CALD Guidelines for Dementia Patients in Aged Residential Care

"By trying to change
others, more challenging
behaviours are created
and maintained. When
we change ourselves,
we also change
everyone around us!"
Jackman, 2015

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Acknowledgements

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Overview

CALD in this resource refers to culturally and linguistically diverse migrants and refugees from Asian, Middle Eastern, Latin American and African backgrounds.

The **CALD Guidelines for Dementia Patients in Aged Residential Care** resource is developed for health professionals, healthcare assistants and caregivers working in residential aged care services; as well as for CALD residents living in ARC facilities and their families. It is recommended that the guidelines are used in conjunction with Waitemata DHB's eCALD® Supplementary Resource, "CALD Older People Resource for Health Providers" (WDHB, 2014).

International literature shows that providing culturally competent care for CALD residents in residential facilities will improve residents' experience and enable them to feel safe and comfortable. Additionally, the provision of culturally appropriate services will facilitate CALD residents to adjust and familiarise themselves with their new environment.

To provide culturally appropriate dementia care for CALD residents, the first and most important consideration when developing "best practice" is to address language and communication issues with residents who are non-English speaking.

> The aim of this resource is to provide cultural best practice guidelines for staff working in residential care facilities so that CALD residents with dementia are provided with culturally appropriate support and care, including the immediate period around the transition from their home to residential care.

The review of international literature summarises the core competencies required working with CALD older residents with dementia. The literature highlights the barriers faced by CALD older people and their families when accessing appropriate healthcare services. As well, the problems experienced when family or carers of the CALD older person require support in the home, and when moving into supported living arrangements and aged care facilities.

The development of the best practice guidelines were also informed by the consumer views and examples of CALD care requirements from staff, residents and families.

In addition to this resource, the authors would also recommend to residential care facilities to refer to the **"Supporting Cultural Diversity in Residential Care - Evaluation and Planning Tool" developed by the Centre for Cultural Diversity in Ageing**. This is a very useful tool for residential care facilities to help evaluate and plan for cultural inclusiveness of their services and care delivery.

Introduction

Dementia is a neurodegenerative disorder associated with high levels of disability and dependence. Most people with dementia will, at some stage, have complex care support needs.

Dementia is the term used when a person experiences a progressive loss of brain function and cognitive abilities due to changes in the structure of the brain. Dementia should not be regarded as a normal part of ageing. Although it is a diagnosis more common for people over the age of 65, dementia can also affect people in their 40s and 50s.

There are many sub-types of dementia, but the most common is Alzheimer's disease. Other sub-types include vascular dementia, dementia with Lewy bodies and fronto-temporal dementia. However, one person can have a combination of these dementia sub-types. Dementia can result in changes in behaviour, cognition, personality and mood in the different stages of the illness (Ames, Burns & O'Brien, 2010).

People with dementia from culturally diverse backgrounds and their carers often face difficulties through the process of early diagnosis to end-of-life care, for example accessing services and being able to choose care and support in the forms that they would like. Diaz's (2002) research states that ethnic minority groups found difficulty relating to, or engaging with, mainstream supports. This difficulty was attributed to the Western cultural norm of questioning and/or challenging those in authority, and discussing conflict and feelings towards caregiving services. Whereas families from CALD backgrounds value respect for those in authority, and harmony rather than conflict (Dilworth-Anderson & Gibson, 2002).

In 2011, there were an estimated 49,002 New Zealanders with dementia. Of these, 1970 (4.0%) were Maori; 1,838 (3.7%) were Asian; 930 (1.9%) were Pacific Peoples and 44,284 (90.3%) were European/Other (Alzheimer's New Zealand, 2008). By 2026, these ethnic ratios are expected to change toward a smaller proportion of people with dementia being in the European/Other group. The distribution for all other ethnicities is projected to increase: 4,493 (5.7%) for Maori, 6,568 (8.4%) for Asian and 2.051 (2.6%) for the Pacific People. Workforce development and service provision are therefore needed to meet the needs of CALD people with dementia and their families (Alzheimer's New Zealand Incorporated, 2008).

The New Zealand Ministry of Health acknowledges and recognises the need for improvement in dementia care. The New Zealand Dementia Care Pathway Framework has been developed to provide guidance for the 20 District Health Boards in New Zealand to implement dementia care pathways as mandated by the Ministry of Health. The framework is underpinned by four principles: (i) person-centred and people-directed approach; (ii) accessible and proactive services; (iii) integrated services; and (iv) highest possible standard of care. It includes and focuses on people with dementia and their family receiving culturally appropriate services (Ministry of Health, 2013).

The transition from home to residential care is a stressful time for people with dementia and for their families. Additionally, CALD families often have difficulty in accessing the information and services required for this life stage transition. Due to their cultural and linguistic differences, CALD people with dementia are likely to have issues with adjusting to new living arrangements (Mold, Fitzpatrick & Roberts, 2006). Furthermore, living in a residential care facility can also be a lonely experience for CALD people with dementia. This can further impact on their psychological well-being and can sometimes lead to clinical depression and anxiety (Bindiya, Seavy, Yound & Bonner, 2015).

Literature Review

There is a paucity of New Zealand evidence identifying the needs of CALD people with dementia. However, Worall (2005) concluded that the construction of a framework or guidelines in New Zealand should:

- incorporate the Treaty of Waitangi with specific competencies identified;
- include cultural appropriateness and culture-specific frameworks;
- be based on consultation with stakeholders, particularly practitioners;
- be tiered to cater for all levels of an organisation or target group;
- identify core competencies that give cohesion across all levels;
- identify core values of the profession to act as a basis for competencies;
- have clearly and stringently defined competencies, with clearly articulated assessment benchmarks and strategies; and
- include a relationship between competency attainment and salary structures.

This review summarises documents relating to the development and implementation of core competencies for the workforce – in particular people who work with older patients suffering from, and living with, dementia. It draws mainly on literature from Australia, which is the only jurisdiction to have taken this step toward including core competencies for a CALD culturally competent workforce. Material from the United States, Canada and Australia is also included in this review.

Access and Awareness

Families from refugee and migrant backgrounds may face barriers to accessing health care due to communication difficulties and a lack of understanding of the New Zealand Health and Disability system (Ou et al., 2010). This is a growing problem with more older people from Asian, Middle Eastern and African communities   moving into supported living arrangements and aged care facilities, or require support at home from family or carers. Dementia, psychological disorders and other health issues can carry a social stigma in traditional societies. Moreover, some cultures may not have been provided with relevant services to deal with these health issues (Ayalon & Arean, 2004). This has been cited as a common reason for people not searching for, or accessing, services in Australia, resulting in people presenting to health professionals at later stages of the disease. Access is recognised as being best supported when it is culturally and linguistically appropriate as well as an ongoing commitment from a range of stakeholders (Mold, Fitzpatrick, & Roberts, 2006).

Language

Language continues to be a major challenge in aged care where health information and service provision is spoken and written mostly in English (Bachhaus, 2011). Australian research shows that the older generation of refugee and migrant communities from CALD backgrounds can lose the ability to use English and revert back to communicating in their first language (Haralambous, Dow, Tinney, Lin, Blackberry, Raynor & LoGiudice, 2014). Additionally, the onset of dementia is usually associated with reversion to the first language learnt. Elderly patients with dementia from non-English-speaking backgrounds prefer, or need, to speak a language other than English, and communicate more with others who speak their language. Better English proficiency was found to lower levels of anxiety and depressive symptoms in elderly members of the Iranian community, and is associated with accessing health care services (Haralambous et al., 2014).

