity of these units poses a challenge when evaluating their effectiveness.

RESEARCH INTO SPECIAL DEMENTIA UNITS

Studies overseas and in several special dementia units in New Zealand (ADARDS 1994; Cooper 1992, 1994; McDougall and Beaver 1994; Campbell 1991) have shown that alternative therapies are beneficial and that all behaviour has a meaning.

Literature and experience in New Zealand (Cooper 1992; McDougall and Beaver 1994) have shown that the introduction of special dementia units and alternative therapies are successful in controlling the aggressive and disruptive behaviour of those with dementia. Carers need to be committed to moving away from the medical model of physical and chemical restraint to an integrated approach. This includes attending to spiritual, emotional, social, intellectual and an expanded concept of physical needs. The programmes offered need to aim at maintaining quality of life and cannot be implemented if the facilities design does not support them.

In recent years there has been an increase in the number of long-term facilities that specialize in dementia care. Units that are self-identified as special units for persons with dementia vary tremendously in terms of their philosophy, environmental design, staff training, criteria for admission and therapeutic approach. In 1993 Government introduced additional funding specifically for

dementia care which has prompted the promotion of these special units. These units provide a secure environment for those with dementia who are wanderers or have been assessed as having behaviour problems or exhibit aggression.

Despite this growth, there is no consensus as to what constitutes special care, and the research literature has not clearly documented the benefits (Berg, 1991; Read, 1992). In 1992 the United States National Institute on Aging announced the Award of \$2.25 million for research into the effectiveness and costs of Alzheimer's special care units. Nine co-ordinated projects to evaluate the impact of these programmes were to be funded under this scheme (Sand, Yeaworth, McCabe 1992). Taft, Delaney, Seman, Stansell, (1993) reported positive outcomes, such as increased ability to perform activities of daily living, decreased agitation, weight stabilization, increased resident interaction, and increased family satisfaction. In contrast, only two of the six studies used as control groups to evaluate changes in residents over time, documented beneficial outcomes (Chafetz et.al. 1991; Coleman et. al. 1990; Holmes et. al. 1992; Maas, 1990; Wells, 1987).

McCracken (July 1994), says to date the most comprehensive study of special care units was conducted by Sloane and Matthew (1991). Thirty-one special units (n = 307) were matched with 32 traditional units (n=318). In this study, the researchers concluded that special care units resulted in better care based on:-

- residents' appearance,
- little difference in weight loss,
- similar range of services to traditional units,
- higher amount of interaction with residents more often out of their room,
- greater mobility,
- fewer medications,
- less physical restraints,
- and similar use of chemical restraints.

McCracken believes that both lack of definition of special care units and too rigid a definition are of concern to those who seek to find better care for persons with dementia. Although lack of definition could lead to 'warehousing' through separation by diagnosis (Boling & Gwyther 1991), it is feared that "implementation of comprehensive regulations at this time could stifle ongoing experimentation with alternative methods of care" (Berg. 1991:1236).

QUALITY OF LIFE

The goal of providing excellence in dementia care is to provide an environment where the needs of people with dementia can be enhanced to improve their quality of life. Quality of life is defined by George and Bearon (1980) in terms of four underlying dimensions, subdivided into subjective and objective. Life satisfaction and self esteem are classified as subjective, whereas general health functional status and socio-economic status are labeled objective.

For many years, a major concern regarding the successful maintenance of quality of life in old age was adjustment to retirement. Miller (1965) believes that the loss of working status represents a degrading role loss. Depending on the capabilities of the individual, leisure and recreational activities can sometimes replace this loss. The elderly with dementia are very responsive to activities that stimulate reminiscence of their earlier years as this uses the part of the brain that stores long term memory which people with dementia usually retain the longest. In residential facilities all staff including the cooks and domestic staff should work as a team to enable each resident to be treated as an individual. This sometimes means allowing that person to bath or have a meal when they are ready, not for staff convenience, and allowing residents to take part in the day to day chores around the unit. When you consider that most women especially, have spent the majority of their lives in the caring role as housekeepers, it is natural for them to consider themselves still in this role. By allowing them to participate in the daily chores around the unit, whether it be helpful or not, gives them a sense of achievement and self worth (McDougall & Beaver 1994).

EDUCATIONAL PROGRAMMES

In one study by Chiverton and Caine (1989), an educational programme to assist spouses in coping with their partners with Alzheimer's Disease was examined. This study investigated whether a brief educational programme improved caregivers' coping skills and also questioned whether the gender of the spouse had an effect on coping ability. The sample consisted of forty spouses who were caring for their spouse suffering from Alzheimer's disease at home. Twenty of the group participated in the educational programme and twenty in the control group did not. Findings indicated that the educational programme was beneficial in assisting spouses to feel more competent in the face of the disease process and to function with greater independence. In the treatment group, the greatest significant increase was in the knowledge domain, followed by therapeutic competence and emotional competence. No overall relationship was found between gender of the spouse and coping ability.

Barnett (1995) describes how 'Dementia Care Mapping' gives staff in residential units the opportunity to study the lives of the residents by observation rather than by communication. The assumption is that people with dementia exhibit much the same indicators of well-being and ill-being in their behaviour and demeanor as people without dementia. By observing residents' non-verbal language staff can learn cues which stimulate the person with dementia and cues that distress the person. These observations are shared with other workers within the facility to promote changes to improve their quality of life.

Alzheimer's Education is a company in Australia that specializes in education for staff working in residential facilities and family caregivers. This company produces videos, written material and audio tapes as educational resources. These resources can be hired or bought from any branch of the Alzheimer's Society in New Zealand. Often these videos are shown in the classroom or at staff training sessions to demonstrate how to communicate with a person with dementia or

methods of coping with difficult behaviour. Several caregivers have also written books telling of their experiences of caring for and living with a person with dementia.

The research design of this thesis in Chapter Eight tests the hypothesis that education is the key to empowering workers to make changes in their workplace to improve the quality of life for their residents. Sand, Yeaworth and McCabe (1992) reported on a survey they conducted on 203 long-term facilities in Nebraska USA. They found that staff training and educational requirements varied from unit to unit and that staff education and training were not in keeping with the demands of the work. Sand et al. concluded that staff should receive both classroom education and supervised clinical experience with specific care approaches. They believe that staff should be recruited with the expectation that specialized skilled care will be required and taught methods to cope with their own emotional responses.

STAGES OF ALZHEIMER'S DISEASE

Alzheimer's Disease has been described in several stages by Barry Reisberg (1983). These stages help caregivers determine the needs of the person with Alzheimer's disease, as the disease progresses. However, Reisberg's research along with other research by Haight (1989) and Kayser- Jones (1989), ends at the beginning of the late stage.

The late stage of Alzheimer's, (see Figure I) often finds the sufferers in nursing homes where obviously the quality of custodial care varies. Haight (1989) suggests that research be conducted to examine the care needed in the end stages of the disease to provide the highest quality of life possible.

Reisberg (1983) likens his seven stages of Alzheimer's disease to the reverse stages of childhood, moving from adolescence back to infancy. Haight (1989),

says if the final stages of Alzheimer's disease is similar to infancy, maybe researchers could search the literature on infant care. She says, for example, if at the end stage the person with Alzheimer's disease is restless, they may need to be wrapped in blankets, just as infant is swaddled to gain comfort, warmth and security. In order to take this approach carers must first put aside their belief that such care speaks of infantilism and be open to alternative modes of care.

FIGURE I

The Global Deterioration Scale

Reisberg's scale describes how the disease's pattern parallels in reverse that of child development - and tells doctors and relatives what to expect next of Alzheimer's victims.

<i>Approx. Age</i>	<i>Abilities Acquired</i>	<i>Alzheimer's Stage</i>	<i>Abilities Lost</i>
12+ years	Hold a job	Borderline	Hold a job
7-12 years	Handle simple finances	Early	Handle simple finances
5-7 years	Select proper clothes	Moderate	Select proper clothes
5 years	Put on clothes	Severe	Put on clothes
4 years	Shower unaided		Shower unaided
4 years	Go to toilet unaided		Go to toilet unaided
3-4.5 years	Control urine		Control urine
2-3 years	Control bowels		Control bowels
15 months	Speak five/six words	Late	Speak five/six words
1 year	Speak one word		Speak one word
1 year	Walk		Walk
6-9 months	Sit up		Sit up
2-3 months	Smile		Smile

REISBERG. B. (1983)

ENVIRONMENTAL EFFECTS

The study of environment and behaviour has captured the attention of research scientists from many disciplines (Kayser - Jones 1989). In recent years understanding the effects of the environment has been a major concern in social gerontology (Kahara 1982). Kahara states that despite the availability of research findings, there have been limited application of these findings to the care of the institutionalized elderly. Most studies have focused on four major features of the environment: the physical characteristics of the environment; the organizational climate; the personal and supra personal environment climate; and the social psychological milieu. The physical aspects include items such as policy, staffing and financing, as well as the presence or absence of mechanisms such as a residential council for residents to participate in the planning of their care and the airing of grievances.

Gunderson (1978) developed a model of therapeutic processes in dementia care. He originally developed this model for working with psychiatric patients with the emphasis on the importance of the social context. Staff play a critical role in building a relationship and creating a culture that supports, involves, and validates the person with dementia. The application of this model is applied to dementia care in Chapter Six.

Kayser-Jones (1989) found in her research on accommodation for the elderly that while the physical structure of a building is important, it is the people, especially the staff who determine the quality of care. Second, the activities and services that an institution provides are of paramount importance. The programmed activities should provide interesting and meaningful recreation for residents every-day.

Activity programme planning requires an understanding of the needs of the older person. A human development theorist Abraham Maslow (1954), identified a human beings 'Hierarchy of Needs'. He purported that once an individuals

basic need for food, safety, belonging and esteem have been met, they can aim at higher needs of friendship, involvement and achievement, (which he terms 'self-actualization'). If one assumes that the living arrangements of most people with dementia addresses their basis needs, then the activity programme can provide an opportunity for these people to address their higher needs.

Transactional models predict outcomes by looking at the transaction between a person and the environment. Richard Lazarus' (1978) 'Stress and Coping Paradigm' is a transactional model that views the environment from the perspective of cognitive psychology. The relationship between the person and the environment is seen as a dynamic process. Cognitive appraisal and coping mediate this transaction to determine how environmental stresses affect outcomes. A study by Dr Kayser-Jones on open ward design, showed that by having a suitable environment, the open wards developed into small communities with unique social organizations. Settings that foster the development of resident communities encourage the expression of social roles and group norms. This model places importance on creating a physical and social environment that maintains the social integration of the residents. The provision of alternative roles is an important element contributing to quality of life. Ongoing staff training is essential and it is important that all staff work as a team to give the person with dementia a purpose in life and the best possible quality of life.

Seman (1990) studied the subjective experience of individuals with Alzheimer's Disease when 100% of the individuals spoke of the loss of independence and autonomy. Danner, Beck, Heacock and Modlin (1992) use research findings to improve nursing care. They believe that cognitively impaired elderly are often placed in long-term care where they become more dysfunctional and dependent, thus diminishing their quality of life. Danner et al. suggest that professionals can maximize functional ability by assessing specific cognitive abilities and using this information to design specific interventions to facilitate and maintain functional ability.

CHAPTER 4

THEORETICAL MODEL

My study is based on the critical theory of Fay (1987) but adapted to working with people with dementia by incorporating the work of Rose and Black (1985) and Rees (1991) on empowerment theory. Because people with dementia are often unable to express their feelings and concerns verbally, it is essential that carers understand non-verbal language and use therapeutic techniques to relieve their distress.

Fay (1987:81) states that happiness is a value that is a necessary part of 'Critical Theory'. He says "Happiness has to do with how one views one's total life pattern, or at least those aspects of it that one takes to be significant". Happiness is an intellectual feeling that involves emotional and cognitive elements. If people with dementia are understood and validated when distressed and appear happy and content, this is often the only way of judging their satisfaction with life. An essential element of critical theory is to understand the 'felt needs' of the people with whom one is working.

THE NATURE OF CRITICAL THEORY

Fay (1987) says, the critical approach is an attempt to understand in a rationally responsible manner the oppressive features of a society. This understanding stimulates its audience to transform their society and thereby liberate themselves. The critical model asserts that in order to have subject matter at all, the social scientist must attempt to understand the intentions and desires of the actors he/she is observing, as well as the rules and constitutional meaning of the social order. The reason for this is that critical theory has its roots in the 'felt needs' and sufferings of a group of people, and therefore it is absolutely necessary that the critical theorist comes to understand these actors from their own point of view at least, as a first step.

Fay (1987:30) says that

“the fundamental criteria for a social science to be critical is that it is to be scientific, critical, practical and non-idealistic.”

The practical component of critical theory requires its audience to be enlightened, through consciousness raising of the oppressed; empowered through the group coming to understand itself and propel itself into revolutionary activity. The end result is emancipation, which results from empowerment. The whole point of a ‘Critical Theory’ says Fay (1987:29),

“is to redress a situation in which a group is experiencing deep but remedial suffering as a result of the way their lives are arranged. Its aim is to overturn these arrangements and put in place another set, in which people can relate in fuller, more satisfying ways.”

A social scientific theory that tries to be scientific, critical, practical and non-idealistic all at once, must consist of a complex set of theories that are systematically related to one another (Fay 1987:31). Fay believes a developed critical theory would comprise all of the following:

I. A THEORY OF FALSE CONSCIOUSNESS : Which

1. Demonstrates the ways in which the self-understanding of a group of people are false, incoherent, or both. This is sometimes called the ideology-critique.
2. Explains how the members of this group come to have these self-misunderstandings, - and how they are maintained.
3. Contrasts them with an alternative understanding, - showing how this alternative is superior.

II. A THEORY OF CRISIS : Which

4. Spells out what a crisis is.
5. Indicates how a particular society is in such a crisis. This would require examining the felt dissatisfactions of a group of people and showing both that they threaten social cohesion and that they cannot be alleviated given the basic organization of the society and the self-understanding of its members.

6. Provides an historical account of the development of this crisis partly in terms of the false consciousness of the members of the group and partly in terms of the structural basis of the society.

III. A THEORY OF EDUCATION : Which

7. Offers an account of the conditions necessary and sufficient for the sort of enlightenment envisioned by the theory.
8. Shows that given the current situation these conditions are satisfied.

IV. A THEORY OF TRANSFORMATION : Which

9. Isolates those aspects of a society which must be altered if the social crisis to be resolved, the dissatisfactions of its members are to be resolved and the dissatisfaction of its members lessened.
10. Details a plan of action indicating the people who are to be 'carriers' of the anticipated social transformation and at least some general idea of how they might do this. (Fay 1987:32).

This organization of four primary theories comprising ten sub-theories is the basic structure of critical social science. Fay (1987), believes that it is only when these elements are presented and related to each other in a consistent and systematic way that a theory of social life can properly be called 'critical'. Using the principles outlined in Fay's schema and the four basic theories this thesis develops a 'Critical Theory' that can be applied to working with elderly persons suffering from dementia.

APPLYING CRITICAL THEORY TO WORKING WITH ELDERLY PEOPLE WITH DEMENTIA

This section develops a critical approach for social and community workers when working with elderly persons who suffer from dementia. This group of elderly people not only suffer oppression because of their disability but also suffer from ageism (the attitude of people towards the elderly). Working with elderly people

with dementia also involves considerable work with the caregivers and families. It is therefore necessary to use an approach that empowers the clients and also advocates for them.

This thesis uses Fay's (1987) basic schema and since there is no critical theorist that I could locate in the area of elderly and dementia, I have drawn on the writing of Rees (1991) on empowerment and Rose and Blacks (1985) advocacy/empowerment approach. Rose and Black's approach is based in the area of mental health after-care which came into focus with deinstitutionalization

I. A THEORY OF FALSE CONSCIOUSNESS

Rees (1991) believes that we need to understand the process that disempowers then find the process that empowers. He uses biography to examine perspectives of students, clients, migrants, poets and prisoners who have often addressed and overcome experience of powerlessness. He says (1991:5),

“That consideration of biography is a significant part of the overall context in which the discussion of political literacy, social analysis and personal skill occurs”.

Rees uses biography as a central concept to achieve empowerment, through historical analysis, by revealing how the irrationalities of social life which are causing the dissatisfactions can be eliminated by taking some specific action. When working with people with dementia this means gathering the life histories of these people from their family and friends to understand how past experiences or unresolved crises during their lives may contribute to their irrational behaviour. In this context empowerment would mean being at peace within themselves, appearing content and happy with life and not displaying agitation or aggression. Rees also draws in the work of feminist writers who have exposed the history of women's oppression as a product of social structure and have shown how some form of liberation could be achieved by examining the political implications of

personal lives. (A knowledge of social expectations of women assuming the role of carer and providing the majority of care to people with dementia).

Rose and Black's approach also assumes that a person's behaviour and emotional experiences are directly connected to biography but also to objective reality. By this they mean that a person's concept of him or herself is a reflection of what they have experienced over time in particular settings combined with their current location in an objectively identifiable environment. They believe that advocacy is issue orientated, focused on objective conditions, and arises from the concrete daily lives of the people. Empowerment emerges as a complementary concept to advocacy and has as its focus a process of development of the people (understood as persons in the social world) which is designed to reconnect subjective responses (presentation of self, self-image, interactive patterns etc.), to the object conditions which form the focus of advocacy.

Rose and Black (1985) argue that a precise formulation of client needs or a problem definition is essential to the development of a positive practice. Problem definition level of theory mediates between the more global theory of society, which establishes a larger context for understanding the broad policy issues and direct implications and articulation of practice theory. It establishes both a direction and a base line for evaluation of practice activities. An example of this is blaming a person who is not coping well with daily living on their individual behaviour or values rather than resulting from poverty.

Rose and Black develop a framework for practice which:

- Validates the person
- Reconnects him/her to the objective context in which he/she lives
- Legitimizes the impact of psychiatric history or self expression
- Engages the person in the process of transformation.

Spouses and families of the elderly suffering from dementia also suffer from a form of false consciousness induced by feelings of guilt. This can occur as the person that they loved and knew, no longer recognizes them and refers to them by another name (e.g. the name of a first wife). The person with dementia often becomes abusive and says hurtful things to those closest to them. It is often difficult for the family to accept this behaviour and finally come to terms with having to place their family member into full-time care.

II. A THEORY OF CRISIS

Rees (1991) believes a crisis has occurred because of the dominant trends of the 1980s and the Government's inattention to social justice. The 1980s and 1990s brought about policies to achieve economic efficiency. Managers were often employed in organizations without specific qualifications or experiences to undertake the activities for which they were to be responsible. There was a move towards efficiency and effectiveness in the human services. Economic policies did not adequately address the social consequences when policy and practice were separated. Rees argues that political literacy (an understanding of government policies) gives people confidence in analyzing issues of powerlessness and thereby participating in finding solutions to problems.

