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Cultural diversity and dementia

*A planned approach
to residential care
for people with dementia
who come from a non-English
speaking background*



CENTRE FOR EDUCATION
& RESEARCH ON AGEING

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Foreword

The need for understanding the burgeoning problem of dementia that is compounded by the cultural diversity of our population has been addressed in this outstanding manual.

With great sensitivity and investigative skills, the authors have clearly identified the needs and, very importantly, proffered practical solutions to assist in the care of those who suffer one of nature's cruelest blights.

As a carer /nurse for many years of my dear mother, Katina Andronicos Zerefos, who came from Greece as a young teenager, I witnessed at first hand the horror of the ravages of Alzheimer's disease on this brilliant individual.

Mother totally regressed to her Greek roots even though she had spent most of her life as an Australian citizen, had been a successful woman and a strong, even domineering matriarchal figure within our family.

The toll of her illness on our family was beyond words. We had to constantly adjust to her slowly diminishing comprehension as she was incapable of understanding her own plight. The initial stages were devastating when this immensely capable woman would fail in her own tasks and cry "what is happening to me?"

It was relatively easy for me to recognise her needs as I knew my patient very well. I spoke Greek therefore automatically responded to her solo use of the Greek language until her eventual descent into total oblivion.

But what of all the poor souls who are stuck in the limbo of dementia and mentally trapped in the language and habits of their lost youth which was spent in a far off foreign land? The problem is reaching epidemic proportions.

This manual has cast sunlight into dark corners and should be compulsory study for all who work in this field or are associated in any way.



Helen Zerefos, OAM

Patron

Ageing and Alzheimer Research Foundation

Concord RG Hospital / University of Sydney

Helen and her mother Katina, 1989

Acknowledgements

Many people contribute to the development and preparation of a resource such as this. We would like to thank and acknowledge some of those who have assisted us in moving from thoughts, ideas and concepts into the development of a resource which will improve the quality of life for people with dementia who come from diverse cultural backgrounds living in aged care facilities.

Firstly to the residents, families and staff at St Basil's Nursing Home, Chow Choo Poon Nursing Home and the Scalabrini Nursing Homes at Austral and Chipping Norton for sharing their thoughts and ideas on caring for residents.

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To all the clients and families suffering the effects of dementia who continue to teach us about learning, loving and living.



The NESB Dementia Project

The NESB Dementia Project was funded by the Department of Health and Family Services as part of the Dementia Education and Management Project, based at the Centre for Education and Research on Ageing, Concord Hospital.

The Dementia Education and Management Project had been conducting education and consultations about care of residents with dementia in nursing homes and hostels since 1993. One of the core strategies used by this project was to encourage staff to look behind the behaviours of people with dementia to try and understand what might be contributing to them.

A model for doing this, called the “TECH approach”, was developed. The model consists of a checklist of questions about the Task the resident is involved in, the Environment, the Communication between the residents and staff or family and the Health status of the resident.

The experience of the project staff working in a number of settings suggested that people with dementia from non-English speaking backgrounds were more likely to be identified as very unsettled, confused and difficult to care for. Nursing home staff said that their challenging behaviour was more frequent and more intense than their English speaking counterparts.

Obviously it was important to sort out whether these differences were simply a matter of staff perceptions, or whether they actually reflected higher levels of distress amongst NESB residents. If it is true that NESB residents are more distressed:

- why is this so?
- what has been shown to relieve their difficulties?
- what is the best way to prepare service providers to offer effective care?

These questions are especially pressing since the number of NESB residents in nursing homes is steadily growing. The majority of these residents will live in mainstream facilities that are not set up to cater for their particular cultural background. As a result it has become vital that we work out ways of optimising the quality of care that these residents receive.

The NESB Dementia Project aimed to examine the practices of ethno-specific nursing homes and nursing homes where clusters of people from the same cultural background live together. The aim was to find the key aspects of those services that minimised residents’ distress and confusion and to select the practices that could be used in mainstream nursing homes.

This manual is the end product of the NESB Dementia Project. It pulls together a framework for care and a number of detailed suggestions about caring for people from a NESB with dementia. While the main target is mainstream nursing homes and hostels it is also relevant for facilities with clusters and ethno-specific facilities.

Using the manual

This manual aims to give residential care workers some tools and skills so they can make sure that people from non-English speaking backgrounds with dementia have the same quality of care as their Anglo-Celtic contemporaries.

It invites service providers to critically reflect on their current practices and offers suggestions on how nursing homes and hostels can effectively plan and deliver services to more effectively meet the needs of this growing group of older people.