Gender has been found to be a significant factor in relation to language and communication, as well as accessing services more broadly. Often women who have arrived as refugees have little or no formal education. Furthermore, the pre-migration and settlement experiences of older (and younger) women from refugee backgrounds are compounded when there is an absence of specifically tailored programmes to address their complex social realities. On the other hand, more educated women with longer years of residence can be subject to greater barriers to accessing health services for their older family members. This group can experience a fear of losing their job, as well as the perception that no one can help in providing care for their relative who has dementia (Dilworth-Anderson & Gibson, 2002).

In the context of cultural differences, the Western and English-language-based approach to supporting and communicating health issues can be problematic (Ou, Chen & Hillman, 2010). This is related to a Western emphasis on the individual and self-management. This can cause issues with cultural approaches that are rooted in more collectivist attitudes, perceptions and lifestyles. In CALD communities, the importance of supporting the elderly is central for the family and there is a general expectation that children should care for their elderly parents. These cultural values can impede help-seeking behaviours, as well as creating financial pressures and stress due to competing family responsibilities. These issues can negatively impact on the level of aged care support being provided by the caregiver. As Boughtwood et al. (2011) note, "[CALD] care-givers do not share the same meanings and interpretation[s] of health and welfare terminology as those from Anglo populations". Evidence also suggests that there are differences in the participation of caregivers from CALD groups in planning and managing dementia services. In addition, caregivers need to be well prepared for participating in the use of the dementia services available to them (Boughtwood, Shanley, Santalucia, Kyriazopoulos, Pond, 2012)

Understanding Dementia

Asian communities may consider dementia as a normal part of ageing, a form of mental illness, a source of shame, or even a result of fate (Dong & Chang 2014). Therefore, they are less likely to seek medical advice during the early stages of the disease's development. Differences in the family's perception of the causes of dementia can influence the length of time from presentation to medical and psychiatric care. This is evident in Punchihewa and Lou's (2013, P11) study stating: "as symptoms progress and become more severe, dementia is also often viewed by families as a form of insanity."

The translation of the term dementia in some non-English languages can also perpetuate the stigma. For example, in China dementia is commonly translated as "crazy catatonic". Family members may ignore memory difficulties in order to "save face" for their elderly relatives; and caregivers may not seek outside/external support and professional interventions out of respect for, and duty towards, their older relatives (Dong & Chang, 2014).

Practitioners undertaking clinical assessments and evaluations need to engage family members and to be aware of somatisation of symptoms. Somatisation generally refers to the presence of physical symptoms where there is no physical pathology evident – the body becomes the vehicle for the expression of social or emotional distress (Paniagua, 2000). Somatisation of psychological or psychiatric symptoms is reported to occur more often in those from collective cultures, particularly Asian, Middle Eastern and African (Paniagua, 2000).

Communication

A recent study found that health literacy in relation to dementia is generic and primarily written in English (Xiao et al., 2013). Therefore, its effectiveness is limited for those from CALD backgrounds. There is a need for more specific and culturally relevant communication strategies such as multilingual health information on a range of platforms, and engagement with social determinants influencing health and wellbeing (Beauchamp et al., 2015).

Moreover, professional interpreters are important for communicating information about ageing and mental health care, particularly when negotiating an understanding of a patient's experiences and symptoms. In a study with older CALD background men from a rural area in Australia, Radermacher and Feldman (2009) identified the need to develop appropriate and responsive health promotion material and information for those who do not necessarily have literacy or English language skills.

Family Caregivers

The New Zealand National Older Person Health Strategy (Ministry of Health, 2016) noted that there is a need for improvement in dementia care throughout the country including: a more patient-centred and people-directed focus; and services that are more integrated and accessible for CALD dementia patients, as well as for their families. The review identified the need for accessible and appropriate information for CALD families about for the services available and the transition into care for the elderly. The patients and their families have difficulty adjusting to new living arrangements which can be both a lonely experience and a time of uncertainty. The consequences of these experiences can impact negatively on psychological well-being and can lead to depression and anxiety. Cultural and linguistic differences must be recognised and catered for in the aged care system to ensure that it has the capacity to respond appropriately to the individual person regardless of their cultural or linguistic background (Bellamy & Gott, 2013).

Culturally Appropriate Aged Care Services and Workforce

Internationally, Australia has shown that it has responded to the challenge as it recognises a large proportion of older people in Australia were born overseas and the proportion of older people from CALD backgrounds is increasing (Australian Bureau of Statistics, 2009). Australian researchers have been able to identify barriers to accessible, and culturally appropriate aged care services. They have found that needs within the different CALD communities and among individuals vary considerably. Therefore, language, religion, education, refugee experience and cultural differences need to be considered in the provision of care.

A recent project exploring help-seeking behaviour in older Asian populations with dementia and their carers in Melbourne, Australia was undertaken to determine the barriers and enablers to accessing Cultural Dementia and Memory Services (CDAMS) for people with dementia and their families from Chinese and Vietnamese backgrounds (Iliffe et al., 2009). Consultations with community members, community workers and health professionals were conducted using the "Cultural Exchange Model" framework (Haralambous et al., 2014). The findings of the project were that carers faced barriers to accessing services which included: the complexity of the health system; a lack of time; transport required to get to services; communication barriers; a lack of interpreters and; a lack of knowledge of services (Haralambous et al., 2014).

Similarly, research shows that community workers and health professionals identified language, a lack of interpreters, and community perceptions of services/aged care services as key barriers to service access. Recommendations from this study, included increasing and improving knowledge by providing information via radio, printed material and education in community group settings (Haralambous et al., 2014).

Culturally Appropriate Aged Care Services and Workforce, continued

Furthermore, health care staff need to recognise the needs of CALD carers who may find it difficult to navigate health and aged care systems. Currently, Australia funds an organisation in each state to equip aged care providers to deliver culturally appropriate care to older people from CALD backgrounds (Department of Social Services, 2016). These organisations provide training to the staff of aged care services, disseminate information on high-quality aged care practices and support aged care providers to develop culturally appropriate services. The training programme provides cultural and linguistic concepts, including:

1. cultural and linguistic responsiveness;
2. cultural and linguistic inclusiveness; and
3. cultural and linguistic sensitivity.

The desired outcome of the training is that staff will provide culturally and linguistically appropriate care which is reflective of, and responsive to, the cultural, linguistic and spiritual needs of the person. The cultural and linguistic characteristics, experiences and perspectives of ethnically diverse people are integrated into the training programme to improve the delivery of aged care services in order for them to be more culturally effective (Lehman, Fenza & Hollinger-Smith, 2012).

CALD Principles

The following principles have been developed to provide a framework for CALD inclusion in all activities and in the provision of aged care services.

1 **Inclusion** – to support the needs of older people from CALD backgrounds, so that their families and carers are included in the development of the Australian Government ageing and aged care policies and programmes on an ongoing basis.

2 **Empowerment** – older people from CALD backgrounds, their families and carers are supported and have the knowledge and confidence to maximise their use of the aged care system.

3 **Access & Equity** – all healthcare areas within ageing and aged care understand the importance and delivery of culturally and linguistically responsive care.

4 **Quality** – care and support services are appropriate to the needs of older people from CALD backgrounds, their families and carers and these services are being assessed accordingly.

5 **Capacity Building** – individuals from CALD backgrounds and CALD communities have the capacity to both articulate their ageing and aged care needs and be involved in the development of services and the workforce to meet these needs.