Rose and Black (1985) believe a crisis occurred with deinstitutionalization. There was a move to community care to empty hospital beds before a programme of after-care was established. This led to the situation of the revolving door whereby discharged psychiatric patients were returning to hospital in large numbers. With the medicalized approach to problem definition uncritically in control, psychiatrically defined services were presumed to be as 'appropriate' to clients needs in the community as they were in hospital. Mental health aftercare, as a concentrated area of policy development in the United States, occurred some twenty years after the practice of massive discharge began. Patients' needs for housing, medical care, income, legal protection and meaningful activity were

subsumed under the aegis of the hospital for the duration of their stay. Virtually no provisions were made for these essential needs in the community during the early decades of deinstitutionalisation.

III. A THEORY OF EDUCATION

Here both Rees and Rose and Black acknowledge the work of Paulo Freire (1972), who aimed to create self awareness among illiterate Brazilian peasants whom he described as having few ways of knowing the sources of their oppression. Friere wrote:

“In order for the oppressed to be able to wage a struggle for their liberation they must perceive the reality of oppression, not as a closed world from which there is no exit, but as a limited situation which they can transform” (Friere 1972:34).

In their account of advocacy and empowerment in mental health aftercare Rose and Black (1995) observed that the power imbalance in conventional user/provider relationships left little room for challenge and change. Current health policies define users of services as customers, indicating that there is a choice of services to choose from. Instead the needs of these customers are assumed by the policy makers and service providers with little or no input from the users. Consumerism is characterized by the acceptance of problems and services defined by someone else whereas the struggle to achieve political identity through empowerment should encourage people to resist being treated as consumers. Empowerment presupposes critical questions and analysis. Rose and Black's goal in working with ex-psychiatric patients was to transfer these people from the status of being known and acted upon to having the experience of knowing and acting. Such a transfer captured the meaning of empowerment and was reflected in ex-patients' self - image.

Changes in the health system in New Zealand where CHE's are run on a budget and expected to generate revenue refer to users of their services as consumers. A health consumer is a person who receives any health care procedure or has a

disability which reduces their independence. The Health and Disability Consumers Information Act which came into effect on July 1st, 1996 set out consumer rights. At the same time an Advocacy Support Service was established throughout New Zealand to assist consumers who are in need of an advocate to assist them with complaints and concerns

One of the important tasks when working with people with dementia and their caregivers is to educate them to understand the process of the disease and how it affects a person's thinking, behavior and personality. Education of careworkers in residential facilities is just as important to allow them to understand the consequences of the disease and learn skills for working with people with dementia in the least restrictive way. Education can empower a person in the early stages of dementia to develop strategies to cope with the effects of the disease. For those who care for people with dementia education can empower them to make changes in the home or workplace to improve the quality of life for those they care for.

Often those involved with the care of a person with dementia need to advocate for that person because they are unable to express their needs or wants. People with dementia have the right to quality care and families have a right to have input into the type of care provided.

Rose and Black (1985:54) use dialogue as a vehicle for uncovering the existential reality and opening it up to reflection. They say dialogue cannot be professional interviewing, application of therapeutic technology, instructions for improved functioning or casual conversation. To unveil oppressive reality is to be willing to enter it more fully, to encourage the elaboration of expression, to support the expression of experiences, to initiate the early steps of critical reflection. How and why did/do things happen as they do? How do we know why things unfold as they appear to? Who benefits from current arrangements? Dialogue thus implies a relation based on trust, mediated by the concrete, objective world for the purpose of transforming it. Dialogue is essential when working with people

with dementia and their caregivers, with the client and the caregiver being seen as equal. Frequently the worker is required to act as an advocate for the client as they seek assistance from General Practitioners, NZ Income Support Services, home support service providers and residential facilities.

Freire's goals include political literacy to demand dignity, justice, and meaningful participation in the politics of everyday life. Freire (1972) emphasizes this concept:

“ All work done for the masses must start from their needs and not from the desire of any individual, however well-intentioned”
(Freire 1972:60).

Rees offers an account about how social justice can be achieved through empowerment theory. He educates and enlightens practitioners by explaining the meaning of politics and power and the necessity to relate policy to practice. Rees also draws on systems theory which provides a model to explain the client's behavior.

IV. A THEORY OF TRANSFORMATIVE ACTION

Rees (1991) believes that once people are enlightened and become politically literate this in turn will lead to emancipation. The process Rees uses emphasizes interactive and political skills. He says whatever time it takes to achieve objectives, the process of change goes through various stages. This change needs to be evaluated at various stages of the process. Using the work of Freire, Rose and Black and Rosenfeld, Rees (1991) developed stages in achieving power which can be applied to working with people with dementia. The theory of transformative action which will be expanded on in the next section draws heavily on the work of Freire (1972) using the action/reflection model.

CHAPTER 5

RECONSTRUCTION

Having identified Rees and Rose & Black as 'Critical Theorists' I now draw on their work to develop a plan of action based on 'Critical Theory', for elderly people with dementia. This plan as seen in Figure II begins at the base using education and information as a vehicle for empowering community services and individuals. These services and individuals are empowered by their increased and new-found knowledge to apply pressure to residential facility management and policy makers to bring about change and emancipation for those suffering from dementia. In theory these changes ultimately bring liberation, happiness and improved quality of life for residents.

Working to improve the quality of life for people with dementia also involves considerable work with their caregivers at home and their families. I wanted my approach to benefit the people who suffer from dementia as there have been several studies conducted on caregivers (Opie 1991; 1992; 1995) and very few on the actual people who suffer from dementia. Alzheimer's Society was originally formed to support the caregivers and it wasn't until 1990 that they included in their aims to provide support and education for the person with dementia as well.

I believe a person suffering from dementia has the right to lead a life as close as possible to that they would have had if they had not become disabled. These people have generally led 'full' lives, held responsible jobs, raised a family, held positions of trust and respect in the community, and have been involved with clubs and organizations. The effects of dementia are devastating and differ from individual to individual with few actually admitting that their memory is failing. As dementia progresses, and the person requires 24 hour supervision or nursing care, caregivers are forced to seek residential care for their family member.

FIGURE II

**CRITICAL MODEL FOR EXCELLENCE
IN DEMENTIA CARE**

QUALITY OF LIFE HAPPINESS LIBERATION



EMANCIPATION

PEOPLE WITH DEMENTIA



CHANGE

MANAGEMENT

POLICY MAKERS



EMPOWERMENT

COMMUNITY SERVICES

FAMILY CAREGIVERS

RESIDENTIAL CARE STAFF AGENCIES



**EDUCATION AND
INFORMATION**

Figure II shows how education and information are the vehicles used to empower caregivers and careworkers to bring about change to improve the quality of life for people with dementia.

Using Fay's (1987) schema, and the principles of other critical theorists, I have drawn up a model of a Critical Perspective (Figure III A Model of Reconstruction) to apply to the area of working with the elderly suffering from dementia.

FIGURE III

A MODEL OF RECONSTRUCTION

I. A THEORY OF FALSE CONSCIOUSNESS

1. Ideology - feeling of helplessness with the health system, welfare agencies, government policies.
2. Theory of the State - how much state intervention should there be in caring and providing for the aged.
3. Feminist Theory - Patriarchal society - women conditioned by society to believe it is their role to be caregivers.

II. A THEORY OF CRISIS

4. Theory of the New Right - user pays, welfare cuts, selling off of assets leading to increased costs for essential services. Deinstitutionalisation, asset testing.
5. Theory of Class - economic differentials between services available. Class advocacy.
6. Erikson's psychosocial theory of development - integrity versus despair resolution versus vegetation

III. A THEORY OF EDUCATION

7. Radical Feminist Theory - consciousness raising, forming self-help groups.
8. Empowerment Theory - taking control, making informed choices, action - reflection.

IV. A THEORY OF TRANSFORMATIVE ACTION

9. Advocates lobbying parliament for more resources, policy submissions
10. Plan of Action - setting up support groups for families, education for caregivers and residential staff

PLAN OF ACTION OR PRACTICE

This plan of action will center around the advocacy/empowerment approach based on the theories shown in Figure III. Rose & Black (1985: 130) describe two types of advocacy: that which relates to an individual's interest or to an issue affecting many individuals; and the other to class advocacy in the interests of a common cause. Often when pursuing advocacy for a single case, a worker becomes aware that this one person or ones family grievance is shared by numerous others. Rees (1991:145) says that qualifications in advocacy do not necessarily derive from legal training or practice. Advocacy to achieve a particular outcome can be facilitated by familiarity with the exercise of power in different contexts and with an attitude which says that in matters of social injustice, the realm of public affairs should become a political domain where people are enabled to represent their own interests.

The process of empowerment addresses two related objectives: the achievement of a more equitable distribution of resources and non-exploitative relationships between people; and the enabling of people to achieve a creative sense of power through enhanced self-respect, confidence, knowledge and skills (Rees 1991:66). Rees believes that these objectives are inter-related. It is also the belief of Rees that if empowerment is achieved, it can have significant effects on peoples physical and mental health and on their attitude to powerful people in institutions. The process of achieving these goals involves an improvement in peoples image of themselves, the acquisition of tangible resources such as money and shelter and intangible resources such as information and the creation of supportive networks.

I. A THEORY OF FALSE CONSCIOUSNESS

Figure III shows a clear inter-relationship between Ideology, the Theory of how the State should intervene in the care of the aged and Feminist Theory. All explain the powerlessness felt by the elderly. Fay (1975) believes a critical theory is rooted in the felt needs and sufferings of a group of people, and therefore it is absolutely necessary that the critical theorist comes to understand these actors from their own point of view. Rees does this by using biography as a central concept to achieve empowerment, through historical analysis, by revealing how the irrationalities of social life which are causing the dissatisfactions can be eliminated by taking specific action. He believes that consideration of biography is a significant part of the overall context in which the discussion of political literacy, social analysis and personal skill occurs.

Economically inspired values which have influenced New Zealand's policy priorities in the past decade have seldom reflected attention to social policy or the social consequences that have resulted. Many elderly people, and especially those with dementia, are struggling to meet increased costs for essential services and extra costs incurred because of their disability. People with dementia especially those living alone lack insight into their present circumstances and are at risk of suffering poor health because they forget to take medication or have forgotten how to prepare meals. They are reluctant to pay the cost or accept support services for example, home help or meals on wheels. They are also open to financial exploitation and abuse often hiding large amounts of cash under their mattress or forgetting where they have put their money. Many of those who have saved for their retirement are reluctant to part with their life savings believing that they still need to save for their old age or wanting to bequeath them to their family. Before entering residential care the person is income and asset tested for eligibility for a government subsidy. Single persons are allowed to retain \$6,500 in income or assets and a pre-paid funeral while married couples are allowed \$40,000 in assets not including home, chattels or car, and \$28,927 in income (Ministry of Health, 1995). Recent changes in the asset testing of married couples have

recognized that the spouse remaining in the family home has similar outgoings to a married couple and entitled to continue living in the way they were accustomed.

Feminist theory believes that women tend to view their caregiving role as an extension of their previous caring and nurturing roles. They experience feelings of guilt when they can no longer care for their person suffering from dementia. This has been observed by several researchers (Gilleard et al.1984; Zarit et al. 1980). Together these theories explain the causes of the self-(mis)understandings of this group of people.

II. A THEORY OF CRISIS

A theory of crisis explains the causes and nature of the crisis in which a social system is caught. Elderly persons with dementia are oppressed by society's attitudes to ageism and also by society's attitude to disabilities. With the expected increase of elderly persons in the population, the stigma that the elderly with dementia and their families suffer needs to be addressed by public education. The Governments adoption of the New Right Theory has caused a crisis in the provision of health services, and shortages in funding to maintain appropriate support services. Deinstitutionalisation meant a move to community care. The question is; What is meant by community care? At present the majority of caring is done by families in their own homes, with little relief. The resources and services that are available in the community have to be fought for and eligibility approved by income testing. Currently home management support and personal care are available to those who hold a Community Services Card. There is a limit to the number of hours a person can receive. Relief care is not income tested but is limited and can be used in a number of ways i.e. relief in the home, daycare or relief care in a resthome on an intermittent cycle, if the person is assessed as requiring that level of care. The funding for community care is administered in New Zealand by four Regional Health Authorities and allocated through contracts to service providers. There appear to be differences throughout New Zealand as

to how these services are delivered as each RHA implements their own policies and decides which services they will fund. Unfortunately they are delivered on an economic basis rather than social one i.e. often a person is put into continuing care because services in the home are limited due to economic circumstances and not sufficient to assist the caregiver to continue caring for the person at home.

In recent years there has been an increasing emphasis on community care as the ideal way to care for a person with dementia. However it must be recognized that caring for these people is physically and emotionally demanding. The majority of caregivers are elderly themselves and often frail and suffering from a medical condition. It is important that the role of carers and the needs of those suffering from dementia are recognized and appropriate resources and services provided.

Successful resolution of Erikson's psychological crisis 'integrity versus despair' occurs in the retirement years (65 and over). Persons suffering from dementia lose their short-term memory and therefore reminisce about their earlier years. Some of these memories produce despair which the person suffering from confusion finds difficult to resolve. Feelings become strong when thinking becomes weak. Strong feelings remembered from childhood become their primary emotions and they make sense of what they see, feel and hear from past experiences.

The work of Naomi Feil (1989) with old-old persons (80+), has provided material for Erikson to add another stage to his developmental theory. This is called 'resolution versus vegetation'. Persons in this stage become mal-oriented. They deny their feelings and anger. Guilt and despair, which are buried, come to the surface in disguised ways. To restore integrity, gain dignity and avoid vegetation, mal-oriented old-old people look for a trusted person to validate them, as they express old feelings, disguised in present day symbols.

III. A THEORY OF EDUCATION

Radical feminist theory emphasizes the social dynamics which indicate the ways in which the social order is changing (e.g. the economy is changing making it necessary for women to seek paid employment, career opportunities and changes in birth control techniques giving women more control over the number of children wanted). Traditionally women have been expected to care for the family, this not only includes the raising of children but also the care of parents as they become elderly followed by the care of their male partner. Basically feminist theory 'raises the consciousness' of the group of people it is addressing in such a way as to undermine the basic ideas that women have of themselves.

Rees (1991) offers an account of how social justice can be achieved through his empowerment theory. He educates and enlightens practitioners by explaining the meaning of politics and power and the necessity to relate policy to practice. Rees uses the following stages in his scheme to achieve empowerment:-

STAGES IN ACHIEVING POWER

Understanding themes

Evaluating self-image and knowledge

Specifying problems

Developing awareness of politics

Developing a notion of choice

Experiencing solidarity with others

Acquiring and using language

Resisting a return to powerlessness

Developing interactive and political skills

Evaluation

(Rees 1991:89)

The emphasis is on the inter-relatedness of initiatives occurring at different stages, where responsibilities are repeated, which show continuity from one stage to the next. Rees (1991:86) argues that successful completion of each of the stages requires constant attention to the gaining of credibility and the maintenance of trust. The process is designed to bring about change which in turn will empower the powerless to achieve social justice.

The process of change goes through stages and the time it takes may vary. Rees (1991) and Rose & Black (1985), have both depicted practitioners and their clients struggling to comprehend political processes and to develop confidence in their abilities.

Common stages can be seen in the following diagram of Rose & Black's scheme of advocacy/empowerment action. This scheme was developed and used in the deinstitutionalisation of mental health patients.

<u>ADVOCACY / EMPOWERMENT ACTION</u>	
VERSTEHEN:	Learning from each other and grasping the essence of oppression
THEMATISATION:	Pictures of objective conditions and subjective reflections
PROBLEMATISATION:	Identifying problems to be solved
ANOMIE:	Overcoming confusion and fear
ANALYZING:	The consequence of action
CHOICE:	Ex-patients making choices
ACTION:	Self-conscious informed participation
EVALUATION:	Includes observations about personal development and changes in personal circumstances

(Rose & Black 1984:61)

Rose & Black (1995) use dialogue as a vehicle for uncovering the existential reality and opening it to critical reflection. This dialogue is based on a relationship of trust between practitioner and client/group. When working with the confused elderly this often means interpreting non-verbal behaviour. Since all behaviour has a meaning it often involves validating emotional memories stored from the past.

Validation workers tune into feelings, pick up rhythms, listen to verbal cues, observe non-verbal clues, and put the feelings into words to give dignity to the elderly suffering from confusion. Validation means respecting disoriented old-old who have lived a lifetime and acknowledging their wisdom (Feil 1989:3). There is also the need to educate the caregivers and their families about dementia so that they themselves can understand the changes taking place in the brain and treat the person suffering from dementia with dignity.

IV. A THEORY OF TRANSFORMATIVE ACTION.

The necessity to be politically literate is central to Rees' (1991) empowerment theory. A knowledge of policy issues and policy change empowers caregivers and careworkers to advocate on behalf of the client/group for social justice. In the midst of major health changes that Government is making in the areas of health and welfare, it is important to ensure that the needs of people with dementia and their carers are not overlooked.

In recent years, submissions have been made to Government by Alzheimer's Society N Z Inc. in regard to changes in the Core Health Services and 'Support For Independence' (1993) policy in the hope that they may favorably influence economic policy decisions. In addition, the Alzheimer's Society N Z Co-ordinator worked in the following areas: as a member of the Department of Health Working Party which drafted the 'National Assessment Protocol'; with major health insurance companies to determine the eligibility of people with dementia for health insurance cover; as a member of the reference group for the

drafting of the Elder Abuse Resource Kit which was developed by Age Concern, and as a member of the working party which drafted the 'National Dementia Plan' for the Ministry of Health which developed guidelines for the management of Alzheimer's Disease and related dementias. Alzheimer's Society NZ Inc. have committed themselves to act as advocates for those suffering from dementia and their families and have established an active advocacy committee with delegates throughout New Zealand.

Empowerment Theory has as its goal emancipation whereby a client/group empowered by its new-found self-understanding, alters its social arrangements and ultimately alleviates its suffering. Emancipation for those suffering from dementia means giving them the best quality of life by ensuring they receive the best quality of care. The plan of action of this thesis to achieve emancipation, draws heavily on the action/reflection model of Freire (1972) as a process for caregivers to gain knowledge through education to challenge the wider factors that influence their situation.

My plan of action involved researching a group of caregivers who were undertaking a 'Dealing with Dementia' course at either the Manawatu Polytechnic Palmerston North or Levin campuses. My purpose was to gauge if this educational course had empowered students to make changes in the workplace to improve the quality of life for residents who suffer from dementia.