The manual will be of most immediate relevance to registered nursing staff or hostel managers who are responsible for planning and supervising the care of residents. It can be used as a source for:

- information about multiculturalism and community resources
- practical strategies and formats for use in direct care of residents such as assessment forms, environmental assessment forms and care planning forms
- lesson plans for staff inservice
- formats for management planning for facilities.

Section 1 provides background information on multiculturalism, dementia and different types of nursing homes for NESB residents. It also introduces a model which allows a planned approach to the care of residents with dementia from a NESB.

Sections 2-7 form the major part of the manual. They work through the steps of the model introduced in Section 1 in a detailed and practical way.

Section 8 provides a comprehensive list of resources which staff can use to consolidate and build on their program of care for residents with dementia. It includes references to policies, training resources and a range of supportive organisations in the community.

Throughout this manual, "NESB" will be used as short hand for "non-English speaking background". The term is used to describe someone whose first language is not English or whose cultural background is derived from a non-English speaking tradition. It is therefore a cultural/linguistic term and may include both people who speak or do not speak English. It includes both people born overseas and those born in Australia.

This manual has been written for staff of nursing homes and hostels. It is acknowledged that nursing homes and hostels will be collectively called "aged care facilities" after July 1997 under the Commonwealth Government's Aged Care Structural Reform Package. The terms "nursing home", "hostel", "residential care facility" and "aged care facility" have been used interchangeably throughout the manual.

Setting the scene

- 1.1 Older Australians - a multitude of cultures
- 1.2 An overview of dementia
- 1.3 People from a NESB with dementia
- 1.4 Different types of nursing homes for NESB residents
- 1.5 A model to improve the care of residents from a NESB



Older Australians - a multitude of cultures

Ever-changing society

We are constantly being told that we are an ageing society. The number of Australians over the age of 65 is expected to more than double over the next 45 years. This means that by 2041 one in every five Australians will be over the age of 65, and there will be more than four times as many people over 80 years old as there are today.¹

In 1991, 23% of the New South Wales population had been born overseas; however, the boom in European immigration between the 1940s and 1960s means that the rate was even higher in the over 65 age group.²

With the broadening of countries from which migrants were accepted during the past forty years, there has been a gradual increase in the proportion of migrants from non-English speaking countries. By 2001, roughly 20% of people over 60 years old will be from non-English speaking backgrounds, compared to 13% in 1986³.

It is anticipated that the number of people affected by dementia will almost double between 1989 and 2011⁴. Because of the increasing proportion of older people from a NESB, there will also be many more people with dementia who come from a non-English speaking background.

Policy frameworks

An overarching framework for issues to do with people from a NESB is provided by the Commonwealth Government's Social Justice Policy. This policy aims to affirm the government's commitment to a fair and just society. The policy is based on the premise of four basic principles: access, equity, participation and equality.

The NSW Government has adopted a Charter of Principles for a Culturally Diverse Society to reflect its commitment to cultural and linguistic diversity. The principles in this Charter apply to all aspects of the social, cultural, political, legal and economic life in NSW.

Both the Commonwealth and State governments have made it clear that people from all cultural backgrounds are entitled to high quality services that effectively meet their needs.

The Commonwealth Government has stated that older people from a NESB in residential care should feel that their needs are:

- "responded to willingly by staff who understand the value of maintaining the sense of continuity and identity based on traditions and practices
- taken into account regarding individual preferences and special dietary needs

¹ Australian Bureau of Statistics (1994) *Projections of the Populations of Australia, States and Territories 1993-2041*, Commonwealth of Australia.

² NSW Social Policy Directorate and Australian Bureau of Statistics (1995) *Older People in New South Wales: A Profile*, Commonwealth of Australia.

³ Rowland, D. (1991) *Care of the Ethnic Aged in Aged Care Reform Strategy Mid-Term Review 1990-91: Discussion Papers*, Commonwealth Department of Health, Housing and Community Services.

⁴ Jorm, A.F. and Henderson, A.S. (1993) *The Problem of Dementia in Australia*, 3rd Edition, AGPS.

- respected in relation to customs encompassing family concepts and relationships
- satisfied in relation to communication.”⁵

Services are expected to take positive action to make sure that everyone has access to the same quality of care, regardless of their race, culture or the language they speak.

What this means for service providers

These broad social changes in the population have a profound impact on the way that we provide services today and how we prepare services for the future.

Aged care services are constantly responding to the pressure to change. There are changing requirements from government, changing expectations from the community and new directions that emerge from health services research. Staff also initiate change as they find better, more effective ways of managing the challenges of caring for a person with dementia.