The Goals

- CALD input positively affects the development of ageing and aged care policies and programmes that are currently inappropriate and not responsive.
- To achieve a level of knowledge, systems capacity and confidence for older people from CALD backgrounds, their families and carers to exercise informed choice in aged care.
- Older people from CALD backgrounds are able to, and have the confidence to access and use the full range of ageing and aged care services.
- Monitor and evaluate the delivery of ageing and aged care services to ensure that they meet the care needs of older people from CALD backgrounds, their families and carers.
- Enhance the CALD health sectors' capacity to provide ageing and aged care services.
- Achieve better practice through improving research and data collection mechanisms that are inclusive of the cultural and linguistic diversity in the ageing population.

Suggested Model of Care for Residents with Dementia in Aged Residential Care

People with CALD backgrounds often require residential care services sensitive to their specific cultural, spiritual, dietary and linguistic needs (Seabrooke & Milne, 2004). This type of care becomes especially important for CALD older people when cultural misunderstandings can lead to older people feeling devalued (Tilly & Reed, 2008). Maintaining a sense of personhood despite the diagnosis of dementia and memory loss underpins this guideline (Innes, 2000).

Previous images of residential care institutions and of residents in the later stages of dementia have portrayed older people as sleeping a lot, not interacting with the people around them and of being disengaged with their environment. Kitwood (1993), in his seminal work showed how the behaviour of people with dementia commonly caused by the way society regarded them and was not necessarily due to their illness. In relation to dementia care, Kitwood's (1993) conceptualises personhood for a person with dementia as the interaction between their underlying personality, physical health, life history, social psychology and the neurological damage to the brain. In this way the person with dementia can still retain their personhood despite environmental or other factors and for those residing in residential care, person-centred care can be provided.

Person-centred Care

People with dementia typically report symptoms such as memory loss, disorientation, poor insight into their illness, visuospatial problems, hallucinations, delusions, word-finding difficulties and poor object or facial recognitions (Ames, Burns, & O'Brien, 2010). Care practices are ideally person-centred rather than the traditional task-orientated focus of service provision. However, providing person-centred care does not remove the need for attending to the tasks of daily living. Person-centred care refers to finding ways to deliver help in daily routines such as recreational and social activities with due consideration to the physical, emotional, and spiritual needs of the person receiving the care (Innes, 2000).

Examples of person-centred care might include getting ready for the day, for example asking if the person being cared for is someone who prefers to rise early or later? Person-centred care takes these personal preferences into consideration when delivering care for residents and, as such, health professionals will structure their personal care activities to accommodate these personal preferences. Eating is often more about social interaction rather than just providing nutrition.

Person-centred Care, continued

In residential care, mealtimes have the potential to be a task to get over with as quickly as possible. However, it can be turned into a pleasurable activity for the residents. Aspects to take into consideration include: how the meals are presented; taking into account people's likes and dislikes; where they eat their meals and with whom. These meal-taking practices help promote emotional well-being (Bindiya Seavy Yound et al., 2015).

Furthermore, recognising a spiritual dimension to a meal includes special cultural festivals, rituals and celebrations such as Diwali, Chinese New Year and Eid (the feast marking the end of the fast of Ramadan). Inviting family, friends and staff to join these communal meals can be a social, pleasurable and joyful experience for all of those involved. Being committed to meeting the needs of the whole person is at the heart of all good caregiving.

The Newcastle Model

The Newcastle Model which supports the implementation of person-centred care is shown below (James, 2011) (Figure 1). The model promotes a collaborative and respectful partnership where the health professional seeks and respects the contribution of the resident and family in planning their health care needs. This includes eliciting information about their values, goals and past experiences. This person-centred framework can assist care staff to develop a deeper understanding of a CALD resident that encompasses all the client's cultural and personal preferences for care. This practice will ensure that all staff 'know' the resident. Having comprehensive information about the resident will also benefit the caregivers if the residents' behaviours become challenging.

The Newcastle Framework provides a template to help nurses and care staff make connections between the person's experience and their behaviour. It helps health professionals understand why the person might find a particular situation difficult and why they may behave in a particular way. There are generally three ways in which a person's needs might be expressed as behaviours that challenge. The person's behaviour may be:

- a way that is intended to fulfil a need. For example, taking food from another resident's plate might be because of a need for food or for security;
- a communication need. For example: calling out repeatedly; or
- a result of frustration when a need is not being met. For example not being able to leave the building to go to work because staff or the environment stops the resident from leaving.

Figure 1: The Newcastle Model (James, 2011)

Life history and experience	Personality	Cognitive impairement
Mental health	**Trigger situation**	Medication
Physical health		Social environment
Behaviour (what do they do?)	Thoughts (what do they say?)	Feelings (how do they appear?)
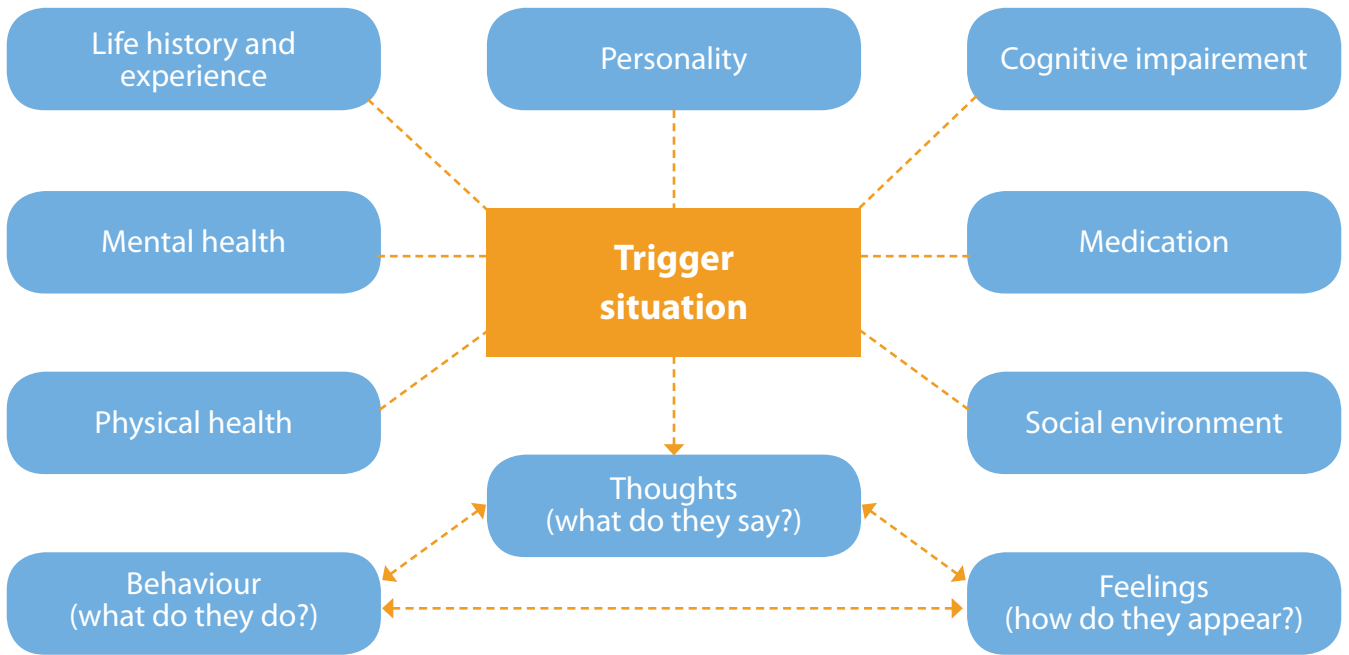
Life Story Work

A person's life and personal history is part of what makes each person unique. Therefore, it is imperative when working with people who are living with dementia that we take account of their life histories, experiences and relationships. We can assume that a person's life history, such as their biography, plays an important part in their experience of dementia. Consequently, health professionals need to consider these personal and relational dimensions when undertaking assessments and developing a person-centred and culturally focused nursing care plan (Woods, Portnoy, Head & Jones, 2005).