Students through the course are expected to gain knowledge of the process of Alzheimer's Disease and related disorders and ways of understanding and coping with the changes that result. Understanding why a person is acting as they are is the first step to staff responding appropriately, e.g. knowing that a resident was a prisoner of war could account for a person's agitation when left alone. This person may :-

- Need frequent reassurance to feel they are not alone
- Be more settled sharing a room with another resident

- Benefit from having a pet or toy close-by
- Respond to relaxing music, aroma therapy or massage.

My plan of action also involved publishing a booklet to assist caregivers at home and their families to choose residential care for their family member who can no longer be cared for at home. The purpose of this was also to measure if the information contained within the booklet had empowered the caregiver to ask appropriate questions and even challenge managers of residential facilities to make changes in line with caregiver expectations.

Understanding and knowing the resident, is the first step of a 'Critical Theory'. Bringing about change for this group, because they are unable to achieve this themselves, relies on empowering caregivers through education. The action/reflection model emphasizes the personal as well as the political. This means that caregivers have to listen to the people with whom they are working, they have to recognize their own weaknesses and attitudes towards the elderly and dementia, and they must be prepared to challenge the people with whom they are working and really engage with them. It is important that caregivers understand non-verbal clues and not rely on the person with dementia to verbalize their concerns. It is this dialogical action that begins the critical process of action - reflection - action as the caregiver relates as an equal, or co-worker, in the process of growth which encompasses both instrumental and personal change. Those working in residential care will not have experienced what it is like to be elderly and suffer from dementia and must be aware of not falling into a 'false equality' trap and, in effect, patronise the people with whom one is working. Differences must be honestly acknowledged in an atmosphere of mutual respect.

Dementia care mapping is a tool for evaluating the experience of people with dementia in formal care settings. This method was developed by the Bradford Dementia Group and the Research Institute for the Care of the Elderly, U.K. (Barnett 1995). It bypasses many of the problems of communication by using

observation and the assumption that people with dementia exhibit much the same indicators of well-being and ill-being in their behaviour and demeanor as people without dementia. It is founded on the philosophy of the crucial importance of preserving the 'personhood' of the individual through positive interaction with others.

This method was used by staff in the Bath Mental Health Care NHS Trust not only as an audit tool but also as an instrument of consciousness raising and attitude change. Barnett (1995) says the actual experience of mapping is a transforming one, as the mapper watches the life of the individual client unfold minute by minute, hour by hour, and the method stimulates in each mapper a fresh understanding of the environment from the clients point of view. Staff were chosen from all disciplines including domestic staff to recognize the importance of their client contact. Staff were required to take on an observational role and record client interactions. These observations are then shared with other staff at the end of each shift. Colleagues trained together, mapped together and fed back to each which proved to be a good team building exercise.

Dementia care mapping is about emphasizing the importance of personal interaction for people with dementia. Unfortunately the demands of caring for people often with great physical frailties as well as neurological impairment, create very considerable strains on staff ingenuity in attempting to meet both set of needs adequately. Inevitably the pressure is to complete those tasks of basic physical care (washing, dressing, feeding, toileting) which are crucial to a person's physical well-being. Dementia care mapping highlights for anyone doing it the enormous psychological and emotional needs of clients which must be fulfilled if they are to preserve their well-being as a person.

CHAPTER 6

WHAT CONSTITUTES QUALITY OF LIFE?

The 'Gunderson Model' (1978), as seen in Figure IV names five elements that can constructively affect the environment: safety, structure, support, involvement, and validation. These five elements can be applied to dementia care to form a holistic approach which provides an environment to enhance quality of life for

FIGURE IV

**APPLICATION OF GUNDERSON'S MODEL
OF THERAPEUTIC PROCESSES IN
DEMENTIA CARE**

THERAPEUTIC	INTERVENTION APPROACHES PROCESS	OUTCOME CRITERIA
SAFETY	Provides a safe environment for wandering. Compensates for physical and cognitive losses. Limit access Balance safety with autonomy.	Safety Measures (falls, injuries, elopements)
STRUCTURE	Provide physical boundaries. Mediate environmental stimuli. Provide orienting clues and task simplification. Provide a predictable framework for organizing daily activities.	Measures of Agitation
SUPPORT	Enhance personal choice. Maintain continuity of self. Validate feelings. Maintain communication.	Measures of Affect and Perceived Social Support.
INVOLVEMENT	Provide social roles. Maintain relationships. Maintain meaningful activities	Measures of Social Functioning.
VALIDATION	Plan targeted interventions. Reduce excess disabilities. Build tolerance and acceptance.	Measures of Individualized Goals and Functional Capacity

Note: Adapted from *Defining the Therapeutic Process in Psychiatric Milieus* by J. G. Gunderson. In Taft, Delaney, Seman & Stantell 1993.

those with dementia. In Figure IV Taft et.al. summarize how ‘Gunderson’s Model’ is applied in dementia care and suggests relevant outcome criteria. I have expanded on these five elements to show how they must be addressed to provide an intergrated approach for quality dementia care.

Staff training programmes and relevant courses in dementia care need to address these five elements. If these elements are understood and transposed into the design of the facility and into the daily care schedule the residents suffering from dementia must benefit. These elements are expanded below.

SAFETY

Because of the necessity to compensate for cognitive impairments, a safe environment is the most basic requirement in dementia care. The challenge for staff is to maintain safety in the least restrictive environment. Operating a safe environment for residents with dementia requires that the staff carefully weigh safety requirements with issues of autonomy. To help residents maintain independence and self-determination requires an assessment of strengths and abilities in order to help residents maintain optimal functioning but avoid the experience of failure.

Moving into a residential facility is clearly a very stressful time for any elderly person. For people suffering from dementia, it is just as stressful and can be even more traumatic. Because they cannot fully understand why they have had to come into care they are at risk of becoming increasingly confused.

The need to pace and wander is a common characteristic of many residents with dementia. Sensory and mobility impairments are common and these need to be compensated for when designing safe and secure wandering areas. Safety needs are also met by staff being able to recognize and intervene when agitated behaviour is escalating. The staff must be able to examine the environment, recognize

stimuli that are distressing to the resident, and remain calm while intervening to interrupt the behaviour.

This first element in Gundersen's Model requires interventions that provide for physical safety. Interventions to meet psychological safety are determined by the remaining elements.

STRUCTURE

In dementia care, structure is provided by the schedule of activities which provide rhythm and predictability to the residents day, and focus energy into meaningful activities. As residents become familiar with routines, a predictable schedule of activities reduces disorientation and anxiety, and provides social stability. Educated staff members recognize the value of familiar routines and then take the residents lead. For example, staff members recognize when an activity is not working and make adjustments to meet the needs of the resident. Group size is determined by the residents' tolerance of environmental stimuli and by their ability to interact socially. The optimal size of residents' groups also varies according to the activity.

From a macroenvironmental perspective, the structure is determined by the design of the building and the way the space within the building is divided. From a microenvironmental perspective, the interior design structures the environment by providing orienting clues, by simplification, and by maintaining homelike associations. Bedroom doors can be identified by number, color, and name as well as a familiar picture or photograph. A study performed by a continence aid supplier to a dementia unit in Essex, England, identified that since the toilet doors in the unit had been redesigned and frames painted red, the use of continence aids such as pads, had reduced by 46 per cent (Bignall 1996). Structure is provided by the physical setting and the activity schedule. If the structure does not fit the needs of the resident, an increase in anxiety results.

SUPPORT

Gunderson (1978:332) defined support as

“conscious efforts to help clients feel better and to enhance their self-esteem”.

The role of the staff is to build a supportive relationship in which the resident feels cared for and understood. The goals of a supportive relationship are to relieve anxiety and maintain a sense of trust, security, and self-worth. Support is provided by reinforcing each person’s identity through strategies such as enhancing personal choice, reminiscing about past accomplishments, and validating feelings. Support also is provided through the relationships staff build with the residents. Communication is at the heart of relationships, and staff use communication skills and assume supportive roles so the residents experience being cared for and understood.

Seman (1990) studied the subjective experience of individuals with Alzheimer’s Disease and found that clients continued to experience the effects of their disease and were able to convey in interviews the discomfort that the disease produced in their lives. One hundred percent (100%) of the individuals spoke of anger and frustration at the loss of independence and autonomy. One way of enhancing personal choice is to invite and encourage residents to participate in activities, but allow them to choose not to participate. Enhancing personal choice had a variety of outcomes in a field study conducted by Langer & Rodin (1976). There were significant improvements in alertness, active participation, and general well-being.

Reminiscence helps the resident to experience being care for and understood as a unique individual. Although short-term memory is severely impaired in dementia, long-term memory remains more intact, particularly in the early stages of the disease. Reminiscence builds on the residents’ abilities by capitalizing on long-

term memory. Even in the later stages of the disease, the use of visual, auditory and olfactory cues helps to unlock memories.

Feil (1982, 1985) describes a supportive communication approach for interacting with disoriented elderly individuals in which staff members focused on accepting a person's emotional reality and validated feelings rather than insisting on the accuracy of the facts and orientation to present reality. Staff members listen to the feelings expressed by the words, interpret non-verbal cues and use their knowledge of the resident to interpret the meaning.

In addition to the support the staff offers to the resident it is equally important to support family members. Those who make the decision to institutionalize their loved one, often experience feelings of guilt. It is important that staff members involve the family in the care plan for the resident. They need to be encouraged to visit and be consulted when decisions have to be made. Families also need to be educated to gain a better understanding of dementia and to be linked into a support group where they can share their concerns and receive support from other caregivers.

Maintaining supportive relationships requires an attitude of empathy and consistent caring on the part of the staff. In order to maintain this level of caring, the staff must be supported. This happens when staff members support each other and engage in problem-solving. The administration provides leadership in defining and maintaining a value system that directs clinical practice. Administration demonstrates a commitment to quality care by creating an expectation of respect for both residents and staff members. Administration also plays a vital role and demonstrates caring by providing adequate staffing and meeting individual scheduling needs.

Staff require positive feedback on performance from both peers and managers to reinforce both the competence required to conduct such work and its basic worth.

The provision of good emotional support for staff is essential if they are not to exhaust their own emotional resources. This type of support may best be provided by a system of clinical supervision.

In Gunderson's Model, interventions that provide empathy and caring serve the therapeutic function of the support variable. Some supportive interventions such as reminiscence may also be useful in application to the variable of involvement. Support differs from involvement because support tends to be unidirectional while involvement requires a two-way relationship.

INVOLVEMENT

Gunderson (1978:335) defined involvement as

“those processes that cause patients to attend actively to their social environment and interact with it.”

According to Gunderson, positive change occurs through a process of social learning. In dementia, learning is not a realistic goal because the reinforcement must be consistent and ongoing. However with consistent supportive approaches by staff who encourage continual involvement, many people with dementia are able to attend actively to their social environment and interact with it.

In Seman's (1990) research on the subjective experience of dementia, two dominant themes were expressed unanimously by those interviewed. As previously mentioned, one theme was anger and frustration at the loss of autonomy and independence. The other unanimously expressed was the desire to remain active and useful. Staff promote involvement by maintaining relationships and meaningful activities in residents' lives.

It is important that staff do not underestimate the ability of residents with dementia to engage in interpersonal communication and maintain relationships. Groups provide an opportunity for expressing feelings and building mutual respect. In

dementia, care activities become the vehicle that supports roles and relationships. The loss of tasks and roles occurring due to Alzheimer's disease leads to loss of identity. Although it is often difficult for individuals with dementia to plan and initiate activities, they may participate in activities initiated by others with encouragement. Client centered activities may be generated in an environment that provides a rich variety of materials and props that build on the past interests and abilities of clients.

Goals of the activity programme should include validation of past roles, purposeful use of time, social interaction, physical activity, and cognitive stimulation. Programmes designed to meet these goals can be found by contacting the New Zealand Society of Diversional Therapists, Alzheimer's Society New Zealand, or publications by Zgola (1987), Feil (1985), Chavin (1991), Hellen (1992), Tooley (1991; 1996) to name just a few.

The therapeutic dimensions of the activity programme do not merely happen. The challenge for the staff is to assess residents needs, abilities and interests. By employing qualified Diversional Therapists or Activity Officers who have a knowledge of therapeutic interventions and experience in using them, individual activity programmes can be planned for each resident. All staff are informed of the programme and can use this information to divert inappropriate actions by the resident when required. In some cases this may mean removing the resident to a quiet place and playing their favourite music to relax them.

VALIDATION

Gunderson (1978:334) describes validation as

“ a therapeutic process that affirms the patient's individuality and leads to individualized treatment programmes.”

Goals must be matched to the residents abilities when staff plan targeted interventions to meet the needs of the specific resident. In dementia care, the staff

designs individualized care plans that specify desired outcomes such as the ability to meet self-care needs and participate in activities, or the need to reduce anxiety and minimize agitated behaviour. For example Teri and Gallagher-Thompson (1991) reported the successful treatment of depression in individuals with Alzheimer's Disease by using cognitive interventions that challenged negative thoughts or behavioral strategies that modified the environment and increased pleasant activities. Choice of intervention strategies was based on the residents level of cognitive functioning and the response of the resident. Declines in scores on depression scales occurred in both groups after treatment. Cognitive therapy proved more successful in residents with mild dementia and behavioral interventions were more appropriate for individuals with moderate to severe dementia.

Individualized treatment plans also include involving the family. Interventions are shared between the family caregivers and the staff to provide for mutual problem-solving and continuity of care. Often family members can provide meaning to behaviour being displayed. Stokes (1996) describes the action of a gentleman (Mr D.) who developed Alzheimer's Disease at the age of fifty-eight. Each day he would go into the garden with his wheelbarrow and dig up the flower-gardens filling his wheelbarrow with dirt. He would then empty the contents onto the lawn and separate out the rocks and stones. These he would then put in neat piles in the garage. Sometimes he would empty the wheelbarrow inside the house causing his wife great anguish. Eventually the behaviour was explained by an experience where this man had been trapped in his business by youths who had smashed the front window with rocks. His conviction was that his home, his secure world, would be attacked in the same way his shop had been. His motivation was to protect himself and his wife from such hazards. Understanding the behaviour helped his wife cope and she was able to reassure him by touch and tone of voice that his actions were acceptable. During the remaining months of destructive behaviour Mrs D. was a more effective and confident supporter and as time passed her husband slowly became less preoccupied with the significance of

collecting rocks. His behaviour acquired the characteristic of a habit from which he was more easily discouraged. Often this sort of behaviour would be treated with drugs to sedate and calm the person. By finding a reason for the behavior and accepting where the person is at in time and place, allows the person to work through the crisis they are confronted with.

Because dementia is inevitably a deteriorating disease, a therapeutic environment in dementia care is one that emphasizes process as well as outcomes. A social model of dementia views people with dementia as individuals who continue to interact with others and maintain relationships despite their illness (Lyman, 1989). The staff validates the human trapped within the disease by affirming the individual and building tolerance.

Gunderson (1978) described building tolerance as a validating role in which staff create an environment in which residents may be sick and unpunished for it. In many institutional long-term care settings, behaviors are framed as 'problems'. Therapeutic approaches reframe behaviour in ways that build tolerance and acceptance. Gunderson (1978) explained that when residents are validated, their symptoms are interpreted as meaningful expressions of the person's inner-self-expressions and should not be terminated or ignored, but rather understood and accommodated.

These elements of safety, structure, support, involvement and validation are essential to provide quality of life for elderly people with dementia at home and in residential care. The environment is changing and it is sometimes difficult to maintain high standards when there are economic restraints. Because recent health and welfare policy has undergone many changes during the time of writing, this thesis is relevant only to the time of writing. The chapter that follows explains some of the policy implications that caregivers and workers are restricted by.

CHAPTER 7

THE CHANGING ENVIRONMENT AND POLICY IMPLICATIONS.

The current national health structure revolves around four RHAs who purchase services from a range of health care providers. In some instances providers compete against each other to win contracts from the RHAs. In others instances, CHEs are exiting services and leaving gaps in service provision.

Because each RHA is funded separately by the Ministry of Health, four quite different health systems in the four regions throughout New Zealand are developing. RHA bureaucracies are seen as being out of touch with the communities on whose behalf they are directed to purchase services. Rather than the CHEs and the RHAs working as partners to provide needed services for their area they appear to be in conflict. Much of the funding allocated for health care is being spent on negotiating complex legal contracts for the provision of each service instead of being spent on planning and providing better services for the people.

There is contention among the various New Zealand Political Parties about the future of the four RHAs. Labour strongly opposes the continuation of the four RHAs and would make the Department of Health responsible for funding the provision of health services throughout the country. This Government Department would be responsible also for the monitoring and enforcement of standards. In the present environment each region determines what services they will fund. This makes it difficult when writing about health policy in New Zealand as what happens in one area does not necessarily happen in another region. However with the introduction of MMP (Mixed Member Proportional) in the elections of 1996 we experienced a coalition between the present National Government and the NZ First Party. This coalition prompted the introduction of a new health policy to come into force in July 1988.

The Coalition Government's health policy intends to remove income and asset testing for those people requiring long-stay geriatric public hospital care and asset testing for long-stay geriatric private hospital care. This will be introduced after 1st July 1998 and in 1999/2000 an exemption will be introduced to allow single people in resthomes \$100,000 on the family home in the income and asset test. It is also proposed to replace CHEs with Regional Hospital and Community Services which will deliver services currently provided by the CHEs. By July 1998 there will be one funding body separate from the Ministry of Health which will carry out functions after consultation with the health sector and a review of the current system. (Government Print 9th Dec. 1996)

The major growth in the number of people with dementia will be one of the most significant consequences of the aging of New Zealand society in the next few years. Alzheimer's Society N. Z. (1996) estimate 38,000 people in New Zealand today have dementia. This is predicted to rise as more people live on into their eighties when dementia affects one in five people. With this in mind the Alzheimer's Society N.Z. have set out recommendations to government and policy makers in a booklet called '*A Fair Go For Dementia*' (1996). The Society proposes that adequate resources need to be made available otherwise the effects of dementia will have tragic consequences for many New Zealand families. Considerable pressure is expected on the health and welfare sectors' expenditure through the:

- breakdown in the health of the carers,
- early placement in residential care for people with dementia
- stress and disillusionment of professional staff and volunteers

Alzheimer's Society has identified a number of serious problems and anomalies existing in the provision of appropriate care for people with dementia in New Zealand. The issues identified were divided into five sections and are summarized here very briefly

Issue No. 1 Assessment.

- Assessment services purchased in each region include input from caregivers
- All centers throughout N. Z. establish a multidisciplinary assessment team and people with dementia are assessed regularly.
- Ongoing training be required for all members of the assessment teams.