The ability to manage change is widely recognised as one of the core tasks of management. Although some managers feel overwhelmed with the prospect of change, many others welcome the opportunity to draw on their experiences, learn from the past and find more effective ways of responding to today’s challenges.

Nursing homes and hostels can gain a lot from taking a planned approach to caring for people from non-English speaking backgrounds with dementia. It is part of sound management as well as social justice.

This manual is designed to assist residential care workers to reflect on their current service and work out a planned approach to respond to the changing needs of their residents. It provides practical tools and strategies to assist staff in this important challenge.

Good customer focus involves providing services which welcome, respond to and reflect diversity.

Responding to cultural and language diversity is about social justice.

It’s about doing what’s fair.⁶

⁵ Commonwealth Department of Human Services and Health (1995) *The ethnic older persons strategy*, AGPS.

⁶ CEIDA and NSW Health (1995) *Bridging the Gap: Working Cross Culturally with Alcohol and Other Drug Issues*, Centre for Education and Information and Drugs and Alcohol.

An overview of dementia

What is dementia?

Dementia is a broad term used to describe the loss of a person's cognitive abilities and a deterioration of social functioning or behaviour. When a person has dementia, the changes in their brain reduce their ability to remember, to think and to cope with more than one piece of information at a time. People with dementia experience changes to their physical, mental and emotional functioning which effect their ability to work, to be involved in social activities, to relate to people, to communicate and to care for themselves. Dementia is a collection of signs and symptoms rather than a disease in itself.

Causes of dementia

Alzheimer's disease

Alzheimer's disease is the most common cause of dementia. It is a progressive disease that effects the cells of the brain. The person gradually becomes more forgetful, confused and unable to sequence their activities. They may develop problems with speech and communication and become lost, even in familiar surroundings.

Vascular (multi-infarct) dementia

The other common cause of dementia is multi-infarct or vascular dementia which is caused by multiple strokes which have damaged particular areas of the brain. The onset of vascular dementia is more abrupt than the gradual decline caused by Alzheimer's disease. The person may show sudden changes in their ability to function and then go through periods of relative stability. Vascular dementia is more commonly associated with movement, gait and balance problems. This form of dementia may co-exist with Alzheimer's disease.

Other causes

Other less common causes of dementia include chronic excessive alcohol use, Pick's disease or fronto-temporal lobe dementia, AIDS dementia complex and Parkinson's disease. Many of these dementias effect the frontal lobes of the brain and are more likely to cause marked personality and behavioural changes than other forms of dementia.

Reversible forms of dementia

Some conditions, such as depression, acute confusion, anxiety, infection, tumors or some vitamin deficiencies can present as dementia. It is important that these conditions are accurately diagnosed as they can be treated and the dementia reversed in some cases.

Signs and symptoms of dementia

Symptoms will vary between people and will occur at different times for the one person. Some of the symptoms which may be associated with dementia are:

- memory loss and language difficulties
- impaired comprehension, reasoning and judgement
- inability to carry out simple purposeful movements
- failure to recognise things or people
- loss of ability to learn new information
- loss of ability to initiate tasks
- disorientation
- gradual loss of ability to undertake the tasks of daily living
- changes in mood or personality
- loss of the internal clock, being active and awake at night
- wandering and pacing
- hallucinations and/or delusions
- challenging behaviours, such as aggression, verbal outbursts, resistance to care, suspicion and accusations, use of obscure or abusive language, agitated and repetitive acts, stealing and hiding things and inappropriate sexual behaviour.⁷

Stages of dementia

Dementia - especially from Alzheimer's disease - is often described as progressing through three stages - mild, moderate and severe. While people do often progress through these stages, it is certainly not uniform for all people with dementia. Furthermore, a person may be effected mildly with one symptom while being effected severely with another symptom. While accepting that the severity of dementia can occur anywhere along a continuum, it may be useful to point out the typical ways that people may present at different stages of their dementia.

Mild dementia

During this phase the person has difficulty remembering things. They may be more self-centred and ready to blame others for stealing mislaid items. They may forget the details of recent events and are likely to repeat themselves. They may find it quite difficult to make decisions.

Moderate dementia

In this stage, the person generally loses recent memories and may become quite disoriented in time and place if they leave their familiar surroundings. They are likely to forget the names of family and friends and require assistance and supervision with tasks. A person with moderate dementia can be very repetitive and may see or hear things that are not there.

Severe dementia

A person in the severe dementia phase tends to be confused, restless and disoriented. They are generally unable to remember for more than a few minutes. They may not recognise everyday objects, their family or friends and will probably require assistance with daily activities. They may present in ways which differ greatly from their previous patterns of behaviour.