There are various methods that can be used to capture and record these life stories. Some care settings have produced life history books using photograph albums, or alternatively developed scrap books. While other health services have used a life story box where significant personal items that have special meaning for the person with dementia, are stored together. These personal items are retrieved as a means of engaging the resident in meaningful interactions. It is recognised that using visual cues is an effective way to stimulate memories and/or conversations (Thompson, 2011).

Understanding a person's life history is a continuous part of caring for a resident with dementia. It can be used to generate and engage in conversation during the provision of personal care, as well as during leisure activities with families and other residents. The collection of life histories is continually added to over time. As the person becomes involved in activities at the facility, the photos and memorabilia of outings can be added to their life story.

It is important to be mindful that some memories have the potential to cause the person to feel emotional distress and/or grief. Therefore, when these memories are inadvertently triggered, the health professional needs to be able to manage these sensitively and/or refer onto specialist services. However, health professionals can stimulate positive memories that can be highly therapeutic to those living with dementia.

The capturing and recording of a person's life history should be an interesting and pleasurable experience for both the health professional and the client. To avoid a sense of feeling overwhelmed by the sheer amount of life history that older adults have accumulated it is not necessary to capture every detail of their history. The accuracy of the life stories can be confirmed by the family. Furthermore, using photographs and the person's preferred language creates a more meaningful story for the resident.

Guidelines for CALD Dementia Residents

Residents who are living with dementia will gradually lose their ability to organise and express their thoughts. As these symptoms of dementia progress, communication issues can become even more problematic for people from CALD backgrounds. CALD residents may no longer be able to communicate to staff or other residents in their adopted language (English) and will therefore, revert to their first language. It is evident that effective communication is critical for residents with dementia (Goldsmith, 1996).

Difficulties in communication can commonly be misinterpreted by staff as 'problem' behaviour. A resident may present as agitated as a result of feeling frustrated when their needs are not being understood or met due to language barriers. A study has shown that care staff who were not able to communicate in a residents' adopted language had a significantly higher rate of prescription of daytime antipsychotics compared to those from non-English-speaking backgrounds who were able to still communicate in English.

Providing culturally competent care for all clients in residential facilities will help enable the resident to feel safe and comfortable. Additionally, providing a culturally appropriate service will facilitate the CALD resident to adjust and familiarise themselves with their environment.

Best Practice Guidelines when Working with CALD Dementia Residents

"If we spent as much time trying to understand behaviour as we spend trying to manage or control it, we might discover that what lies behind it is a genuine attempt to communicate" (Anon)

The first and vitally important consideration when developing 'best practice' provision of culturally appropriate dementia care is to address issues around language and communication.

Summary of Best Practice Points

- Ensure dementia assessments including the InterRAI-LTCF are: culturally appropriate; have been reviewed for cultural bias; and recognise the impact of culture and the migration experience on individual behaviour. Comprehensive assessments must take a multidimensional interdisciplinary approach to understanding a client and their family and carer needs.
- Use professional interpreters who are familiar with aged care settings; dementia assessments, and the development and review of care plans if required.
- Identify and support the cultural, linguistic and spiritual needs of people with dementia to ensure care plans are person centred.
- Consider the different cultural representations and perceptions of dementia when discussing the residents and their families.
- Provide residents and their families with dementia information in their preferred language if available.
- Ensure that culturally competent care is provided across all care delivery services.
- Implement a culturally appropriate activities programme with therapies that are designed to promote and enhance the quality of life for people with dementia e.g. culturally appropriate music therapy and reminiscence therapy.
- Ensure the physical environment is culturally appropriate and supports people with dementia by providing a safe, comfortable, familiar and orientating environment.
- Ensure that all staff have received dementia training that is person centred in approach, and training in communication.
- Ensure that all staff have received cultural awareness training such as CALD 1 Culture and Cultural Competency, CALD 2 Working with Migrant Patients, CALD 3 Working with Refugee Patients, CALD 4 Working with Interpreters as well as have viewed the CALD Older People Resource for Health Providers available via www.eCALD.com.
- Ensure all managers have access to "Managing Culturally Diverse Teams" training.
- Ensure all staff have access to "Working in Culturally Diverse Teams" training.

1. Communication

As dementia progresses, it is common for bilingual people to lose the ability to communicate in the more recently acquired language. This can present as a serious problem if the person with dementia reverts to a language that is not familiar to the people who are caring for them.

It is not uncommon for adult children of migrants not to speak their native language. The difficulty this presents for an adult child communicating with their elderly parent will be compounded if even a spouse cannot communicate in the same language as the person with dementia. A Chinese couple may raise their family in New Zealand and speak both Cantonese and English, but it may happen that one of parents may lose both their Cantonese and English and revert to a Cantonese dialect that they spoke as a young person but which is not known by other members of the family. This can lead to difficulties in communication, and frustration and grief for all involved.

Communicating with someone who can no longer speak in words or sentences can sometimes seem like a tough task.

✓ **Best Practice Points:**
Use different ways of communicating

People with dementia still do communicate, even if they can no longer use words or sentences. Today we know that most people with dementia retain the ability to communicate, at least in one-syllable words, such as Yes or No.

The only exceptions to this rule are people in the final stage of dementia or who have suffered a stroke or similar condition that may have affected their speech circuitry.

A Yes or No answer can be given in three different ways, by:
1. **Saying** the words out loud.
2. **Shaking** or nodding the head to indicate a response.
3. **Using facial expressions** e.g., looking up and making eye contact; smiling or looking down for a Yes, or: looking straight into space or giving no reaction at all for a No.

Research has shown that words are not our only means of communication. We use three components when communicating a message:
1. **Words** – make up 7%;
2. **Tone of voice** – makes up 38%; and
3. **Body language** – makes up 55%.

1. Communication, continued

This means that **93%** of our communication is non-verbal, and it is through our tone of voice and body language that meaning is conveyed. We can say a word or sentence, but give it a completely opposite meaning through our tone of voice and the look on our face.

The reality is that people with dementia who have 'lost' their speech (only 7% of their communication) still retain the ability to share all their emotions by communicating non-verbally in actions and sounds.

General Care Principles:
Be a good listener and be compassionate

The objective of communicating with someone who cannot put words or sentences together is to help the person make sense of what is going on inside his or her mind and to express it.

The first essential to being a good listener is to listen with your heart, to listen with feeling. Ask yourself:

- What is the person attempting to communicate?
- What is the need that is not fulfilled?

When communicating with CALD residents who have lost the ability to speak it is particularly important to have families or local communities prepare word boards which staff can refer to which are written in the client's language.

Communicating with compassion

Compassionate communication is the art of connecting with another person, heart-to-heart. It brings us in touch with our natural empathy, enabling us to overcome labelling language that blocks compassionate interactions. Compassion is defined as:

- our innate desire to enrich another person's life; and
- the joy we experience when our actions nurture another person.