Issue No. 2 - Family support: Community services for people with dementia and their carers.

- All RHAs purchase support services for people with dementia and their caregivers.
- A range of support services be made available to these people.
- Relief care in the form of day-care and carer relief in the home needs to be increased.

Issue No. 3 - Education/training.

- Training and education be available for carers at home and for those working in residential facilities.
- Training be incorporated into service contracts.
- All health professionals working in acute medical wards should be required to have undergone dementia training.

Courses at postgraduate level on aging and dementia should also be available.

Issue No. 4 - Residential care provision.

- There needs to be a realistic national subsidy level set for those in residential care which recognizes the high dependency needs of people with dementia.
- Facilities need be responsive to the needs of those people with dementia, national standards be set and the quality of care monitored and enforced.

Issue No. 5 - Research

- Research which contributes to the knowledge and management of Alzheimer's Disease should be adequately funded by Government.
- Planning for the future requires national statistics on the incidence of dementia to be collected.
- National research should be planned in co-operation with the Alzheimer's Society N. Z.

These issues are addressed in the booklet '*Fair Go For Dementia*' (1986) Appendix VI.

Jan Harrison, National Co-ordinator Alzheimer's Society N. Z. asked the four RHAs, CHEs throughout New Zealand and the Ministry of Health to respond to questions asked in booklet. Their responses highlighted the lack of consistency in policy between them and highlighted the lack of a national approach in the care of people with dementia and support services for themselves and their caregivers. Correspondence was received from the Ministry of Health, three RHAs and MidCentral Health (CHE). There was no response from Midland Health (RHA) or from other CHEs.

Northern RHA had not yet implemented standards and guidelines for assessment of support needs and co-ordination of services for older people. They propose to have this in place by 30 June 1997. They have funded two pilot courses for carers of people with dementia with positive results. As a result they have specified in their contracts for specialist dementia residential care (Stage 3), that all hands on care staff have attended an endorsed course on dementia care (Spratt Casas 1-7-96).

The Southern RHA was instrumental in the establishment of dementia care courses in the southern region for staff in residential dementia care as a result of their service specification requirements (Penman 5-8-96). The Central RHA consider

education and training of staff an important component of the quality improvement programmes included in contracts for providers of services for people with dementia (Hall 11-7-96).

The Ministry of Health specifies in the Policy Guidelines, that RHAs purchase education and training for the people needed to deliver quality services. The Clinical Training Authority (CTA), is charged with the responsibility of purchasing post entry health professional education and has identified nursing courses for care of the older person as priority for this financial year (1996) (D'Audney 12-6-96). All RHAs in their service contracts with service providers specify it is the responsibility of the provider to ensure that residential staff receive appropriate training. This highlights how the RHA has moved the responsibility for training to the providers of services.

THE NATIONAL HEALTH COMMITTEE

The National Health Committee was established in March 1992 as the National Advisory Committee on Core Health Services. Their legislative brief comes from the Health and Disability Services Act (1993) which defines their role as providing independent advice to the Minister of Health on:

“all kinds, and relative priorities, of public health services, personal health services and disability services that should, in the committee’s opinion, be publicly funded”.....[and advised on]... matters that impact on the public health” (cited in Sutich 1996:1).

This committee has a specific interest in Alzheimer’s Disease and Dementia following a report “Care for Older People” (Richmond et al. 1995) which identified needs particularly relevant for people with Alzheimer’s Disease or Dementia. The National Health Committee set the terms of reference for developing guidelines for the management of dementia to explore some of the fundamental issues relating to the management of the disease. The guidelines developed will form the basis of the National Health Committee’s advice to the

Minister of Health on the relative kinds and priorities of services that should be publicly funded for the management of Alzheimer's Disease and dementia.

Many of the issues identified in the report have already been identified in the booklet *'A Fair Go For Dementia'* (1996). It has been suggested to the Health Committee that the recommendations made by the Alzheimer's Society in this booklet be adopted and actioned rather than reinventing the wheel and unnecessarily wasting public funding.

INCOME AND ASSET TESTING.

Income and asset testing of elderly people entering residential care has been a topic of debate in recent years. More recently people assessed as requiring long-term hospital care have been expected to fund this themselves if their assets have exceeded \$6,500 for a single person or in the case of a couple when their assets exceed more than \$40,000. This level for a couple does not include their family home and car. From 1961 people in private resthome were subject to an income and asset test under the Resthome Subsidy Scheme whereas people in public hospital geriatric beds contributed their New Zealand Superannuation less a personal allowance after thirteen weeks. This was considered unequal and in 1993 with the move for long-term care to be provided by private facilities, a universal income and asset test was introduced. In 1994 Government announced that the maximum amount of \$636 per week would be payable by people requiring long-term residential care that is purchased by the RHA.

For people with Alzheimer's Disease the progression of the disease can sometimes take up to twenty years and long-term residential care is sometimes required for a great number of these years once they can no longer be managed in a Stage II facility. This can erode the life-time savings of couples who have worked hard to provide security for their children and grandchildren and in the case of a single person the family home maybe sold or a caveat secured against the property.

Currently there are around 31,000 people in long-term residential care (Ministry of Health August 1996). Of these, approximately 22,000 are supported through the Residential Care Subsidy. Only a small percentage (7.4%) of people over the age of 65 will ever need residential care. The vast majority of people live in the community where they care for themselves or are cared for by others. The Government considers that older people who can afford to pay for their care should do so in order that those in financial need can be assisted. In 1994 one person in nine was over the age of 64; by 2031 this is expected to be one in five. With ten percent (10%) of the over sixty-five's suffering from some sort of dementia and twenty to twenty five percent (20% - 25%) of the over eighties developing dementia many of these will eventually find themselves in long-term care. A considerable number of residential beds will be taken up by those with dementia making those families more liable to be disadvantaged from the results of income and asset testing. There has been considerable pressure on Government recently to do away with asset testing for the elderly in residential care following a gentleman in Northland being taken to court for non-payment of hospital charges for his wife who has Alzheimer's Disease and who requires 24 hour nursing care. Government decided to reserve their decision on the income and asset debate until after the election.

SERVICE DESCRIPTION FOR RESIDENTIAL SERVICES

The service description for residential care for subsidized residents is the responsibility of the RHA and described in Schedule (96) *Age Related Resthomes* (April 1996). This service description sets out the scope of the services to be provided and the criteria to meet the expected standards. These standards define the criteria to be met with regard to staffing levels, personal care and lifestyle plans for each resident, along with clinical, hotel and utility services. For these standards to be met the RHA specifies how these standards will be measured and monitored.

To comply with this service description :

- The service is expected to achieve the listed standards at least 95% of the time.
- The service is expected to include these standards in their formal quality improvement programme which is also expected to include the standards each service has developed.

On-site evaluation will be used by the RHA to:

- ensure compliance with the requirement for a formal, written quality improvement plan;
- verify achievement of the standards and/or the accuracy of reports (Central RHA April 1996).

The service description does not cater for the special needs and higher staff ratio required for the care of persons with dementia in Stage II care. The service description for Stage III facilities specifies a staff resident ratio 60% higher than specified in Regulation 36, Old Peoples Homes Regulations 1987 (CRHA Aug, 1996). For a facility caring for twenty residents this equates to 1.6 full time equivalent staff on duty at all times. These staff are often expected to prepare and serve food and drinks and clean up after, as well as attending to all personal needs. The monitoring of standards is based on written documentation rather than observation.

The Ministry of Health has a complaint procedure for anyone wanting to complain about the standards of care and services within residential facilities. Ministry of Health staff will investigate the complaints but often these are not followed through by the person who originally made the complaint. This may be because of fear from management in the case of a staff complaint and fear of care being jeopardized in the case of caregiver or resident complaint. Under the present Government each of the four RHAs are responsible for establishing their own standards and criteria for residential care. This has tended to lead to each RHA identifying different issues to address and no consistent national policy. As each RHA is responsible for contracting and negotiating contracts with providers,

negotiation by a central agent would eliminate wastage of public funding which could be better spent on service provision.

PUBLIC EXPENDITURE

TABLE 1: Projected Changes in the Proportion of Public Health Expenditure Going to Population Aged 65 and Over.

(Source: Blank 1994:27)

	1980	2000	2020	2040
Australia	34.5%	40.2%	46.4%	56.0%
similar to NZ				
Belgium	21.8	21.8	25.0	30.4
Canada	32.4	39.4	48.9	57.1
England	42.5	43.0	45.6	54.1
Japan	31.3	42.4	52.5	55.9
Sweden	51.5	54.2	59.6	63.3
United States	47.0	48.8	56.9	62.9

Table I illustrates the estimated increases in health expenditure that will need to be directed towards the elderly. Although there is significant variation by country the trend towards a heightened concentration of health care resources in the elderly segment of the population is universal, with most countries registering over fifty percent by the year 2040.

The burgeoning need of an aging population not only requires an increased proportion of health care spending but has considerable potential impact on the type of health care provided. Obviously, the growing number of older people will generate a greater demand for elderly care and thus a proportionate increase in the provision of residential facilities and personnel to care for them. Because the incidence of illness and dementia is higher among the elderly than in other age

cohorts, the aging of the population will put additional pressure on existing facilities and resources. Even if improved lifestyles and medical technologies are successful in reducing the major causes of premature death, we will be left with a rapidly growing population whose additional years may be dominated by non-fatal but highly debilitating conditions such as Alzheimer's disease. The result could be longer life but worsening health.

A major preoccupation of policy makers worldwide is with the cost of care for an aging population. How much we spend on elder care cannot be determined without reference to ethical principles. If we place no value on life after economic productivity ceases, then logically we should not waste resources on health services for the elderly. Ebrahim (1995) believes health care policy should seek not simply to ensure equity of distribution of resources in relation to population but should aim to target resources where they will do the most good.

There is an absence of adequate data and research on the long-term benefits of specialized dementia care where inputs to achieve quality of life for persons with dementia can be measured. Clinical ethical values e.g. beneficence, (doing the best possible for the individual patient) run counter to the utilitarian ethic (the greatest good for the greatest number).

ETHICAL ISSUES

Research involving elderly with dementia is often difficult due to the difficulty of obtaining informed consent from subjects and gaining approval from the appropriate ethics committee. Historically, human research ethics committees have been set up as a check against abuse of scientific experimentation on humans. The emphasis is on adherence to set protocols, regardless of the individual qualities of the persons who undertake the process of data collection and analysis. The personal integrity of the researcher is either assumed or ignored altogether. Often dilemmas encountered while conducting the research are glossed over. Once in the field carefully developed protocols and undertakings to act in

particular ways become difficult to sustain, impeding not only the research process but also making sensitive interactions with research participants difficult. The researcher often has a greater investment in the successful completion of the project than the well-being of the participants. Researchers need to ensure that participants' rights are protected and respected at all stages of the research. To maintain respect for elderly participants with dementia the researcher needs to be sensitive to their needs and use moral integrity and a flexible approach. Respect also needs to be maintained for the ethical codes and protocols, and for oneself as a researcher and a person.

Ethical issues frequently arise in dementia care. Dementia causes loss of insight which leads to risks to personal autonomy and decision making. The problem often arises where the person with dementia may have such impaired insight that they fail to recognize the need of assistance from another person. A person who fails to acknowledge that they have memory problems often refuses to give another person authority to act on their behalf. An Enduring Power of Attorney is a legal document which gives the caregiver or another person authority to act on their behalf in matters of their personal affairs and property affairs. A person with dementia cannot be placed in residential care against their will if they have not given this authority to another person. In these circumstances an application needs to be made to the Family Court under the Protection of Personal Property and Rights Act (1988) to appoint a welfare guardian to make decisions for the person with dementia. Dilemmas often arise when people with dementia are living alone in the community and are unaware or do not acknowledge that they have memory loss. It is often difficult to know when to intervene and how to convince the person they should be in residential care. Often the safety of the person is the determining factor. In instances where a family member has had to make the decision for residential care, the person with dementia can become very angry and abusive to their family member when they try and settle them into residential life.

The possibility of genetic testing for Alzheimer's Disease has raised considerable debate as regards ethical issues when it comes to planning and paying for health care. Family members of a person with Alzheimer's Disease will often ask the questions, "Is it hereditary? Am I going to get it?" In recent years research has been published identifying a genetic risk factor for Alzheimer's Disease in older people. A genetic factor has been identified and it is only a matter of time before a diagnostic test will be available (Saunders, 1993).

The benefits of this could be improved support for the person with the disease and their family. Also early diagnosis could mean better response to drugs already being trialed to slow down the disease which researchers hope will eventually halt the disease. Accurate diagnosis will enable drugs to be developed which target the particular neurochemical deficits of different kinds of dementia making them more effective and less wasteful.

A diagnostic test will also raise ethical dilemmas for physicians and family members. Individuals will enter the health system earlier putting pressure on existing services and set budgets. The cost of drug treatment will be balanced with the contribution these people can give to society. In the United States sales of Cognex (a drug used to stimulate memory), in the first year were in the order of \$60 million (Cayton 1994).

When a diagnostic test is available ethics will require physicians to share this knowledge with their patients. Support agencies like the Alzheimer's Society will have to provide more services in the way of counselling and support for the people who have been diagnosed with the disease whereas presently services are more for the support of the caregivers.

The implications of genetic screening are :

- Who has access to this information? Employers, insurance companies both health and life insurance covers.

- Genetic information also has commercial value. A researcher can patent a discovery and make financial gain by selling his/her knowledge.
- It may lead to more abortions and medical killing dressed up as euthanasia.

There must be a requirement that genetic information is used for the benefit and liberation of the many rather than the control of a few.

CULTURAL ISSUES

There is a need to determine prevalence rates of dementia in the Maori population as there is a lack of literature available to substantiate the proportion of Maori elderly who suffer from dementia. My knowledge of these issues comes from speaking with Maori people, working with Maori clients and contact with resthomes and hospitals.

Few elderly Maori persons appear to be cared for in residential care. Traditionally they are cared for within their whanau. There are several reasons that could explain why elderly Maori with dementia do not present often in residential care:-

- Lower life expectancy for Maori over the age of eighty because of high mortality rates from other diseases.
- Anecdotal evidence may suggest the added responsibility expected by Maori culture that elders take on the leadership of their people in decision making, guidance and education of their young, may keep brain cells active in elderly Maori. (The term “use it or lose it” may apply here).

Those that do enter residential care have often been isolated from their iwi or whanau through urban migration and mixed marriage. A Maori client feeling stressed from caring for her elderly mother who requires twenty-four hour care recently expressed how her mother, the matriarch of the family, had expected her to also care for her mother’s defacto partner who had Alzheimer’s Disease. She refused, telling her mother that it was the responsibility of his family. It is becoming increasingly difficult for Maori families to provide care for a dependent

family member. Often the responsibility falls on female family members but because they are solo parents with dependents they are forced into paid employment to provide an improvement in their own lifestyle.

A paper presented at the Alzheimer's Society Conference by Mark Byrd (1996), discussed the results of research he had conducted on the effects of caring for an elderly relative. Results strongly indicated that caring for a relative with dementia causes serious disruption in middle-aged caregiver's families. This generation of caregivers is referred to as the 'sandwich-generation' where caregivers must balance their care and assistance between both elderly and adolescent family members and also their own grandchildren. Data showing the perceived level of burden and the perceived degree of impact was also significantly higher in this group.

Central RHA contracts for a Maori liaison service in each sub-region to ensure that Maori have access to a full range of services appropriate to their needs. In the case of a Maori family I was involved with where the husband gave up paid employment to care for his wife, home support services refused to pay the husband for the personal care he was providing for his wife, which was their personal preference. I had explained their personal circumstances by letter and how the wife because she was blind preferred her husband to do all her personal cares. Home support services replied saying they would only fund someone outside the family to provide the same care which demonstrates that their philosophy to provide appropriate services to meet the needs of their clients and their culture is not flexible and not culturally sensitive.

Recently North Health held two hui as part of the qualitative research they were conducting into specialist dementia care (Spratt-Casas 1996). Development for services in North Health is through mainstream enhancement, Maori provider development and co-purchasing. I believe support services must be flexible to

meet the needs of different cultures with monetary recognition of the role that family caregivers provide, if that is the preference of the client.

Hospitals (CHEs) in the Manawatu and Wanganui areas are implementing cultural safety programmes and providing Treaty of Waitangi workshops for all staff to make them more aware of cultural issues, however the wider policy issues have not been addressed.

CHAPTER 8

RESEARCH DESIGN

The research design incorporated the survey method, as the aim of the research was to gauge attitudes of resthome managers and to collect quantitative data on the benefits of staff education.

I chose to survey a class of students who were enrolled in the 'Dealing with Dementia' course at the Manawatu Polytechnic in Palmerston North. This is a course that is offered to caregivers of people with dementia to give them a theoretical and practical understanding of dementia. It also teaches practical ways of improving the surrounding environment and ways of understanding and coping with difficult behaviour. Students are assigned practical homework exercises which they are expected to implement in their workplace. The result of these interventions are shared with the group at their next session and discussed. The course consists of one full day (7 hours) per week for four weeks.

In my initial proposal I expected to get fifteen to twenty respondents but at that stage it was unknown how many enrollments there would be for the course. Discussions with the tutor informed me that the same course would be repeated the following month at the Levin campus and I could conduct the same survey there if I needed more respondents.

The results of this survey did not yield conclusive data that education of the workers was empowering enough to improve the quality of life for those residents with dementia. In discussion with my supervisors of other ways of putting pressure on managers and policy makers, we believed the family caregiver or the principle caregiver of the person with dementia, also needed to be educated. They needed to know what questions to ask, and why these questions should be asked, before the person they cared for was placed in residential care. Educating the

caregivers to know what quality of care they should expect, and why, would hopefully prompt managers of residential services to deliver this level of care.

In the present economic climate, in most major towns and cities, there is competition amongst many of the Stage II residential facilities to keep their beds full. This competition can have the effect of promoting a better quality of service to attract more residents. There is little competition and few residential facilities to choose from for Stage III dementia care where we find residents with dementia who have behavior problems and who cannot be managed in a Stage II facility. Residents in these facilities are reliant on caregivers working in the facility and family caregivers to promote and provide quality care. Education of these caregivers is essential to empower them to promote change. As a result of this discussion, I began to put together a booklet for caregivers to assist them in choosing resthome or long-term care for a person with dementia.