⁷ Office on Ageing (1995) *Being There: The NSW Government's Action Plan on Dementia 1995-1999*, NSW Office on Ageing.

People from a NESB with dementia

Cultural notions about dementia

Dementia is found in all cultures. It is now clear that past reports suggesting that some cultures have a higher or lower incidence of dementia may have been too simplistic. The differences that were first reported are now understood to be more related to the way that the disease is diagnosed, rather than how many people are actually affected.

The way that dementia is defined and understood varies between different cultures. Within the Anglo-Australian community, there is an increasingly accurate understanding of the term "dementia". However, that is not the case in all cultural communities.

Polish speaking people tend to associate the Polish term for dementia with mental retardation. Dementia is also commonly referred to as arteriosclerosis. In the Spanish language, the term "demencia" means madness or insanity. It is common for people to use the term "arteriosclerosis" or blame age when a person gets forgetful and has signs of dementia. "Dementia" according to the Arabic dictionary means madness. People from Arabic speaking countries believe that as the person is getting old they may "lose their mind".⁸

How the community understands and perceives dementia has an impact on whether the problem is picked up, whether early help is sought, whether the problem is seen as treatable, whether it is considered to have shame attached to it and whether the situation is freely discussed within the family and the community.

Poor access to health services

People from non-English speaking backgrounds may have had a lot of trouble getting access to services, including dementia services. In some areas this has been compounded by health service providers who have had the idea that NESB people do not use services "because they don't really need them".

Of course the real picture is quite different, as suggested by the following points.

- Many people have no idea what services exist or what they might be entitled to expect.
- People may feel overwhelmed by the language barriers, and the limited responses of many service providers.
- Their culture may expect them to manage without assistance from outside the family.
- They may not have become familiar with recent approaches to understanding dementia.

⁸ Based on discussions with Adly Anwar, Arabic Ethnic Health Worker, Liverpool Health Service, Katarzyna Stack, Polish Interpreter, SWSAHS and Yvonne Santalucia, Ethnic Aged Adviser, SWSAHS.

Providers of health and community care - including nursing homes and hostels - have a responsibility to make their services responsive to the needs of their local community - including groups within that community from different cultural and language backgrounds.

Effect of dementia on language

While all people with dementia suffer a deterioration in their ability to communicate with others, the problems will often be more acute for people from a NESB. Dementia can have a devastating effect on a person's competence with English, as the changes in their brain reduce the person's ability to use the more recently acquired language.

Some of the language disorders which people with dementia may have include:

- word finding problems
- losing the meaning of common words
- circular speech
- inability to follow conversations
- losing the ability to read in their own language
- using incorrect words or jargon.

Assessment of whether or not such problems are present in residents from a NESB will benefit from the assistance of a professional interpreter.

Language deterioration can be devastating for families. For example, one couple who came from different cultural backgrounds had lived together for 40 years using English as their common language. When the husband developed dementia he began to use his original language which was incomprehensible to his wife and his children. The result was grief, confusion and tremendous feelings of powerlessness for everyone in the family.

The impact of this aspect of dementia will be profound because of the large and increasing number of people in residential care from a NESB.

Diagnosis of dementia

Unfortunately, people from non-English speaking backgrounds are less likely to be diagnosed in the early stages of dementia.⁹ This seems to be related to communication problems and the difficulty diagnosticians have in accurately assessing changes in a person's behaviour, emotions, thinking and personality if they speak little or no English. It is also due to the fact that people from non-English speaking backgrounds may not present early because they are unaware of the types of services available.

⁹ Lydall-Smith, S. and Moorhouse, B. (1995) *Culturally Appropriate Dementia Assessment*, Centre for Applied Gerontology at Bundoora Extended Care Centre.

Lack of cross-cultural communication skills by staff

Serious problems can occur when communication is confused by cultural misunderstandings. The misunderstanding may be due to ignorance, misinformation, incorrect stereotypes or simply occur when a person misinterprets the message that someone was trying to convey.

Residents from a NESB may suffer if staff make assumptions about their needs or beliefs JUST on the basis of their cultural background. Examples of this may be that Arabic people do not like to take part in group activities or that Chinese people will not want help from community services.

Residents will also suffer if staff DO NOT consider their cultural background at all. In this case, the staff regard and treat all residents the same - as if they all share the needs and beliefs of the general Anglo-Australian community.

Section 2-7 of this manual offers guidelines on how to develop a planned approach to caring for NESB people with dementia. It suggests some ways of building better cultural understanding and improving communication between staff, residents and their families so that the problems can be minimised.