1. Communication, continued

A good way to start is to think of someone with whom we have a natural bond such as a close friend or family member. This will help us get in touch with your compassionate human qualities.

What blocks compassionate responses

Compassionate responses can be unconsciously blocked through analysing, judging, and labelling, which isolate us from the vulnerability of other people. This approach tends to put us in a position where we act as if we know better. This alienates us from compassionately stepping into the shoes of the other person and discovering how they feel. This is essential for all dementia patients but even more so for those from culturally diverse backgrounds.

2. Food and nutritional needs of CALD dementia patients

Eating and drinking well are important in staying healthy. A healthy and varied diet is likely to improve a person's quality of life. Not eating enough can lead to weight loss and other problems including vulnerability to infection, reduced muscle strength and fatigue which can often lead to a resident falling. People with dementia often experience various problems with eating and drinking. Eating a healthy, balanced diet is important and can help maintain physical and mental well-being. Care staff need to obtain information on CALD residents' food and fluid cultural and personal preferences from family and significant others. This will enable staff to individualise and customise meals particularly as the resident's dementia progresses. CALD residents' cultural food requirements are integral to the person-centred care plan.

Best Practice Points:
Ways to encourage eating

The person with dementia is often distracted from eating; there should be a range of snacks available and placed within the resident's sight. This allows for walking around, digesting food and engaging with others in the process.

Ensuring finger foods are prepared in advance means that if the person forgets or has difficulty with cutlery they can still enjoy their food with dignity. This may also encourage more eating – as mentioned previously for people with dementia under-nourishment is often an issue.

Encouraging appetite

There are lots of ways to stimulate appetite and interest in food and drink. Knowing the CALD person will help, as everyone has their own routines, preferences and needs. This will provide staff with a better idea about their likes and dislikes. It is also important to think about what they can physically manage.

♥ General Care Principles

- Regular snacks or small meals may be better than set mealtimes for some residents.
- Make food look and smell appealing. Use different tastes, colours and smells. The aroma of cooking can stimulate someone's appetite.
- Look for opportunities to encourage the person to eat. If the person with dementia is awake for much of the night then night-time snacks may be a good idea.
- Provide food the person likes and that is culturally preferred. Try not to overload the plate with too much food; small and regular portions often work best.
- Try different types of food and drinks.
- Food tastes may change so experiment with stronger flavours or sweet foods.
- Do not withhold desserts if the person has not eaten their savoury meal. They may prefer the taste of the dessert.
- If food goes cold it will lose its appeal. It can help to serve half-portions to keep food warm, or to use a microwave to reheat food.
- If the person is having difficulties chewing or swallowing, try naturally soft food that is culturally familiar, i.e., porridge (congee), or well-cooked curry in the first instance, before considering pureed food.
- If you do consider pureed food, seek advice from a dietitian or speech and language therapist and the family to make sure it is nutritious and remains flavoursome.
- Encourage the person to get involved at mealtimes. They could help prepare the food or lay the table.
- A relaxed, friendly atmosphere with some soft music that is culturally appropriate may help.
- It is always best to aim for the least stressful solutions. Common sense and a creative approach often help.

✓ Best Practice Points:
Recognising food and drink

People with dementia may struggle to recognise food and drink, which can result in it going uneaten. This can be due to the damage that dementia causes to the brain, or unfamiliar food, or how food is presented. Discuss with the family, or find out through research, how culturally significant food might be presented to reinforce past memories.

Concentration

People with dementia may not be able to concentrate well, which means they may have difficulties focusing on finishing a meal. This may be because they are tired or do not like the food that has been served. Do not assume someone has finished because they have stopped eating. Finger foods and smaller portions can help to make the task easier. Get families to participate in meal times and allow them to eat their meal with the CALD resident. Always try to get the resident to feed themselves for as long as possible. The food can become cold or the process may be overwhelming so make sure you can reheat the meal and provide a quieter environment for such events.

Motor difficulties - Problems with coordination

People with dementia may struggle to handle cutlery or pick up a glass. For CALD residents this can be a challenge when they have been used to chopsticks for most of their adult life. They may also have trouble getting food from the plate to their mouth. A person with dementia may not open their mouth as food approaches and may need reminding to do so. This could lead them to avoid mealtimes because they are embarrassed by their difficulties or want to avoid struggling.

- If the person is struggling with a knife and fork, chop up food so it can be eaten with a spoon or fingers.
- If the person appears to have difficulty using cutlery, you may need to prompt the person and guide their hand to their mouth to remind them of the process involved.
- Try finger foods such as sandwiches, slices of fruit, vegetables, cheese and quiche. These are often easier to eat when co-ordination becomes difficult.
- Let the person eat where they feel comfortable.
- Speak with the family about any special utensils that might help with this difficulty.

Chewing and swallowing problems

As dementia progresses, swallowing difficulties (called dysphagia) become more common, although these can vary from person to person. If a person is having difficulty with swallowing, a referral to a speech and language therapist can help. Difficulties can include holding food in the mouth, continuous chewing, and leaving harder-to-chew foods (e.g., hard vegetables) on the plate. Weight loss, malnutrition and dehydration can be consequences of swallowing difficulties. Always discuss these issues with the CALD residents' family as they may need to introduce more traditional foods to encourage eating.

Drinking enough

The sensation of thirst changes as people get older, which can sometimes mean the person is not aware they are thirsty. A person with dementia may also have similar problems. The CALD resident's drink preferences should be noted (e.g. a Japanese resident might like a specially prepared green tea provided in a special drink container; drinking this should be encouraged throughout the day). For CALD residents with more advanced dementia just placing a drink in front of them does not mean they will drink it. This activity needs to be monitored closely.

♥ **General Care Principles:**
Ensuring adequate fluid intake

- Have a drink on hand whenever the person is eating something.
- Use a clear glass so the person can see what is inside, or a brightly coloured cup to draw their attention.
- If possible, offer the person the cup or put it in their line of sight.
- Describe what the drink is and where it is, so that if the person has a problem with their sight they are still able to find the drink.
- Offer different types of drink (both hot and cold) that have been identified by the family throughout the day.

General Care Principles:
Changes in Eating Habits and Food Preferences

People with dementia can experience changes in eating habits, both in terms of how much food they eat and when, and what food they prefer.

As a person gets older it is common for taste and smell senses to decline, which can lead to food being perceived as less palatable. People may have a preference for additional sugar and salt. It is not uncommon for people with dementia to develop a fondness for sweet foods. It is important to find out CALD residents' dessert and sweetmeats preferences if this becomes an issue. People with dementia may enjoy unusual flavour combinations or ways of eating. Often people mix sweet and savoury food and flavours. People may start to have a less varied diet, only eating certain types of food.

CALD residents with dementia can exhibit even greater problems with their sense of smell, especially with odour memory. Being aware of a resident's food preferences before the onset of dementia is critical to overcome this difficulty.

As dementia progresses, a person may put non-food items into their mouths, e.g., napkins or soap. There could be a number of reasons for this, including:

- The person no longer recognises the item for what it is or understands what it is for. It is important to remove any items that the person may confuse for food.
- The person may be hungry. Offer food that is more culturally appropriate as an alternative.

2. Food and nutritional needs of CALD dementia patients, continued

Table 1. Key consideration and religious requirements regarding nutritional needs of Muslim residents including those with dementia.