Before surveying students at the Manawatu Polytechnic I was requested to submit a proposal to the Ethics and Resource Management Committee of the Polytechnic outlining the purpose of the research and the methodology. The Polytechnic was concerned about giving me access to their records and thus breaching the Privacy Act. In my proposal, I stated that I would not require access to their records and my survey would guarantee confidentiality and anonymity of the respondents. I also offered in return to address the class to inform them of the purpose of the Alzheimer's Society and how it operates, both nationally and locally and the different services that are available. The approval letter received from the Polytechnic can be seen in Appendix I.

I also presented to the Polytech a draft of the questionnaire I intended to use. Permission was received in time for me to survey the class on the last day of their course. After consultation with my supervisor and other professionals it was decided my proposal met the conditions required by the Massey Ethics Committee and a meeting with them was not required.

This report will be divided into two sections with the survey of the 'Dealing with Dementia' course described as Survey I and the survey of the recipients of the booklet 'Excellence in Dementia Care' as Survey II.

METHOD

SURVEY I

For some time I have had a working relationship with the Manawatu Polytechnic, giving their nursing students practical experience of working with dementia in the Marion Kennedy Centre, and also providing them with a knowledge base of the effects of dementia, ways of coping and ways of stimulating people who suffer from dementia. One of the aims of the Alzheimer's Society is to provide education for professionals and carers and raise public awareness. I knew several people who had previously completed the course and two of these people agreed to pilot the questionnaire. Feedback from them assisted with the layout of the questionnaire form.

The questionnaire (see Appendix II) was administered to the class on the last day of their course. I had previously been approached by the tutor and asked if the course could be concluded by allowing the students to visit the Marion Kennedy Centre to view the facility and see for themselves activities in progress and learn about how the service operates. This educational component was given first, followed by a brief overview of the work I am currently undertaking for my thesis and about my research. They were each given an information sheet (see Appendix III) and asked to complete the questionnaire if they agreed to participate. Two people asked to take the questionnaire away with them to complete and they were given envelopes addressed to myself to post them back. A further three people were not able to attend on the last day. The tutor offered to pass on the questionnaires to them with return envelopes attached. Out of these five people two were returned making sixteen responses out of a possible twenty.

On discussion with the tutor I decided to also survey the course to be held in Levin. I was curious to know if the attitudes and support of management and peer workers was any different in a town compared to a city.

One month later I attended the final session of the Levin course. There I talked to the students about the work of Alzheimer's Society Manawatu and the services they provide and the purpose of my research. Twenty questionnaires were passed out and all were returned giving me a total return of thirty six out of a possible forty.

RESULTS

SURVEY I

Out of thirty-six (36) returns twenty (20) who stated their occupation as either nurse or caregiver felt that they were not able to implement specific changes in the workplace to improve the quality of life for the residents. Some of these commented that their own knowledge and understanding had improved which they found beneficial in their work. They could understand better the meaning of the behaviour that residents with dementia display and cope with it better.

The results of the survey were divided into two categories for analysis. Those able to implement changes (these comprised a total of sixteen from the thirty-six returns) and those not able to implement changes (a total of twenty from the thirty-six returns) These results of questions 1 - 6 have been summarized and can be seen in Table Two.

DESCRIPTION OF THE SAMPLE

Gender - of the sixteen respondents who were able to implement changes 2 were male and 14 were female. Of those unable to make changes 3 were male and 17 were female.

Age - The majority of the people in the sample were over 35 There was no obvious differences in ages and gender between the two groups.

Occupation - There was an obvious difference in occupation between respondents in this category. Of the group (total 20) who were not able to implement changes seventeen identified themselves as caregivers as compared to the other group (total 17) where only three identified themselves as caregivers. This group of twenty generally had lower qualifications and less status in their job title

TABLE II
*Results of Survey Research on 36 Subjects on Completion of
 "Dealing With Dementia" Course.*

TOTAL NUMBER OF RETURNS 36

		Those able to Implement Changes Total 16	Those not able to Implement Changes Total 20
1. Sex			
	Male	2	3
	Female	14	17
2. Age			
	15 - 25	0	1
	26 - 35	4	4
	36 - 45	7	9
	46 - 55	4	6
	55+	1	0
3. Occupation			
	Manager	3	0
	Registered Nurse	4	0
	Enrolled Nurse	3	1
	Recreational Officer	1	0
	Co-ordinator	2	0
	Caregiver	3	17
	Volunteer	0	1
	Unemployed	0	1
4. Qualifications			
	Degree	1	0
	Registered Nurse	4	0
	Enrolled Nurse	5	2
	Advanced Core Cert.	1	0
	Resthome Core Cert.	3	15
	No Qualification	2	3
5 & 6 Enrollment Fees			
	Employer Paid	10	6
	Employer/Self	2	4
	Self Paid	2	10
	Other	2	0
7. Paid Time to Attend			
	Unpaid/allowed time off	10	6
	Not allowed time off	2	4
	Unpaid & had to change shifts	2	10
	Volunteer	2	0

Qualifications - Of the group of twenty people, fifteen had completed the Polytechnic 'Resthome Core Course' and one was in the process of completing it. Two people were enrolled nurses and two had no qualifications at all. In contrast, as shown on Table Two eleven of the sixteen people who were able to implement changes had higher qualifications than the Resthome Core Certificate.

Enrollment Fees - COST \$90.00. Ten of these twenty paid the enrollment fee themselves, four the employer contributed and six were paid to attend by their employer.

Paid time off work - Three of the group of twenty not able to make changes were allowed time off work and paid to attend the course. The remaining seventeen either swapped days off or were given unpaid time off.

Of the group of sixteen who were able to implement changes, ten had their enrollment fees paid by their employer, two were paid 50% by the employer and the rest themselves, two paid themselves and two were funded by other means. All of this group were given time off to attend the course with only one of this group being unpaid.

Question 8. *Do you consider education about dementia to be essential for people working in this field?*

All of the respondents considered knowledge about dementia essential for people working in this field. Although not all were empowered to make changes in the workplace, all had benefited from the course by increase in their own knowledge and understanding of the causes of dementia and ways of coping with difficult behaviour.

Question 9 & 10. *Were you able to implement changes in your workplace?*

Those that considered that they had made changes found activities learnt on the course could be used as diversion when a resident was becoming restless and agitated and reminiscing activities were very rewarding as they stimulated discussion.

Some of the changes that were implemented were:-

- a registered nurse set up in-house training sessions for co-workers.
- all dementia residents in one resthome were transferred onto one wing
- life history albums were made for residents to stimulate discussion and interest and placed importance on the life of the resident.
- menu boards were introduced
- validation therapy was introduced which recognizes and acknowledges where the resident is in time and place.
- a support group was set up for relatives and friends
- there was improved communication between staff and family
- time was allocated for residents on an individual basis
- finger food was introduced for those who could no longer manage a knife and fork
- one resthome was producing information forms for families to fill in on the history of residents e.g. occupation, family, interests.

Question 11. *If no, what would you consider the barriers to be?*

Of the twenty people who said they were unable to implement changes ten stated management as the barrier, others stated staff attitudes, lack of time and staff shortages as reasons. Some of the comments received were:-

- “lack of power in the workplace”
- “lot of staff have closed minds”

- “ the manager does not listen to what the caregiver says “
- “lack of management support”

Those who had introduced changes also commented on the barriers as being:

- “staff and management attitudes”
- “lack of time and staff shortages”
- “other priorities being considered more important”

Question 12. *What part of the course did you find most helpful?*

There was no clear individual answer that stand out in this question. All the respondents can be put into categories. Seventeen people felt all of the course was helpful and relevant. Six people found the most helpful part of the course was the understanding of the causes of dementia and the behaviour associated with it. Another eight people felt that learning about activities for people with dementia was the most helpful and another five found the interaction and discussion with people in different working situations was the most helpful for them.

Question 13. *Length of course.*

Of the thirty-six surveyed, sixteen felt the course was too short and twenty felt the length was satisfactory.

Question 14. *Was there anything you would like to see added to the course?*

Nineteen people either didn't reply or said there wasn't anything they felt should be added. Of the other sixteen, time seemed to be a major factor with people commenting that they felt there could have been more depth in drug therapies and restraints. Also people felt there could be more visits to other dementia units. An overwhelming sixteen people said that they would have liked to have some resthome managers speak about exactly what they require from the workers.

Question 15 *Was there anything you felt to be irrelevant?*

Thirty four of those surveyed felt the whole or most of the course was relevant. One person felt many of the ideas were too idealistic and costly, one person said there was too much repeating of ideas.

Question 16. *Would you like to expand your knowledge further?*

Thirty three people replied 'yes' to this question and three suggested an advanced course would be a good idea.

DISCUSSION

The results of the survey were divided into two categories. Those able to implement changes (these comprised a total of sixteen from the thirty-six returns) and those not able to implement changes (a total of twenty from the thirty-six returns).

There was little significant difference in the age and sex of the two groups. What appears to be significant is those who were able to implement changes were those who were more highly qualified and who stated their occupation as manager, registered nurse, enrolled nurse, recreational officer or co-ordinator. This does seem to indicate a relationship between education and change. It could be assumed, therefore, that education has empowered these workers to bring about change in their workplace. There is also the possibility that the status of the worker in the facility also empowers them to challenge their employers and bring about change. The results in Table Two appear to support this relationship.

There is also evidence that those workers who hold higher status and higher educational qualifications were more likely to have paid time off work to attend the course and have their course fees paid by the employer. Of the two groups only two people in the change group paid their own fees compared with 10 (50%) of the group who were not able to make changes.

It appears that employers are more likely to support continuing education for their higher status, higher qualified staff. It could also be presumed that because these staff are empowered by their higher educational level they are more assertive and expect and challenge their employer to provide the course fees. It could also be assumed that they expect paid time off to attend courses.

LIMITATIONS

Limitations to this study included lack of participants from all socio-economic groups and from non-white ethnic groups. No data was collected on peer support within the workplace which could have a bearing on staff's ability to be empowered and make changes. Also personality characteristics could influence the results.

It was difficult to measure the results of the changes made as the residents were not involved in the evaluation. The careworkers felt they had made changes to improve the lives of the residents as well as knowing the new found knowledge equipped them to cope with increased confidence.

However the findings are useful to suggest that education has the effect of empowering workers to make changes to improve the quality of life of residents who suffer from dementia. Gaining specialized knowledge on how to deal with dementia can assist in the development of a sense of competence and of self-confidence in the face of an incurable progressive disease.

Further studies are needed to observe the long-term effects on residents who appear to have their physical, emotional, spiritual and recreational needs met. Does increased quality of life result in a longer life for residents? I am hopeful that by promoting education as essential for all caregivers it will benefit the quality of life for the residents.

CHAPTER 9

SURVEY 11

METHOD

This survey involved producing a booklet for caregivers to assist them when choosing residential care for their person with dementia. The purpose was to give information and questions to ask when selecting a facility and guidelines as to what constituted quality care.

The process of producing the booklet was a lengthy one with several drafts written after feedback from my supervisors. The final draft was distributed to peer workers, Committee of Alzheimer's Society Manawatu, Alzheimer's Society N.Z., and social workers working with the elderly in Wanganui and Palmerston North. Also copies were sent to the Ministry of Health and the Central Regional Health Authority.

Feedback was received from Alzheimer's Society N.Z. which is based in Christchurch with the comment that the process of assessment of a person with dementia in their Southern Regional Health Authority was different to that outlined in the booklet. On the whole feedback was positive and Alzheimer's Society Manawatu approved funding from a bequest they had received to print two hundred booklets.

The booklets (Appendix IV), were distributed by the Co-ordinator of Alzheimer's Society Manawatu in and around Palmerston North and in Wanganui by the Social Worker for Senior Services. A questionnaire see Appendix V, was enclosed with some of the booklets where it was known that these caregivers were in the process of either selecting residential care or struggling with the decision of coming to terms with handing the care of their loved one to someone else.

Caregivers were asked to post back the questionnaire or return it back to the co-ordinator in order to protect the confidentiality of the respondent. The distribution of the booklets was problematic. Firstly, because they were ready for distribution just before Christmas and secondly, people did not enter residential care all at the same time. Six months later no questionnaires had been returned.

A social work student on placement with the Co-ordinator of Alzheimer's Society Manawatu was requested to follow up caregivers who had received booklets and personally approach them for feedback. The student contacted these people by telephone and had lengthy discussions with all of them and also visited some of them in their own homes. Ten questionnaires were returned and collated.

RESULTS

SURVEY 11

The results yielded positive feedback with some of the respondents adding more comments than others. Some caregivers stated that they were so overcome with guilt feelings about placing their loved one in residential care that they forgot to ask many questions. One of the community newspapers which delivers a free paper in the Palmerston North area wrote an article about the publication of the booklet and its aims. Several people phoned the Alzheimer's Society requesting a copy of the booklet which was helpful in distributing it to unknown caregivers. Copies were also sent to all resthomes in the area and to the assessment wards at Palmerston North and Wanganui hospitals. A request was received from the nursing tutor at the Hawkes Bay Polytechnic requesting to purchase several copies to use as a resource for her nursing class.

The results from the questionnaires were collated and are summarized in Table Three.

TABLE III

SUMMARY OF SURVEY II

<u>QUESTIONS</u>	<u>COMMENTS</u>
1. What parts of the information did you find most useful?	<ul style="list-style-type: none"> • Different stages of resthomes • Staffing levels • Philosophy • Staff training • Info re responsibilities & letting go
2. How if at all did the information make you feel more confident?	<ul style="list-style-type: none"> • Good guidelines • Knowledge of what questions to ask • Able to discuss with others in similar circumstances • Wouldn't have thought of asking those questions • Knew to observe staff and resident interaction
3. Did you have a choice of resthomes to choose from?	<ul style="list-style-type: none"> • YES = 3 • NO = 4 • LIMITED CHOICE = 3
4. Did you find the staff helpful?	<ul style="list-style-type: none"> • Very helpful - 1 2 3 4 5 - Not helpful No of replies 4 2 4 1 0
5. How well did they answer your questions?	<ul style="list-style-type: none"> • Very well - 1 2 3 4 5 - Not well No of replies 4 2 4 1 0
6. Is there other information you would like to see in the booklet?	<ul style="list-style-type: none"> • Very adequate • Prices of resthomes and subsidies • What is included in the cost and not included • Treatments used to control residents • Drugs used and side effects • Found book helpful
7. Are there any suggestions that you think could be helpful for other caregivers?	<ul style="list-style-type: none"> • Differences between Stage II & III resthomes • Stages of dementia • Give them a copy of the book • Look at resthomes more than once • Take a friend with you • Watch how people react to staff

DISCUSSION SURVEY II

Caregivers were all personally telephoned by the student. Some were also visited at home and had the opportunity to discuss their experiences with the social work student who was following up the return of the questionnaires. This may have resulted in briefer comments than expected. Unfortunately the student did not make detailed notes on the discussions.

Respondents all felt the information was useful and prompted them to ask questions they otherwise would not have considered. Caregivers often struggle to come to terms with the decision to place their family member with dementia into full-time care. Feelings of relief that someone else is going to relieve the stress of not coping, are overcome with feelings of guilt and failure. The caregiver also grieves for the loss of the person they once knew and for the life they once had. Often couples have been married and together for fifty to sixty years. Coming to terms with having to now live apart can be a devastating experience.

The results showed that only three caregivers had a choice of resthomes and one of these was forced to transfer her mother to another facility. The majority of resthomes available are Stage II which gives caregivers a selection to choose from providing that their person does not wander or display aggression or agitation. Often these resthomes are staffed by untrained workers who do not have the skills or knowledge to care for people with dementia. The purpose of the booklet was to empower these caregivers to know what to look for in a resthome and what questions to ask. It could be assumed that since one of the caregivers had transferred their mother to another facility he/she was not satisfied with the care they were receiving and felt confident enough to make the decision to transfer her. The remaining seven respondents commented on either very limited choice (30%) or no choice at all (40%). The choice of Stage III resthomes is very limited in each area. There is a limit on how many Stage III beds the Regional Health Authority will subsidize in each area. In Palmerston North city there are two facilities. If one of these is full (which is often the case) caregivers are left with no

choice if they do not want to travel to another town to visit. Often these caregivers are elderly themselves and have to rely on others for transport. Stage III resthomes specialize in the care of people with dementia with behavior problems, those who wander or have sleep disturbances. Their staff ratio is expected to be 60% above that specified in Regulation 36, Old People's Homes regulations 1987 (Central RHA Aug. 1996). Stage III resthomes must have weekly input from a registered nurse who has had experience and training in the care of people with dementia. The service description for Stage III care states that there must be documented evidence that all staff undergo continued training to care for people with dementia that is appropriate to their role in the resthome. The service description also states that this training should occur at least annually.

Respondents found staff on the whole were helpful. On the scale of 1 to 5, 40% found them very helpful with another 40% grading them as average. The same result was seen in the next question of how well the staff answered the questions. Each resident is expected to have a key worker who acts as an advocate for the resident, establishes a trusting relationship with the resident and carer and is responsible for the individual lifestyle plan and ongoing treatment. The lifestyle plan must involve input from the carer or significant other and be audited by the service to meet the service description requirements.

When respondents were asked to comment on any other information they would like to see in the booklet there were several comments concerning subsidies and what is covered by the subsidies. Some caregivers are finding they are receiving accounts from the resthomes for doctor visits, transport to the hospital for appointments, incontinence pads etc. These costs are the responsibility of the resthome covered by the subsidy the RHA pays for subsidized residents. These are all set out in the service description but caregivers would not normally have access to this information unless they ask. Providers (i.e. residential facilities) must have formal and written quality improvement plans and copies of these standards

are made available to subsidized resident and carer advocacy groups by the Central RHA.

Eight of the respondents contributed several suggestions that they thought would be helpful to other caregivers. Results showed that they all valued the support of family and friends and aside from information caregivers also need the opportunity to work through their feelings with support from other caregivers or professionals.

LIMITATIONS

There were several limitations to this survey and evaluation of the booklet. It was not a representative sample of the population as it only reached those caregivers who were at the time choosing a residential facility for their person with dementia. Also, comments may have been general following the conversations and meetings caregivers had with the social work student while she was gathering the data. Caregivers may have considered they had expressed themselves sufficiently to the student and this information would have been passed on. Another limitation was the inability to measure the extent to which the benefits of the education the caregivers received had trickled down to the person they care for with dementia. Mainly this is due to the problems of surveying people with dementia because of the damage to their short-term memory. However, the findings did show that caregivers had benefited from the information contained in the booklet and Alzheimer's Society Manawatu have had sufficient feedback from these caregivers to know how this information is valued. Several commented that the booklet should be available when a person is first diagnosed with dementia. This information has prompted the society to include one of these booklets in the 'starter packs' which is a folder containing helpful information on dementia and available supports when a person first makes contact with the society.