Approved (Halal)	Forbidden (Haram)
Meat and substitutes Chicken, beef, lamb killed by Muslim slaughtermen. All seafood Eggs cooked in water, butter, vegetable margarine or vegetable oil Dried beans and lentils, baked beans	Pork and all pig products (bacon, ham, salami, non-halal gelatine, etc)
Mild and mild products Mild, yoghurt, cheese, ice cream made without animal fat e.g. tofu ice cream, halal gelatine or sherbet	Ice-cream made with animal fat.
Fruit and vegetables All fruit or vegetables raw, dried, dripping canned or cooked using water, vegetable fats	Any food fried or roasted in lard or dripping
Bread and cereals All breakfast cereals. Bread, cakes and biscuits prepared without animal fat other than butter (read labels) Rice cooked without animal fat Pasta	
Fats and oils Butter, vegetable margarine olive oil, peanut oil, vegetable oils	Lard, dripping, suet, other animal butters, vegetable margarine, fats except butter and other food made with or cooked in them
Beverages Tea, coffee, water, fruit juices, soft drinks, mineral and soda water, cordials	Alcohol and foods cooked with alcohol e.g. trifles, puddings, sauces
Soups Any vegetable soups and soups made with halal meat and without pork, ham or animal fats	Any ham bone stock
Desserts Any without alcohol, lard, dripping or suet e.g. fruit-based, custards, tofu, ice-cream, halal gelatine or sherbet fat Pudding made with butter or vegetable margarine, egg dishes, rice dishes	Any with alcohol lard suet, or suet dripping, ice-cream with animal fat
Miscellaneous Coconut milk spices, including chilli, curry powder. Pickles, chutneys	Non-halal gelatine Vanilla essence (alcohol base)

(Adapted from Waitemata DHB's CALD Older People Resource for Health Providers)

3. Eating environment

The environment plays an important part in the eating and drinking experience. It can affect how much a person enjoys eating and the amount they eat. A good mealtime experience can have a positive impact on the person's health and well-being.

Best Practice Points:
Improving Eating Environment

- Eat with the person. This will help make eating a social activity and can also help maintain independence as they may be able to copy you.
- Make the environment as stimulating to the senses as possible: familiar sounds of cooking, smells of the kitchen and food, and familiar sights such as tablecloths with flowers can all help.
- Let the person with dementia choose where they sit and eat. They should also be able to choose what they want to eat, within reason.
- Use colour to support the person – the colours of the food, plate and table should be different. Avoiding patterned plates is important.

Try not to worry about mess – it is more important for the person to eat than to be tidy.

Food services

As well as meeting CALD residents' nutritional needs, it is important that food services also meet their cultural and spiritual needs. Representing more than simple nourishment, food connects people to their homeland, culture, past and family. It is also central to many people's religious observances and practices.

Respecting the dietary needs and preferences of your residents from culturally and linguistically diverse backgrounds will enable them to maintain significant practices, a meaningful connection to the past and a joyful relationship with food.

3. Eating environment, continued

✓ Best Practice Points

Identify and support your client's religious and cultural requirements and preferences concerning diet and food preparation using a culturally designed food plan. If a resident's language needs change, try to present menu choices in the preferred language of the resident.

Involve residents in food preparation (where appropriate).

Involve family members and residents by asking them to provide recipes and instructions on the correct way of preparing these dishes.

Celebrate special occasions and festivals with a culturally appropriate dish, and invite family and friends.

Examples

Asian Special Occasions: New Year in many Asian countries, the New Year does not start on January 1 but with the first day of the Chinese lunar calendar.

Traditional New Year food might include:
- China – fish, chestnuts and fried dumplings
- Korea – dumpling soup
- Vietnam – meat-filled rice cakes

Ensure kitchen staff and catering companies responsible for meal preparation are familiar with the dietary preferences and culturally determined dietary restrictions of residents: for example Halal meat for Muslim residents (refer Table 1).

3. Eating environment, continued

Case Study

In an aged residential care setting a number of residents were being admitted from a wide variety of cultures. The chef in a facility situated in an ethnically mixed suburb undertook consultation with management and families and then set about redesigning the menus to provide much more diverse food selection.

Currently, in this facility they offer a daily menu that caters for Indian, Pacific Island and African food preferences. This is well received by all residents especially those with a diagnosis of dementia. The chef was quoted as saying, "We are able to meet those flavour cravings that CALD residents have but also provide a real, nutritious meal in a way that they can enjoy."

4. Personal care

At first, a resident may need only prompting or a little help when completing personal care activities. They will deteriorate slowly, eventually requiring care staff to be responsible for all personal care. Loss of independence and privacy can be very difficult for the resident. Being aware of the person with dementia's reactions, abilities and fears is important. To ensure culturally appropriate, person-centred health and personal care, staff need to consider the individual's cultural, linguistic and spiritual needs.

Best Practice Points

- Ensure all health and personal care plans and reviews identify and support the cultural, linguistic and spiritual needs of CALD residents.
- Establish the cultural and religious impact on the acceptability of certain treatments and medications.
- Ensure family members' role in decision-making about care has been clearly established and documented.

NB: Two personal care activities, bathing and dressing, are considered the most challenging.

4. Personal care, continued

Bathing

Bathing is often the most difficult personal care activity that care staff face. Because it is such an intimate experience, people with dementia may perceive it as unpleasant or an intrusion. They may show their discomfort or distress by screaming, crying, resisting or hitting. Such behaviour may occur because the person does not remember what bathing is for or does not have the patience to endure such unpleasant parts of the task as lack of modesty, being cold or experiencing other discomfort.

Developing person-centred care plans that encapsulate specific cultural beliefs and values will prevent or minimise negative behaviours. Refer to Figure 1 The Newcastle Model to assist in this process.

♥ General Care Principles: Bathing

There are many reasons why a person may not wish to have a shower – some might be based on cultural reasons while others might not. It is important to keep in mind that there is always a **strong, personal, and meaningful reason behind the refusal**. It is up to staff to find out what lies behind the response so that we can work around the underlying issue. The most successful solutions, however, are the ones we come up with intuitively when we know the individual person. To find the best solution, we need to use information from the family, your own intuition and intimate knowledge about the person and combine these with your creativity. Be prepared for trial and error.

NB: A gentle reminder: We cannot change the person with dementia. We can only change the way we deal with the situation and our own responses.

NB: When a person refuses to take a bath or a shower, you have three choices:
1. Find out what is the real reason for the refusal and act accordingly.
2. Find out if there is a time of day when it is easier for the person to feel comfortable showering or bathing.
3. If nothing seems to work at that moment, drop it and try again at a different time.

Remember that the best solutions are the ones you come up with intuitively or with the families' help.

4. Personal care, continued

General Care Principles:
Dressing

Physical appearance contributes to a person's sense of self-esteem. For a person with dementia, choosing and putting on clothes can be frustrating. The person may not remember how to dress or may be overwhelmed with the choices or with the task itself.

Assisting with personal care in the late stages of dementia:

- Be flexible - adapt to the person's preferences that are culturally appropriate.
- Help the person be as independent as possible
- Guide by using easy, step-by-step directions
- Use a picture board of resident dressed in clothes that the family have provided
- Encourage, reassure and praise the person
- Watch for nonverbal communication
- Experiment with new approaches
- Be patient, demonstrate understanding and sensitivity

5. Psychosocial perspective

Each person who has dementia is unique. As previously mentioned, the way a person presents results from a complex set of interactions including their life history, personality and social psychology. Each person needs to be treated individually.

CALD older people with dementia who come from the same ethnic background do not necessarily behave in the same way. There is no single, correct approach to the management of dementia. What might be successful for one person may prove ineffective for another (Woods & Bird, 1999). Not all of a person's symptoms are directly due to the brain disease. Physical and psychological environments might have a major influence on behaviours.

Physical environment

Moving into a residential aged care facility can be an unsettling experience for any person. The experience can be even more overwhelming for people from CALD backgrounds, who may find many aspects of their new life completely unfamiliar to them. Taking into consideration residents' cultural backgrounds and preferences in the facility will help to create an immediate and ongoing sense of familiarity and belonging.

5. Psychosocial perspective, continued

> ### ✓ Best Practice Points
>
> Consult local communities to find out how your facility can be made more appealing and appropriate for people from CALD backgrounds.
>
> For example: Shanti Niwas in Auckland is working to ensure that recent older Indian immigrants successfully integrate into communities they live in including residential care. Consider the needs and preferences of your residents from CALD communities when designing and decorating private rooms and public living spaces.
>
> Ensure interior decorations in public areas represent the cultural diversity of the local community and clientele – e.g., posters in community languages, maps and pictorial representation of other countries.
>
> Consider the language needs of your residents in the physical environment of your facility – e.g., provide signage in community languages. Clear labelling through the facility can lessen confusion; residents' room could be labelled using the first language of resident. For CALD residents, pictures may be more easily understood than written labels. NB: do not assume that CALD residents and their family are able to read or write in their own language.
>
> Provide facilities for a variety of religious and spiritual observances – e.g. a prayer room.

6. Spiritual and personhood

An understanding of particular religious practices and beliefs will assist you in the provision of culturally appropriate spiritual support. However, it is always important to identify individual needs and preferences and not assume that all people who speak the same language practise the same religion, or that all people following the same religion practice the same rituals or share the same beliefs. The religious beliefs of some of residents may require strict adherence to rituals and this may influence all aspects of their daily lives. The needs of your residents may also change over time; some people may become more aware of, and interested in, spiritual matters, perhaps for the first time in their lives.

From a cultural perspective simply asking which religion a person belongs to does not adequately determine spiritual needs.

6. Spiritual and personhood, continued

Assessing the spiritual dimension of a resident's quality of life is especially important for individuals whose physical and mental capacity has declined due to chronic and life-threatening illnesses (Byock & Merriman, 1998). The person with dementia frequently experiences a diminished sense of self-worth, and social workers need to be attuned to the clients' subjective sense of spiritual well-being as it often becomes their central quality of life domain.

✔ Best Practice Points

Identify and support the spiritual needs of your residents, including current and desired practices and beliefs, and schedule regular reviews.

- Conduct assessments and reviews of spiritual needs in the preferred language of your residents as the need arises.
- Ensure that the resident's religious preferences are documented and strictly followed including personal care and dietary requirements.
- Provide facilities for a variety of religious and spiritual observances in your facility.
- Facilitate outings to places of worship to assist residents to maintain existing religious networks. For example visiting the local mosque or Hindu temple regularly.
- Establish contact with representatives of local religious organisations who share the religion and language of your residents.
- Acknowledge and observe days of religious significance to your residents in a culturally appropriate manner.
- Ensure that resources are available in the preferred language of your residents to support their spiritual needs – e.g. DVDs, CDs and books.
- Tap into the person, not the disease; consider the following from a spiritual perspective.

The person with dementia needs the following Spiritual Framework

- To feel connected
- To have a sense of belonging
- To feel competent
- To be able to share
- To be useful
- To be respected

- To be successful
- To be appreciated
- To be loved and to love
- To have a sense of control
- To have a sense of hope.

6. Spiritual and personhood, continued

📚 Case Study

Harry Kim is a 75-year-old Korean male. He has been a resident in the local dementia unit for several months having been diagnosed with Dementia with Lewy Bodies. He claims no affiliation to any particular religion or spiritual practice. According to his family, he left Christianity when he was young because of his mistrust of church authority. However, the family know that he calls himself a "spiritual seeker" as he has previously studied different types of spiritual teaching including Eastern philosophy. The Pastoral Carer at the facility explored some spiritual questions with him and his family using the spiritual framework to in Figure 2 to get a sense of his level of spiritual well-being.

7. Emotional support

Entering an aged residential care facility is an enormous change for older people with dementia. They may experience feelings of loss, anxiety, frustration, anger or grief. This change might also cause some people especially those from culturally and linguistically diverse backgrounds to relive past traumas. The experience can be even more emotionally overwhelming for people from CALD backgrounds, who might find many aspects of their new life and environment completely unfamiliar – and who might be at greater risk of isolation due to language barriers. (Ayalon & Arean, 2004).

To ensure emotional supports are provided well, communication needs in particular must be addressed. Encouraging and facilitating activity in the preferred language of residents enables participation, reduces social isolation and facilitates a sense of belonging.

✔ Best Practice Points

- Identify, address and regularly review the emotional support needs of residents.
- Provide emotional support services in the preferred language of residents in consultation with family members.
- Encourage families to visit and support their family member in care.
- Assist residents to maintain community and other support networks.
- Explore the availability of volunteers who are conversant in the resident's preferred language for CALD residents who are isolated.
- Ensure that all care staff understand that a person's expression of emotion – including his or her response to loss and grief – is influenced by culture.

7. Emotional support, continued

♥ General Care Principles

To experience what the person means by the words, "I want to go home", we need to ask ourselves, "What does home represent?"

Our answers are most likely to be **emotional** representations of home and this is also true for people with dementia. It is unlikely that they are actually thinking of the physical home that they are either living in right now or have left in order to move to a residential care facility. Some residents may be searching for **emotional** fulfilment of unmet needs.

The five universal emotional needs often unmet for people with dementia are to:

1. be needed and useful;
2. have the opportunity to care;
3. love and be loved;
4. have self-esteem boosted;
5. have the power to choose.

When these needs are not fulfilled in the care setting, the person with dementia may go back in their memory to a time when their needs were met. When a person wants to go home they are usually looking for love – unconditional love.

Instead of using band aid solutions in dementia care, take the opportunity to make a conscious decision to move care to a deeper level. Seek out the underlying social, emotional and psychological causes of the behaviour. There is much we can do to prevent behaviours we normally think of as challenging. It takes willpower, creativity, understanding, patience, love and a desire to do things differently.

8. Traditional therapies

Traditional medicine often means different things to different people. A single medicinal plant may be classified as a food, a dietary supplement or an herbal medicine. Integrating traditional medicine into modern healthcare is becoming more acceptable to Western health providers (Dong, 2013).

Societies with ancient histories of traditional medicine are attempting to find ways to modernise their own medical heritage. In China, for instance, modern and traditional medicines are practised alongside each other at every level of the healthcare system.

Best Practice Points:
Traditional Medicine Definitions

Complementary/alternative medicine:
The terms 'complementary' and 'alternative' medicine are sometimes used interchangeably with the term 'traditional medicine'. They refer to the healthcare practices that are not part of a country's own tradition and are not integrated into the dominant healthcare system.

Herbal medicines:
These include herbs, herbal materials, preparations and products that contain plant materials or combinations of plants as active ingredients. Herbalism is the practice of making or prescribing plant-based herbal remedies for medical conditions and is considered a form of alternative medicine.

Integrative medicine:
This term refers to the blending of conventional and natural/complementary medicines and/or therapies along with lifestyle interventions in a holistic approach, taking into account the physical, psychological, social and spiritual well-being of the person.