These two surveys have shown that information and education can empower both caregivers looking after a person with dementia at home, or caregivers working

in residential facilities to make the changes necessary to improve the quality of life for those with dementia.

This thesis has discussed how the theory of education is an important component of critical theory and essential for creating an environment that is responsive to the needs of people with dementia. I have demonstrated how the elements of safety, structure, support, involvement and validation are essential to provide quality of life for elderly people with dementia in residential facility. The chapter that follows what is needed to provide this quality of life explains some of the policy implications that caregivers and workers are restricted by. The environment is changing and it is difficult to maintain quality standards when there are economic restraints. Because recent health and welfare policy has undergone many changes during the time I have been writing this thesis it is only relevant to the situation at the time of writing. I conclude with recommendations for policy makers and residential facilities which I believe would ensure quality care and quality of life for people with dementia.

CHAPTER 10

RECOMMENDATIONS AND CONCLUSIONS

This thesis has examined quality of care for elderly people with dementia from a critical perspective. Research undertaken indicated that education can be beneficial to empower caregivers at home and those working in residential care to make changes to improve the quality of life for this group of people.

The framework of Fay's 'Critical Theory' has been used to explain how a 'Critical Theory' is developed. Although this is a complex set of theories, basically critical theory aims to educate and inform its audience to empower them to make changes in their lives, or the lives of those they work with.

Considerable stigma is attached to 'losing one's mind'. For some, dementia is a synonym for 'insanity' and because of this people with dementia and their families fail to admit there is a problem and often delay obtaining support services until a crisis develops. Others with dementia may not accept support (apart from their carer) as this would define their condition and reinforce their independence.

Most elderly people experience loss of independence in some form as they grow older. The dynamics surrounding giving and receiving help are complex especially when a person fails to acknowledge their loss of memory. Loss is also experienced by the elderly as they grow physically frail, and experience the deaths of spouses and /or friends. Feelings of personal well-being are greatly influenced by the way help is offered emphasizing how important it is for residential staff and support services to be trained to respond in an appropriate way.

The adapted Gunderson Model (1978) outlined in Chapter 6 specifies five areas that need to be considered when planning and implementing quality care for people with dementia. The following recommendations based on this model need to be considered by policy makers, residential facilities and support services.

FACILITIES

Specifications for facilities for dementia care must compensate for the physical and cognitive losses, of those with Alzheimer's Disease and balance safety with autonomy. They need to be of a design which offers security for those who wander and minimize sources of confusion, while still providing a pleasant environment. The design of the facility should meet the philosophy and goals of the provider rather than being restricted by financial resources or organizational restraints. Interior factors to be considered are:-

The **Atmosphere** should be pleasant, homely, cheerful, clean, and attractive. Avoid patterned floors and wall coverings.

Walls and floors should consider mobility and visual problems. Use colors and furnishings to decrease confusion and assist the confused person to find their way.

Orientation cues provide cues to orientate confused people to their physical environment (common areas and personal space), and provide orientation cues to assist orientation to time and place (calendars, clocks, amenity signs, names on doors etc.)

Lighting Bright indirect lighting and non-glare surfaces provide the best lighting and minimize the effects of sundowning.

Temperature should be kept at a constant level as people with dementia are often unable to identify when they are hot or cold. Staff should help residents dress accordingly and take into account variations in temperature variations throughout the day.

Noise should be kept to a minimum as this can increase confusion and agitation and distract concentration.

Special provision needs to be made for the care of those who have severe behavior disturbances associated with dementia. The differing needs of younger people with dementia and Maori and other cultures need to be addressed also. National standards need to be established and monitored on a regular basis by inspection of the facility to monitor if what is documented in the records is actually happening.

STAFF TRAINING

Staff development programmes should be seen as central to definitions of quality care within health organizations and should come within the definition of a good employer. The absence of qualified staff to develop training courses could be responded to by importing skilled practitioners on a regular basis to conduct staff training courses. Alternately it could be done through distance learning using audio, video tapes and written literature in regular sessions. This could lead to local groups of interested persons then establishing regular training days to continue to develop their techniques.

There is presently wide variation in training methods used throughout the country and even within regions. Standardized, mandatory training needs to be implemented in the training for medical students, nursing staff and all allied health professionals at the undergraduate level. There also needs to be postgraduate nursing courses available that meet the standards the N.Z. Qualifications Authority and sanctioned by the Alzheimer's Society. Alzheimer's Society has recommended that information, support and training for carers and community education be recognized as a service to be purchased by the RHA. They also recommend that national minimum standards for dementia-specific training for all staff in residential facilities be set and incorporated into service contracts. Alzheimer's Society N Z could monitor these services under contract from RHAs.

Employing staff who are trained in dementia care would improve the support caregivers need when they place their loved one into care. By allowing family caregivers to participate in the care plan of their person with dementia, staff learn

about the person with dementia and can then plan appropriate strategies to enhance their introduction into residential care and improve their quality of life.

Residents need to retain their sense of independence and staff training should encourage staff to assess a resident on what they can do, rather than what they can not do. Every effort should be made by staff to provide assistance where necessary to allow the person with dementia to retain dignity.

Residents should be encouraged to participate in the daily activities of their facility which can often support the role they have performed during their lives, e.g. homemaker, gardener.

ACTIVITY PROGRAMMING

A trained diversional therapist or recreational officer should be employed in each facility to provide individual and group activities. These activities should be planned to incorporate the physical, spiritual and emotional needs of the person. They should aim to stimulate the person through their sensory modalities and through reminiscence of their early years. They should also stimulate the interests and life time skills of each individual.

EDUCATION

Dr. Martin Orrell, University College, London (Alzheimer's Newsletter UK 1996), reviewed a number of studies showing that the more we use our brain, the more connections are made between brain cells. He wanted to know if increased brain connections could compensate for loss of some cells in Alzheimer's Disease. Several studies showed a link between education and dementia. Orrell (1996) cites a study by Sahakian 1995 who reported a fourfold risk of Alzheimer's Disease among people with the lowest educational status and another study by Bonaiutu 1995 who found that Alzheimer's Disease occurred in 7.2 per cent of illiterate people reducing to .5 per cent of those who had studied to fifth grade or more. Elderly people appear to have a reserve capacity of intellectual function

which can be activated to improve mental performance. Therapy programmes involving stimulating mental activity has also been found to have beneficial effects on mental performance in persons with dementia.

Setting up support groups for those in the early stages of Alzheimer's Disease is another way of providing education. Support from each other, and the opportunity to share feelings, frustrations and strategies, make coping with the disease easier for some.

ASSESSMENT

Assessment services need to be accessible and available throughout the country with reassessment annually or as needs change. Assessment services and service providers need to work in partnership to eliminate delays between, when an assessment is completed and when the support services actually start. All those involved in the assessment and allocation of services should be trained to understand the special needs of those with dementia and their caregivers, as well as the wider social implications of dementia. The assessment team also needs to be familiar with legal requirements as often the caregiver does not have the written authority to make decisions on behalf of the person with dementia. A person cannot be placed in residential care without their consent if there is no Enduring Power of Attorney in place or a Welfare Guardian has not been appointed by the family court under The Protection of Personal and Property Rights Act (1988).

RESEARCH

There are still no known causes or prevention for Alzheimer's Disease. Currently the Health Research Council is the main funding source for New Zealand Health research. In 1994, \$585,713 was granted for research into neurological disorders (Ministry of Health 1994). This amount was not specifically tagged for dementia research but since President Bush declared the 1990's as the decade of the brain in the USA, this has stimulated further research initiatives towards

finding the cause and a cure for Alzheimer's Disease. Increased Government funding is required to extend research that is already underway in New Zealand at several sites. Research is required on a national level to ascertain accurate figures of the number of people affected by dementia. This will be required to plan services for the future. Alzheimer's Society N.Z. should be funded by the Ministry of Health to take responsibility for developing national policies and guidelines to be implemented by the Regional Health Authorities throughout New Zealand. These policies should specify the services and support caregivers and people with dementia require. They should also address the special needs of people with dementia in their transition into residential care to ensure that their quality of life is enhanced.

It could be suggested that Alzheimer's Society would have the monopoly on developing policies which could lead to a closed door approach and the interests of the Society's hierarchy being served rather than the interests of the clients. Over the past years Alzheimer's Society has established an accountable service to its members, communities throughout New Zealand, and to Government agencies. It has advocated on behalf of its members on many occasions to have the needs of caregivers and people with dementia recognized. The structure of the organization comprises firstly its members made up of people with dementia, their caregivers and families, and many health professionals, residential facility staff and allied workers. Each group is autonomous but affiliated to Alzheimer's Society N.Z. The structure works to protect the interests of its members and recognizes the necessity that the role of advocacy plays.

CONCLUSION

The increasing age of the population in New Zealand and the marked increase in the prevalence of dementia with increasing age means that residential facilities will be expected to care for a greater number of elderly people with dementia. The impairment of short-term memory and other cognitive impairments seriously limits the person's ability to communicate a coherent judgment of the care they need. For those people with dementia who can no longer be cared for at home, residential care is their only option. Carers need to be committed to moving away from a medical model of physical and chemical restraint to an integrated approach. For people with dementia this includes attending to the spiritual, emotional, social, intellectual and an expanded concept of their physical needs. The programmes offered need to aim at maintaining quality and can not be implemented if the facility design does not support them. Adequate care within residential facilities is dependent on several factors as outlined in the recommendations.

When working with people with dementia the greatest need is to understand their need. People with advanced dementia are often unable to communicate verbally their dis-satisfaction with life. This needs to be assessed by observing and monitoring behavior and non-verbal responses. Staff training is essential to understand the needs of the person with dementia and also assist the caregiver through the grief and guilt process. For training to have real meaning it needs to be delivered within a multidisciplinary framework and responsive to identified needs within the residential facility. Family caregivers need to feel valued and worthwhile and encouraged to assist their person with dementia with the transition into residential care. It is important to recognize the individuality of people with dementia and their family caregivers and strive to adjust services to meet their needs.

The results of the author's research on caregivers working in residential facilities and family caregivers indicated that education is empowering and gives people the

knowledge and confidence to make changes that improve the quality of life for people with dementia. Disparities in services have highlighted the need for a national plan for dementia. This leads to the debate of, who is responsible for the training of staff? The Ministry of Health specifies in the Policy Guidelines that RHAs purchase education and training for the people needed to deliver quality services. The RHAs state in their service contracts that the training of staff is the responsibility of the service providers. Service providers are constrained by economic factors and only employ the minimum of trained staff. Obviously policy makers and funders must seriously consider the importance of specific dementia training for all staff employed in the care of persons with dementia. Residential facilities must respond to the challenge of providing a quality service to achieve '*excellence in dementia care*'.

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A MEMBER OF THE ASSOCIATION OF POLYTECHNICS IN NEW ZEALAND

"ADDRESS ALL CORRESPONDENCE TO "THE CHIEF EXECUTIVE"

30th May 1995

Ms Trish Melling
Alzheimers Society Manawatu (Inc)
Marion Kennedy Centre
50 Ihaka Street
PALMERSTON NORTH

Dear Trish

The Research & Ethics Committee considered your proposed research topic at its 12th May 1995 meeting and have approved your proposal.

You are required to liaise with Martin Woods over ethical issues. You will also be required to provide me with a copy of your final research report - or a suitable extract, whichever is most appropriate, on the completion of the research.

I wish you well with your project and look forward to reading the results.

Yours sincerely

Terry Barnett
MANAGER, ACADEMIC DEVELOPMENT & RESEARCH
Executive Officer, Research & Ethics Committee

cc: Martin Woods
Jan Lockett-Kay

tb/atg/437

APPENDIX I

~QUESTIONNAIRE~

1. Sex male female
2. Age 15-25 26-35 36-45
46-55 56+
3. Occupation

4. Formal Qualifications (eg: Registered nurse, Resthome core course)

5. How was this course funded self
employer other

6. Were you allowed time off work to attend this course yes no

7. If yes, were you paid or unpaid paid unpaid

8. Do you consider education about dementia to be essential for people working in this field yes no
unsure

9. Were you able to implement changes in your workplace yes no

10. If yes, what were the changes

11. If no, what would you consider the barriers to be

12. What part of this course did you find most helpful

13. Was the length of the course

too long
ok *too short*

14. Is there anything you would like to see added to the course

15. Was there anything you felt to be irrelevant

16. Do you wish to expand your knowledge further

yes *no*



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**FACULTY OF
SOCIAL SCIENCES**

**DEPARTMENT OF
SOCIAL POLICY
AND SOCIAL WORK**

Information Sheet For Students

Research Title:

A survey of students who have completed the 'Dealing With Dementia' course run by the Manawatu Polytechnic.

The Researchers:

The principle researcher is Trish Melling who is completing a Masters of Social Work degree. This research forms part of a thesis which studies the partnership between education and industry. This project is supervised by Maryann Brackerville on behalf of the Social Policy and Social Work Department at Massey University, with the approval of the Massey University Ethics Committee. It has also been approved by the Research and Ethics Committee at Manawatu Polytechnic.

What The Study Is About:

The study will explore how the knowledge and skills gained from attending the course can be implemented in the workplace. My aim is to improve the quality of life for people with dementia and I believe for this to happen workers need to have access to training and education.

Theory has shown that education is empowering, but in order for change to occur there needs to be partnership between industry and educational institutions, supportive management and a supportive environment.

What Is Required Of The Participant:

Each participant is asked to complete the enclosed questionnaire and place it in a box when they leave the room. I do not need to know your name or your workplace, but I will be available to discuss any issues this questionnaire may have raised for you after the course if necessary.

The information you provide is on the understanding that it is completely confidential to the researchers. All information is collected anonymously, and it will not be possible to identify you in any reports that are prepared from the study.

If requested you will be given access to a summary of the findings from the study when it is concluded.

Answering the questionnaire is voluntary and you may choose not to participate.

Thankyou for your time and interest. I am available to be contacted if required.

Trish Melling,
Ph: 0-6 327 5171 home
Ph: 0-6 357 9539 work

Consent Form

Project: A survey of students who have completed the 'Dealing With Dementia' course run by the Manawatu Polytechnic.

I have read the information sheet for this project and have had the details of the study explained to me.

I understand my participation is voluntary and I am free to withdraw or decline from answering some of the questions.

I will participate in this survey and agree by completing the enclosed questionnaire.

**DO YOU KNOW WHAT YOU ARE
LOOKING FOR?**



**IN
DEMENTIA CARE**

**A HANDBOOK FOR FAMILIES,
CAREGIVERS, SERVICE
PROVIDERS & POLICY MAKERS**

PATRICIA MELLING
Author

APPENDIX IV

ABOUT THE AUTHOR

Trish Melling is a Social Worker employed by Alzheimers Society Manawatu Inc. as Manager of Marion Kennedy Centre, a daycare service for people suffering from Dementia.

ACKNOWLEDGEMENTS

This booklet has been written as partial fulfillment of a thesis for a Master in Social Work Degree. I wish to acknowledge the assistance and support of my Supervisors at Massey University, Mary Ann Baskerville and Mike Garland. Also thanks to my peer workers and associates who have commented on my draft and provided support and encouragement. A special thank you to Sally and her computer skills who made this publication possible.

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INTRODUCTION

This booklet has been compiled to assist caregivers and families in their selection of a rest home or continuing care for a person with dementia.

For most families this choice is a difficult one as often the main caregiver is coping with feelings of guilt and grief while coming to terms with the decision to relinquish the 24 hour care of their loved one.

The aim of this booklet is to provide the information needed when choosing a rest home. What to look for, what questions to ask and why these things are important to ensure the best quality of care and the best quality of life for a person with dementia.

It is also hoped that the same information will prompt policy makers to ensure these standards are met in all resthomes and continuing care units.

This information relates to residential care in New Zealand at a time when many changes are occurring in the health and welfare areas. Policy changes in the future may alter the information contained within.

ASSESSMENT

Government funding for health care in New Zealand is allocated by the Ministry of Health and is distributed to the Regional Health Authority (RHA) on a population basis. The RHA is responsible for administering this funding for health services within its allocated area. This is done through contracts with Crown Health Enterprises (CHE's) and community support services.

When a person can no longer be cared for in their own home they are assessed by the Senior Assessment Team which is generally a service provided by their nearest hospital. In consultation with the caregiver and other health professionals, a Support Needs Assessment Form (SNAF) will be completed which assesses the person's support need level. Chart I shows how the support need level relates to the different categories of care.

LEVELS OF CARE

CHART I

CATEGORY OF CARE	SUPPORT NEED LEVEL	COMMENTS
STAGE I	1 - 3	This level of care is less often recommended as community services are provided for those who prefer to remain in their own homes
STAGE II	3 - 5	Recommended for people requiring 24hr supervision or those requiring assistance of one person to perform daily tasks
STAGE III DEMENTIA CARE OR PSYCHOGERIATRIC CARE	5	Often attached to a Stage II Rest Home or Hospital for people with Dementia or psychiatric problems who display difficult behaviour such as aggression or wandering and requiring care in a secure environment.
HOSPITAL CARE OR CONTINUING CARE	5	For people who need 24hr nursing care requiring two persons assistance.

Sometimes a person with a support need level 3 may be recommended for rest home care depending on special conditions such as lack of a support network, health problems or early dementia requiring supervision. Following assessment, if a person is recommended for rest home or hospital care, the caregiver is referred to a service co-ordinator who will explain how the care will be funded, either privately or via Government subsidy, and provide the caregiver with a list of available rest homes in the area. Pamphlets are available from RHA or your Senior Assessment Team which explain all about rest home subsidies and who will qualify.



CHOOSING A REST HOME

If you are looking at care in a specialised dementia unit your local choices may be limited. Ask about options further afield. Often the person with dementia is happier in a facility which is caring and provides quality care. If you as the caregiver know your relative is happy you may feel the need to visit less often and make each visit quality time together, rather than coming away feeling stressed and guilty because your family member is unhappy and insisting on returning home.

Letting go of your responsibility as main caregiver is often difficult. Women especially have been conditioned by society to think that their role in life is to care for people. A commitment by marriage to care for each other for better or worse, till death do us part can leave caregivers feeling guilty. Caregivers need to accept that they can no longer provide the constant supervision, 24 hours a day that

dementia requires. You need to feel comfortable about the facility you choose to give this care.

The aim of this booklet is to help you select an appropriate facility where you can feel part of the transition and relinquish the care at your own pace.

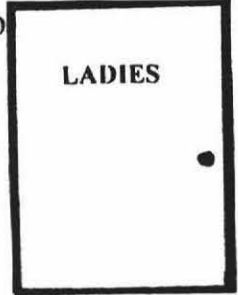
PHYSICAL STRUCTURE AND ENVIRONMENT

Because of the necessity to compensate for memory loss, a safe environment is the most basic requirement in dementia care.

The structure is determined by the design of the building and the way the space in the building is divided. Communal areas need to be small in order to foster social interaction. Chairs placed around the walls in a room evoke appropriate responses and may remind the older adults of doctor's waiting rooms and other public places. Extra lighting in rooms

can often prevent 'sundowning' i.e. increased agitation and wandering in late afternoon.

Colour is used to identify areas. Because as we age the eye becomes less responsive to pale colours the use of strong primary colours can aid in the identification of areas. Toilets and bathroom doors should be labelled to make identification easier.



Contrast is achieved by the use of colour and texture in carpets and wall coverings. Residents' doors can be individualised by attaching a familiar object to it, for example a family photograph or a favourite tapestry. This creates a strong sense of familiarity for the person and reduces environmental confusion.

Residents should be encouraged to bring some items of personal furniture and decorative belongings to make their bedrooms feel like home. A favourite chair or picture can bring much comfort to a person who feels lost in a

strange and confusing environment. There needs to be a secure and safe outdoor area where residents can wander. These areas need to be interesting and reminiscent of the older style garden and backyard where many activities took place such as hanging clothes, potting, stacking wood, sweeping leaves, growing herbs in raised gardens etc. Where seating and paths are placed will determine how successfully outside areas are used.



PHILOSOPHY

Check the philosophy of the rest home.

- Does it promote a holistic approach which includes the physical, mental, spiritual and emotional wellbeing of the resident?

- Does it promote respect and affection for the elderly resident?
- Does it recognise different cultures and religions and respond to them?
- Does it acknowledge the Treaty of Waitangi?



FACILITY POLICIES

What is their policy on:

- (a) Physical restraint e.g. stopping a person from wandering by tying to a chair.
- (b) Chemical restraint e.g. the use of drugs to prevent aggression and wandering.

There are many alternative ways of supporting people who have dementia. Ask to be involved

or for an explanation of why these restraints are considered essential

- Are incidents and accidents documented?
- Are residents allowed to smoke/drink alcohol?
- Do staff adhere to the Privacy Act, a code of ethics and sign a confidentiality code?
- Fire safety policy - are sprinklers installed and/or smoke detectors?



STAFFING

Minimum staffing requirements are set by the Regional Health Authority and monitored by the Ministry of Health. These levels (as seen on the chart II) are inadequate to provide individualised quality care for residents with dementia. Caregivers employed by the facility are the main providers of care in rest homes yet usually have received the least training. Staff require ongoing supervision and in house training to communicate with people who suffer from dementia in order to minimise their confusion, to prevent or defuse disruptive or aggressive behaviour and to provide a stimulating environment.

Staff also need to be tolerant and accepting of the person with dementia and not label their behaviour as "the problem". Staff should be experienced in interpreting behaviour as a meaningful expression of the person's inner self-expression and the behaviour should not be

terminated or ignored but rather understood, accommodated and responded to where appropriate.

Domestic staff are also part of the residential environment and frequently have direct contact with residents. They too require training on how to interact with residents and to involve them in some of the domestic tasks.

***A MESSAGE FROM PEOPLE WITH
DEMENTIA***

Memory is not essential for enjoyment.

***It does not matter if we cannot remember
where we went yesterday. It is important
that we are doing it. We can carry the
feeling of wellbeing even if we do not know
why we have it.***

OLD PEOPLES HOMES MINIMUM STAFF REQUIREMENTS

CHART II

STAGE I

No. Of Residents	Minimum total hours to be Worked per week by Staff
3 - 5	60
6 - 10	120
16 - 20	200

21 or more, 200 + 40 additional hours for every 4 additional residents or part of that number

STAGE II

3 - 5	69
6 - 10	138
11 - 15	184
16 - 20	230

21 or more, 230 + 46 additional hours for every 4 additional residents or part of that number

STAGE III

3 - 5	96
8 - 10	192
11 - 15	256
16 - 20	320

FROM: MINISTRY OF HEALTH - JULY 1995

QUESTIONS:

- What courses on dementia have staff attended?
- Is regular in-service training and education provided for staff?
- How many fulltime equivalent registered nurses are employed?
- How many fulltime equivalent caregivers are employed?

When viewing a rest home observe the attitudes of staff to residents.

- How do the staff communicate with residents?
- Do they treat residents with respect?
- How do residents, interact with each other?

Allowing carers to continue to share the care of their relative in residential care can make the decision to give up fulltime care easier for family carers. It allows staff the opportunity to get to know and understand the new resident, their likes and dislikes, habits and routines. It can make the transition from family care to residential care less stressful for all.

QUESTIONS:

- Do staff welcome family involvement in the care of their person with dementia?
- Do they involve family in decision making and care plans?

LISTEN TO THE MUSIC



NOT THE WORDS

PERSONAL CARE

Some rest homes offer double rooms which often can be off-putting as you would not feel comfortable yourself sharing a room with a stranger. However for people with dementia who have been accustomed to sharing a room with their spouse it can be comforting to them to have company in their room during the night. People with multi-infarct dementia who have suffered strokes are stimulated by sharing a room with a person in a similar situation. They encourage each other to use the limbs that have been affected by the stroke.

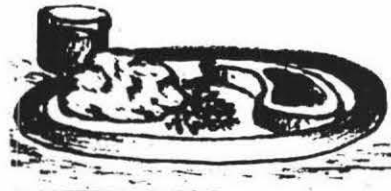
Ask to inspect the room that your family member could move into and if they are going to share a room, allow opportunity for the proposed room-mates to interact with each other.

- Look at the residents. Are they clean and well groomed?
- Do residents have the choice of shower or bath and how often?

- Is there access to a hairdresser, podiatrist, manicurist. If so, who pays?
- Are there extra charges for laundry?
- Bedtimes - are they flexible?
- Do residents have access to their rooms at all times?
- Is there a private place where you can visit with the resident, make a cuppa?
- When is visiting permitted, can you come and go as you like?
- Are private needs and confidentiality respected?
- Are individual needs recognised - e.g. going for a walk, listening to favourite music, watching sport, attending church, having a drink in the local pub, visiting the TAB.



MEALS



For the person with dementia meal times are usually a focal point of their day. Well presented food can stimulate all the senses and often evokes past memories of favourite people and events. Sharing a meal time with a loved one can be a special time. Often having an extra person present to assist with feeding can also be beneficial to staff.

- Food should be colourful and look good to stimulate sense of sight.
- Smell good to stimulate sense of smell.
- Taste good to stimulate sense of taste.
- Feel of food in mouth and to the touch can stimulate sense of touch.
- The sound of food cooking, pop corn popping, crunch can stimulate auditory senses.

- Ask to see the menu.
- Are meal times flexible e.g. a person may prefer their main meal later in the day?
- Can residents have breakfast in bed?
- Can residents have meals in their room?
- Is a balanced diet of finger food available for those who can no longer use utensils?
- Is there a range of interesting and tasty alternatives for those on special diets e.g. diabetics?
- Can a spouse join his/her partner for the main meal? How much would it cost?



MEDICAL CARE

Some rest homes have their own doctor, but often a resident can continue to be attended by their own doctor if agreed to by both doctor and rest home. It is important that the rest home is given a history of the resident's medical condition and medication.

QUESTIONS:

- Who pays for medical costs and prescriptions?

Usually if a person is receiving a rest home subsidy all medical costs are covered by the rest home.



ACTIVITIES AND RECREATION

Activities and recreation for the person with dementia does not necessarily just involve programmed activities that are provided by most rest homes for a limited number of hours a week. Stimulating a person with dementia is often achieved by involving the resident in the day-to-day routine of the facility. Encouraging the resident to assist with maintenance of their room, in dining room and kitchen activities, can often give the person a sense of worth and usefulness. People who have led active lives need direction and supervision to involve them in purposeful activities throughout the day.

Programmed activities that involve music, singing, use of numbers and reminiscing can be enjoyed by all people with dementia. For those with dementia who are continually wandering and inclined to be physically aggressive, alternative therapies can be used by staff to eliminate the use of physical and chemical restraints. Some examples of these are:

- **WATER THERAPY**

A large container filled with warm water and bright coloured objects that residents can sit around. The warm water often stimulates those in the advanced stages of dementia to interact with other residents and the objects in the water.



- **PET THERAPY**

Pets either belonging to the Rest Home, residents or brought in by owners. This stimulates sense of touch and reminiscence.

- **ART THERAPY**

Allowing residents to express themselves through use of colour on paper, fabric or other materials.



- **DOLL THERAPY**

Introducing dolls or soft toys which are often adopted by residents who attach significant meaning to them.

- **AROMATHERAPY**

Using essential oils to bring relief, to soothe or stimulate certain parts of the body. These can be used as inhalations, in baths, vaporised or as a massage.

- **MUSIC THERAPY**



This can be live or recorded music. Residents can sing-a-long, listen or dance. It is used to energise, encourage communication, reminiscence, laughter and enjoyment.

- **VALIDATION THERAPY**

Validating emotional memories from the past. Accepting the confused person where they are in time and place. Assists

them to restore past life, to regain dignity and self esteem.

- REALITY ORIENTATION THERAPY
This engages the person in the present by discussion of present day events and happenings to remind them where they are in the present time and place.

QUESTIONS

- Ask if a diversional therapist or recreational officer is employed?
- How often?
- How many hours per week?
- Ask to see the activity programme.
- Are outings organised?
- Are residents involved in community events?
- Are residents encouraged to participate in daily tasks?
- Are pets allowed?
- Is there a secure outdoor area where residents can wander and participate in activities?

HOUSEKEEPING QUESTIONS

- What is the weekly cost of care?
- What does this include - i.e. laundry, doctors?
- How and when are payments made?
- What extras will you have to pay for?
- Do you have Power of Attorney or has the Court appointed someone under the Personal Protection and Property Rights Act to act on behalf of the person with dementia? More information about this can be obtained from your solicitor, Law Office, or Public Trust.
- Is there a waiting list?
- Is there a committee for caregivers?
- Is there a committee and advocate for residents?

FURTHER COMMENTS

Visit several facilities on your list before making a choice. It is advisable to make an appointment with the manager to enable him/her to spend time with you, answering your questions and showing you around. Spend some time getting the feel of the place.

Are you made welcome? Is it warm? Do other residents look content and relaxed? Before deciding, take your person with dementia to visit and share a cuppa with other residents. Observe the interaction with other residents.

Generally, a person suffering from dementia will progress to the final stages of the disease and will become totally dependent on staff for care. Ask how long a person can remain in the facility. Some rest homes have a long term unit attached to them where a person who has deteriorated can be transferred. Others may have to transfer to another facility that can provide the quality of care required and recommended.

Be prepared to allow for a settling in period and address any concerns you may have to the staff and management. If you have grave concerns or complaints that have not been addressed, contact the Ministry of Health and they will send you an official complaint form and will action your complaint.

If you are still unsatisfied with the care provided you are entitled to move your person to another facility.

Join your local ADARDS support group for carers. These operate in most centres and provide caregivers with support and information. Members of the group who have already experienced placing their relative in residential care are usually very supportive and willing to share their experiences with you.

REMEMBER, rest homes exist for you and your loved ones. You have a right to feel comfortable and happy about the care received.

Your local ADARDS contact is:

ALZHEIMERS SOCIETY MANAWATU
INC.

P O Box 527, Palmerston North
Ph: 06-3579539

ALZHEIMERS SOCIETY N.Z. LTD
P O Box 2808, Christchurch
Ph: 03 365 1590

OFFICIAL COMPLAINTS TO:
Ministry of Health
P O Box 5013, Wellington
Ph: 04 496 2000

*This booklet is funded by donations from caregivers,
families and friends to Alzheimers Society Manawatu
Inc. in memory of those suffering from dementia.*

*Printed by Massey University
Palmerston North
November 1995.*

**ALZHEIMERS
SOCIETY
MANAWATU INC.**

THANKYOU FOR YOUR TIME
AND
PARTICIPATION

APPENDIX V



**EXCELLENCE
IN DEMENTIA
CARE**

DEAR CAREGIVER

This booklet has been published to assist you to choose an appropriate residential facility to care for your family member with dementia.

To assist me with my survey research for my thesis I would appreciate you answering the questions and returning them to either Linda Edge (Fieldworker) or to the Alzheimers Society Manawatu Inc. in the enclosed envelope.

With thanks

Trish Melling

QUESTIONS

1. What parts of the information did you find most helpful?

Please comment:

2. How, if at all, did the information make you feel more confident asking questions?

Please comment:

3. Did you have a range of resthomes to choose from?

YES NO
(please circle)

4. Did you find the staff helpful?

Very helpful 1 2 3 4 5 not helpful
(please circle appropriate number)

5. How well did they answer your questions?

very well 1 2 3 4 5 not well

(please circle the appropriate number)

6. Is there other information you would like to see in this booklet?

If so, please specify

7. Are there any suggestions that you think could be helpful for other caregivers?

Please comment:



A FAIR GO FOR DEMENTIA

Produced by: Alzheimers Society New Zealand

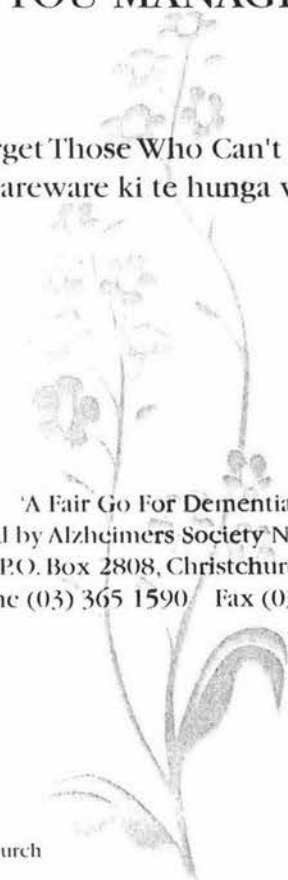


Don't forget those who can't remember
Kei wareware ki te hunga wairehu

Memory

HOW WOULD YOU MANAGE WITHOUT IT?

Don't Forget Those Who Can't Remember
Kei wareware ki te hunga wairehu



'A Fair Go For Dementia'
Produced by Alzheimers Society New Zealand
P.O. Box 2808, Christchurch.
Telephone (03) 365 1590 Fax (03) 379 8744

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March 1996

APPENDIX VI

WHAT IS DEMENTIA?

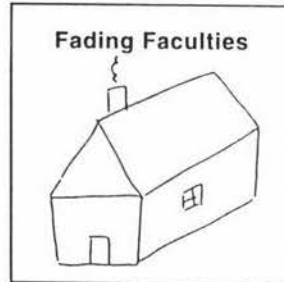
Dementia, sometimes called senile dementia, is an umbrella term which describes the syndrome of intellectual deterioration affecting memory, other cognitive functions and personality. It leads to confusion, memory loss and the inability to cope with daily living until, in the terminal phase, the person is completely dependent on others for basic care. We now know that dementia is a consequence of a variety of diseases, and not a normal part of ageing.

The most common form of dementia is Alzheimer's disease. Despite an enormous amount of research in the United States and elsewhere, the cause of Alzheimer's disease remains unknown. There are no preventions, no drugs to halt its progress and no cure.

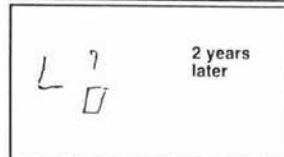
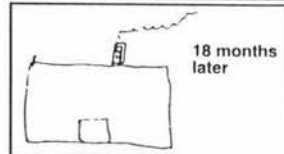
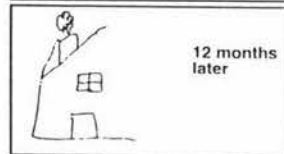
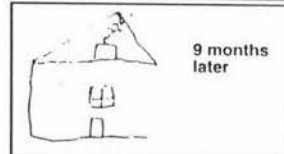
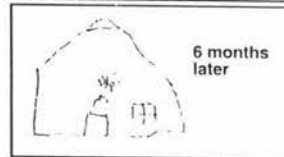
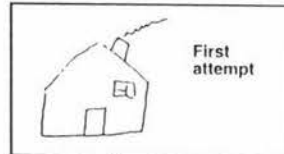
Other common forms of dementia are those resulting from multiple small strokes (multi-infarct dementia) and alcohol abuse.

Adults reading this document have about a one-in-eight chance of developing dementia. A greater proportion of the population will have a relative affected. Dementia is an illness which will touch most of us directly or indirectly.

The disease itself is a particularly tragic one. It involves the gradual but irreversible deterioration of all memory and personality functions. People with dementia are generally in good physical condition but become increasingly dependent upon their primary carers for such basic needs as toileting, bathing and dressing. The level of supervision and/or personal care involved results in substantial demands on the time of primary carers and generates much anguish and concern.



To assess degeneration in function, Alzheimer's patients are asked to copy, at intervals, a simple drawing. These were made by a 58 year old man.



PLANNING FOR DEMENTIA SERVICES

- An estimated 38,000 New Zealanders have Alzheimer's disease or a related dementia.
 - 1 in 10 over 65
 - 1 in 5 over 80
 - 1 in 3 over 85
- More commonly a disease of old age, dementia can however occur in people under 65. Just under 1% of people with dementia will be between the ages of 40 and 60. Currently these dementias are irreversible and cannot be halted or cured.
- As we approach the 21st century, caring for dementia will be one of the major challenges facing the community and health and welfare services. Our ageing population will mean a steady increase in the incidence of dementia.
- It is estimated that by the year 2000 an estimated 40,000 people will have dementia - and this is now only four years away.
- Dementia affects all ages with its impact on families. For every one person with dementia, approximately four others will be directly affected.
- Dementia is slowly progressive. Caregiving can continue for as long as 20 years.
- The burden of caring for someone with dementia is likened to a "36-hour day". The physical, psychological, social and financial costs are enormous.
- Approximately 70% of all people with dementia are cared for in their own home, more often than not by one person, often elderly.

DEMENTIA HAS NO AGE

KEY QUESTIONS FOR POLICY MAKERS

What action will you take to ensure that dementia assessment services are specialised, readily accessible and of a professional standard?

What policies will you put in place to ensure that families and people with dementia have access to a range of high quality community support services?

How do you plan to increase the minimum allowance of carer relief from its current level of 28 days and ensure that the previous allowance of 28 days is not eroded?

What measures will you put in place to ensure that education and training of all those involved in dementia care is purchased by RHAs?

How will you ensure that specialised residential facilities for people with dementia continue to be developed and realistically funded?

What changes will you make to asset and income levels to ensure that families are not disadvantaged by the extended time a person with dementia may need subsidised services?

How will you ensure that accurate statistics on the incidence of dementia will be collected nationally?

What is your commitment to the ongoing recognition and funding of the services provided by the national and local Alzheimer's/ADARDS groups?

How will you ensure that services meet the needs of Maori and other cultural groups who comprise our ageing population?

THE DEMOGRAPHIC IMPERATIVE

The major growth in the number of people with dementia will be one of the most significant consequences of the ageing of New Zealand society in the next ten years. In New Zealand today, an estimated 38,000 people have dementia. Because New Zealand is experiencing an unprecedented growth in the over eighties population, in the next decade the number of people with the disease will escalate. The risk of developing dementia increases exponentially with age. One in ten New Zealanders aged 65 years or above, and one in five of those aged 80 years or above, will develop the disease. The

cultures in the next decade, it is imperative that these issues be addressed, that Government policy be clearly defined and that adequate resources be made available. If not, this disease will have further tragic consequences for many New Zealand families and place considerable pressure on the health and welfare sectors' expenditures through the breakdown in the health of carers, early placement in residential care of people with dementia and the stress and disillusionment of professional staff and volunteers. This document includes a series of key questions. These questions are of special

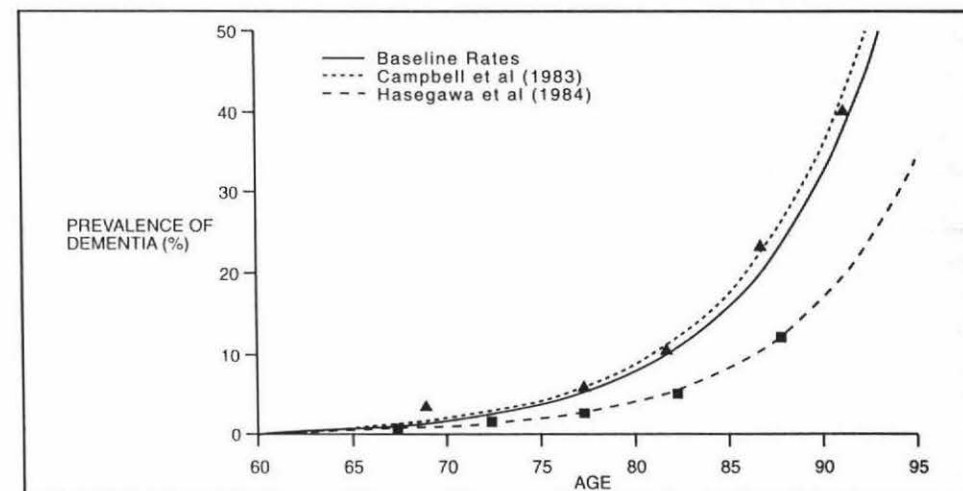


figure above shows this graphically. Yet the New Zealand community and the health and welfare systems are still largely unprepared and generally untrained for the impact this disease is having and will have. Given the scale of the problem and its impact on all facets of New Zealand life and all

interest not only to all older New Zealanders, but also to their middle-aged children who will have much of the responsibility for their care if they develop this disease. We seek responses to these vital questions. A number of specific concerns are dealt with in more detail later in the document.

ALZHEIMERS SOCIETY NEW ZEALAND

The Alzheimer's Disease and Related Disorders Society already has over 90 support groups operating in all main centres and many rural areas throughout New Zealand. This level of support is indicative of the



Society's significance to the community. Alzheimers Society NZ Inc. is the only national consumer organisation representing an estimated 38,000 people with dementia and their carers. Most of the Society's members are, or have been, primary carers of people with dementia. Other members are professionals in aged care or mental health services.

This membership base provides Alzheimers Society NZ with access to the direct experience of a significant number of health care cotôumers. Locally based groups throughout New Zealand provide information, education and mutual support to the hard-pressed families of people with dementia. Specific education in the understanding and management of people with

dementia are offered to family carers and professional carers from a variety of public, private and non-governmental day care and residential settings. Some local Alzheimer's/ADARDS groups offer direct services in the form of day-care and sitter services.

Drawing on the expertise of the local groups, Alzheimers Society NZ Inc. has identified a number of serious problems and anomalies existing in the provision of appropriate care for people with dementia in New Zealand. These problems are outlined in this publication, with recommendations aimed at rectifying the situation.

The Society recognises the new directions for health and their emphasis on community care. We believe it is vital that provision is made for adequate and high-quality services for people with dementia, their caregivers and families. This means a continuum of services has to be available to allow progression from community to residential care.

THE ISSUES

- Issue No.1: Assessment
- Issue No.2: Family Support :
Community Services for People
with Dementia and their Carers
- Issue No.3: Education/Training
- Issue No.4: Residential Care Provision
- Issue No.5: Research

THE ISSUES

ISSUE NO. 1: ASSESSMENT

Assessment is the gateway to services and the key to support, information and effective management of dementia.

Assessment services must be

- accessible
- community based
- comprehensive
- linked with medical, psychiatric and psychogeriatric services
- available in a crisis
- provided by highly trained assessors
- multidisciplinary in practice, not just theory.

The primary carer and the person with dementia must be treated as a unit during the assessment process. The carer's observations from dealing on a day-to-day basis with the person with dementia are crucial for an accurate assessment of needs.

Assessment teams must develop and maintain a close working relationship with general practitioners to maximise early, planned intervention and minimise crisis intervention.

Reassessment must be available on an ongoing basis, as dementia is a progressive disorder and the needs of the person with dementia and their caregiver can change very quickly.

Assessment must lead to the appointment of a key worker or case manager who maintains regular links with the person with dementia and caregiver and monitors the situation in order to be in a position to effect reassessment when

circumstances change.

Currently there is a division between needs assessment and service co-ordination in the AT and R units which leads to delays in implementation of services. Rural areas need to be better serviced by assessment teams.

Recommendations

We recommend that

- the RHA's evaluation of assessment services purchased in their region include input from caregivers of people with dementia.
- initial and ongoing training be required for all members of assessment teams.
- multidisciplinary assessment teams fulfilling the above criteria be established and maintained in all centres throughout New Zealand.
- a system of regular reassessment be introduced for all people with dementia.



ISSUE NO. 2: COMMUNITY SERVICES FOR PEOPLE WITH DEMENTIA AND THEIR CARERS

In light of the current philosophy to keep people in the community as long as possible, specialised community services for people with dementia and their carers need to be developed, supported and maintained.

The vital community services are:

1. Information and support for people with dementia, carers and families.
2. Respite care/relief services.

Dementing illnesses are long-lasting and terminal. People with dementia require care for many years through the mild to the severe stages. Because of the continuing and increasing levels of stress, caregivers become the unseen victims of dementia. The demands of caring impose considerable physical and mental strain on carers, and this can be aggravated by financial strains imposed by the costs of long-term illness where official monetary benefits are inadequate and personal resources are exhausted.

Information and Support

Accessible information and support for people with dementia, their carers and families is vital. These services need to include ongoing social work contact and a range of support for carers and people with dementia. The Alzheimers Society (ADARDS) provides some of these services, and the growth of the society and the demand for its services demonstrate the growing community

need. The role of the social worker in AT and R units increasingly seems to be limited to short term contact, thus reducing support to families.

Respite Care

For many people with dementia, institutional care is inevitable, but families want to manage at home for as long as possible. To avoid crisis situations there must be relief to prevent the illness of one family member from precipitating health problems in others.

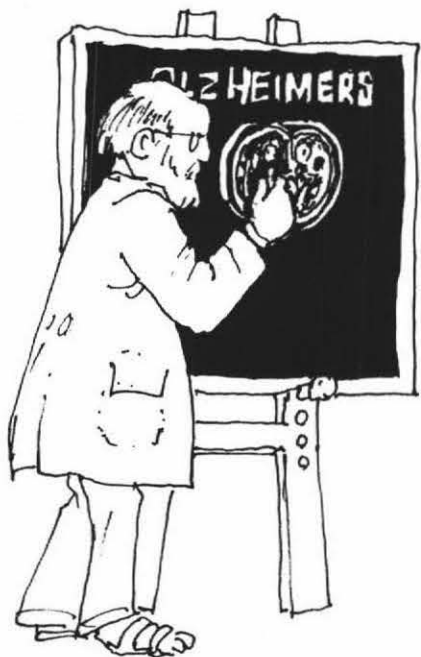
Respite care includes:

- a) Carer Relief - currently 28 days per year which can be used for periodic relief of the carer.
- b) Day Care and Night Care. There are variations around the country in these services, and there are no national standards or monitoring in place.

Recommendations

We recommend

- that RHAs be required to purchase support, information and counselling services for people with dementia and their carers.
- that a range of affordable, flexible home care services be provided to support people with dementia and their carers at home.
- that the establishment of affordable specialised day care be encouraged nationally.
- that the Carer Relief (Alternative Care) scheme be standardised to 56 days per year.
- that the Ministry of Health continue to purchase policy advice from Alzheimer's Society NZ.



There is still a large, unmet need for education of the general population. Education about dementia is the key to families' understanding and ability to cope with its devastating effects.

Written information and educational talks provide the vehicle for increased awareness and understanding, and training courses extend this knowledge and provide practical skills and ideas for caring for those with dementia.

Training

Training needs to be provided at all levels, from family carers to driving assessors, police etc. through to specialist physicians, to improve

management and care of people with dementia. All training should respect the needs of Maori and other cultural groups.

General Practitioners

The GP remains the cornerstone of assessment and continuing management of dementia. In 1993 the Alzheimers Society produced and circulated an information kit on dementia to over 2,500 GPs throughout New Zealand. Progress has been made with the inclusion of dementia in the course content for GP training. However, there is still a need for greater awareness of the importance of early identification and management of dementia to ensure that people with dementia and their families receive support and services throughout the course of the illness.

Specialist Physicians

Neurologists and specialist physicians for older people play a vital role in the assessment and diagnosis of dementia. They need to be aware of the needs of families for ongoing access to information, services and support.

Registered Nurses

At present the basic education and training for nurses does not adequately prepare graduates to work in rest home or hospital care for people with dementia. Staff of respite care services have a particular need for training, not only in the skills required for managing difficult behaviour amongst clients, but also in coping themselves with the stress of working with a particularly demanding group.

Social Workers, Occupational Therapists, Physiotherapists

These professionals play a key role in the assessment, support and care of people with dementia and their families. Training in the specific needs of these people and their families is vital.

Care Workers, Nurse Aides, Home Assistants

These people are the main providers of care in rest homes, specialized dementia units and home support schemes, yet they usually have little or no training. Comprehensive training packages should be developed and implemented nationally. Staff need training in how to communicate with people with dementia, how to prevent or defuse disruptive or aggressive behaviour and how to provide the appropriate emotional climate and environment. Training needs to be ongoing, with opportunity given to expand on knowledge and update skills.

Activities Officers (Diversional Therapists)

Diversional therapists are important members of the multidisciplinary team. They also need to be fully trained in the special needs of the person with dementia. In future years rest homes and hospitals should be able to have the choice of employing qualified therapists.

Domestic Staff

These staff are an essential part of any residential environment and frequently have direct contact with residents. They also require education and training,

especially in the area of interacting and communicating with residents.

Education and Training for Caregivers

Appropriate education and training packages need to be set up for family caregivers to enhance their skills and knowledge and minimise their stress levels.

Community Education

There is a need to educate people in the community so that their greater awareness makes them able to support more effectively those caring for someone with dementia at home.

Recommendations

We recommend

- that information, support and training for carers, and community education be recognised as a service to be purchased by RHAs.
- that national minimum standards for dementia-specific training of all staff in residential facilities be set and incorporated into service contracts.
- that all health professionals working in acute medical wards have undergone training in dementia care, preferably in their core training at undergraduate level.
- that postgraduate education on ageing and dementia be readily available.

ISSUE NO. 4 : THE PROVISION OF QUALITY RESIDENTIAL CARE

The provision of residential care is critical both short term for family relief, and long term when families can no longer cope with the demands of caring at home. It must also be emphasised that many people with dementia have no family able or willing to care for them at home. The exact numbers of those in this category are unknown in New Zealand, but the Office of Technology, USA (1987) has estimated that in the United States about 10% are likely to have no family to care for them. In New Zealand, rest homes and hospitals have traditionally played a major role in caring for these people. A significant proportion of people in residential care have dementia. Alzheimers Society NZ Inc believes that a sufficient range and supply of high quality residential care for people with dementia is not yet available throughout New Zealand.

1.1 Suitable residential care for people with dementia

Residential facilities (i.e. hospitals and rest homes) for people with dementia need to be of a design which offers security for those who wander and minimises sources of confusion, while still providing a pleasant environment. Staffing levels need to recognise the special needs of people with dementia, especially those who are able to move around without assistance. Staff must be trained in the specialised management of people with dementia (see Issue 4).



Special provision needs to be made for the care of those who have severe behavioural disturbances associated with their dementia. With the emphasis on community-based care, it is vital that these specialised facilities be available nationally and that an adequate subsidy is available for residents in these units. Younger people with dementia and those with early memory loss need to be accommodated in units which recognise their differing needs. The particular needs of Maori and people of other cultures must be addressed as their population is also ageing. The person who has a long-term psychiatric disorder, or who has been cared for in a psychopaedic service and who develops a dementia as they age, requires specialist care. These people's needs are very different from those of the frail older person with dementia.

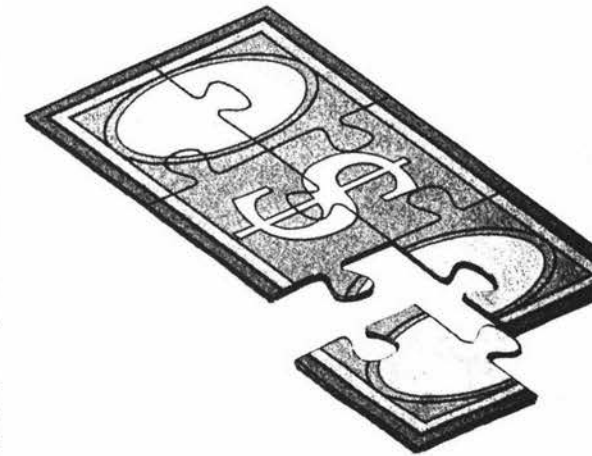
1.2 Monitoring of Residential Care Standards

RHAs are now responsible for the purchasing and monitoring of residential care. Standards for dementia care need to recognise that this a specialised area and must be regularly monitored and enforced. Monitoring must ensure that written policies and procedures are evident in the day-to-day running of the care facility.

Recommendations

We recommend

- that the Ministry of Health set a realistic national subsidy level for residential care which recognises the high dependency needs of people with dementia.
- that innovative and flexible models of care which address differing cultural needs be encouraged and supported to ensure that people with dementia and their carers have a choice of care options.
- that appropriate residential care continues to be available and easily accessible.
- that national standards for the care of people with dementia and effective monitoring and enforcement procedures be put in place.
- that facilities are developed to meet the specialist needs of different groups of people with dementia, e.g. the frail elderly, the younger person, the person whose primary disability is a psychiatric illness or intellectual disability.



RESEARCH

Despite worldwide funding of research into the causes and treatment of Alzheimer's disease and related dementias, at present there are no known preventions and no cures for dementia.

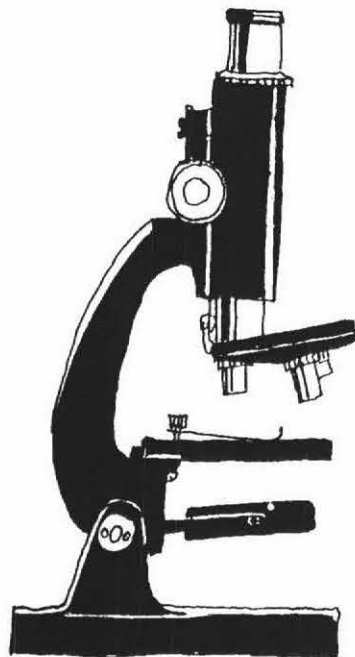
All areas of research need attention - basic science, clinical aspects, sociology, service delivery, neuropsychology, economics. New Zealand has the expertise to devise and direct research projects in any of these fields.

Currently the Health Research Council is the main funding source for New Zealand health research. Funding has not been specifically tagged for dementia research, but the following amounts have been given for research into neurological disorders impinging on dementia:

1994 - \$585,713

1993 - \$715,453

In the United States in 1992 their government spent \$280 million on Alzheimer's research. This represents \$1.12 per person. If we were spending the equivalent in New Zealand, this would amount to \$4.14 million annually.



Recommendations

The Alzheimers Society recommends:

- that there be realistic Government funding to encourage the continuation and development of programmes of research which contribute knowledge about the nature and management of Alzheimer's disease and related dementias.
- that national statistics on the incidence of dementia be collected so that accurate planning for future services can be undertaken.
- that national research be planned in co-operation with Alzheimers Society NZ.

RECOMMENDATIONS SUMMARY

We recommend that:

- the RHA's evaluation of assessment services purchased in their region include input from caregivers of people with dementia.
- initial and ongoing training be required for all members of assessment teams.
- multidisciplinary assessment teams be established and maintained in all centres throughout New Zealand.
- a system of regular reassessment be introduced for all people with dementia.
- RHAs be required to purchase support, information and counselling services for people with dementia and their carers.
- a range of affordable, flexible home care services be provided to support people with dementia and their carers at home.
- the establishment of affordable specialised day care be encouraged nationally.
- the Carer Relief (Alternative Care) scheme be standardised to 56 days per year.
- the Ministry of Health continue to purchase policy advice from Alzheimer's Society NZ.
- information, support and training for carers and community education be recognised as a service to be purchased by RHAs.
- national minimum standards for dementia-specific training of all staff in residential facilities be set and incorporated into service contracts.
- all health professionals working in acute medical wards have undergone training in dementia care, preferably in their core training at undergraduate level.
- postgraduate education on ageing and dementia be readily available.
- the Ministry of Health set a realistic national subsidy level for residential care which recognises the high dependency needs of people with dementia.

- innovative and flexible models of care which address differing cultural needs be encouraged and supported to ensure that people with dementia and their carers have a choice of care options.
 - appropriate residential care continues to be available and easily accessible.
 - national standards for the care of people with dementia and effective monitoring and enforcement procedures be put in place.
 - facilities are developed to meet the specialist needs of different groups of people with dementia, e.g. the frail elderly, the younger person, the person whose primary disability is a psychiatric illness or intellectual disability.
- there be realistic Government funding to encourage the continuation and development of programmes of research which contribute knowledge about the nature and management of Alzheimer's disease and related dementias.
 - national statistics on the incidence of dementia be collected so that accurate planning for future services can be undertaken.
 - national research be planned in co-operation with Alzheimer's Society NZ.