Traditional medicine:
The overall body of knowledge, skills and practices based on the theories, beliefs and experiences indigenous to different cultures, whether they can be explained or not. These might be used to maintain health as well as prevent, diagnose, improve or treat physical and mental illness.

See more at: http://www.scidev.net/global/medicine/feature/traditional-medicine-modern-times-facts-figures.html#sthash.X4mmem6n.dpuf

8. Traditional therapies, continued

♥ General Care Principles

- Establish whether traditional herbal medications (TM) are being taken and check for potential adverse effects.
- If TMs are being taken, it is important to check their compatibility with other prescribed medications.
- Support residents and families in accessing complementary or traditional therapies, and assist them to make informed choices if this is requested.
- For Indian communities, there are a range of traditional healers available including: religious leaders, astrologers and Ayurvedic practitioners who are often consulted alongside Western medical practitioners.
- Chinese people may have more trust in traditional herbal and other remedies but will accept Western medicine as well.

9. Meaningful Leisure Activities

Addressing cultural diversity in leisure programmes and daily recreational activities is essential to maintaining person-centred care and a quality of life for residents from CALD backgrounds. A culturally appropriate activities programme will help to bring pleasure into the lives of residents as well as foster self-esteem and a sense of purpose and belonging.

✓ Best Practice Points

Consider the cultural, linguistic and religious needs and preferences of residents when planning and reviewing recreational activities, with input from their families and other relevant people.

- Foster links with local community organisations that share the culture, language and religion of residents.
- Facilitate community and family involvement in activities.
- Plan regular outings to places of significance for your residents from culturally and linguistically diverse backgrounds.
- Involve families in festivals and religious, special days and ask how they would like to observe these occasions.
- Explore the availability of community volunteers to provide social visits conducted in the preferred language of residents.
- Provide residents with access to their own preferred ethnic media (including radio, TV and newspapers).

9. Meaningful Leisure Activities, continued

> ### ♥ General Care Principles
>
> Activities for CALD residents with dementia should always be created with an aim to improve their social, emotional and spiritual well-being in a culturally meaningful way, in order to help them blossom and grow.
>
> Meaningful activities should be created which tap into a person's past skills, memories and interests. These do not have to always be structured but do need to stimulate the senses and encourage participation, boost self-esteem and fulfil one or all of our five universal emotional needs.
>
> Activities and therapies from a cultural perspective might involve dance, movement, colour, walking or quiet time in conversation. The true focus is not about the activity itself but the quality and joy of the interaction. Combining both cognitively stimulating and physical activities together may have a better long-term effect and should be considered.
>
> **Memory suitcase**
>
> Seek help from local ethnic communities and families to develop memory suitcases that are culturally appropriate for CALD residents. Many people may forget their name or who family members are, but then are stimulated by seeing a photo, a cooking utensil, a game, or soap and spices included to stimulate evocative memory smells.

10. Palliative care: End-of-life care
(Adapted from CALD Older People Resource for Health Providers)

End-of-life care for people with dementia present a variety of issues and a broad approach to palliative care is suggested as the best model for dementia patients. It is important to note that palliative care aligns with the philosophy of person-centred care as both approaches stress a holistic and inclusive view of the person in the context of their family and with attention to symptom control and an overall quality of life (Cha & Kayser-Jones, 2005).

Addressing cultural diversity across all integrated palliative care services will assist you to maintain the comfort and dignity of residents in a culturally appropriate manner that respects and values the uniqueness of each person.

10. Palliative care: End-of-life care, continued

Culturally appropriate palliative care necessitates a special type of cultural awareness – an understanding of death and dying from different cultural perspectives.

The cultural and religious rituals which surround death and dying are among the most significant and sacred events of all societies. It is therefore imperative that palliative care services respect and support the customs, beliefs, rituals and practices that provide meaning and comfort to residents and their families at this time. Refer to "CALD Older People Resource for Health Providers" for further information regarding CALD specific end-of-life care and palliative care guidelines, pp. 84-101.

Below is a brief overview of key points to consider when caring for a resident with dementia and culturally diverse needs.

✅ Best Practice Points

Use professional interpreting services when care plans are developed and reviewed – and whenever informed consent is required.

Prior to the palliative care assessment, establish the willingness and ability of residents and their families to discuss issues around death and dying, including the appropriateness of such terms.

- Consult residents and their families regarding whether or not open discussion of diagnoses and prognoses is acceptable – and balance this with legal requirements around issues of informed consent.
- Ensure all palliative care services identify and support the cultural, linguistic and spiritual needs of residents and their families, including rituals and practices around death and dying.
- Establish the resident's cultural and religious preferences for certain treatments and medications. For example, some Chinese may find some aspects of Western medicine distasteful (e.g. diagnostic tests). Some cultures are upset by the drawing of blood.
- Understand that people will have different interpretations of the concept of quality of life, and that these may be culturally determined.
- Clearly establish the role of family members in decision-making about care and treatment of the resident.
- Resolve any conflicts around palliative care between staff and residents and/or family members by finding culturally appropriate strategies that are acceptable to all involved.
- Provide information about palliative care and support services in the preferred language of residents and their families

11. Staff caring for CALD residents with dementia

Cultural awareness

Having a culturally competent health care workforce has many benefits including the knowledge of cultural customs which enables the provision of better care. CALD Cultural competency training will help avoid misunderstandings among staff, residents and their families (Centre for Cultural Diversity of Ageing, 2000a).

An essential skill in the provision of culturally appropriate services is cultural awareness. Cultural awareness entails an understanding of how a person's culture may inform their values, behaviours, beliefs and basic assumptions.

Cultural awareness recognises that we are all shaped by our cultural background, which influences how we interpret the world around us, perceive ourselves and relate to other people. You do not need to be an expert in all cultures or have all the answers to be culturally aware. Instead, you need to be culturally aware of your own values, bias, behaviours and beliefs and have the ability to recognise cultural difference, be culturally sensitive to explore cultural issues and accommodate the identified needs of your residents.

Information about specific cultural practices will help to increase your knowledge of an overview of cultural characteristics and issues. However, it is always important to identify individual needs and preferences and remember that no individual can be reduced to a set of cultural norms.

Cultural awareness entails an understanding of the migration process itself. Migration is a key influence on a person's life. A resident's experiences pre-migration, and of migration and settlement will influence their health and mental health in a new society (Shanley, Boughtwood, et al., 2012).

While some migrants undergo a relatively easy transition, most migrants will undergo some – if not many – challenges in adjusting to life in a new country.

Some of the many post-migration stressors include: the stress of separation from homeland, family members, friends and support networks; racial discrimination; changes in lifestyle and socio-economic status; culture shock; language barriers; and the ongoing trauma of pre-migration experiences, which may have included war and political instability, physical and psychological abuse, and travelling as a refugee or living in a refugee camp.

✅ **Best Practice Points**

- Be aware of your own cultural values and influences.
- Be aware of judging other people's behaviour and beliefs according to the standards of your own culture.
- Be aware of making assumptions about cultural influences and applying generalisations to individuals.
- Understand that the behaviour and beliefs of people within each culture can vary considerably.
- Understand that the extent to which people adopt the practices of their new country and retain those from their cultural background can vary within communities, even within families.
- Understand that not all people identify with their cultural or religious background.
- Understand that culture itself is a fluid and dynamic concept. Cultures changes as a result of globalisation, migration and the diasporic influence of the settlement of new ethnic groups.
- Increase your knowledge about different cultural practices and beliefs through seeking information about the cultural and religious practices of the residents in your care and/or resources and CALD cultural awareness training.
- Understand the importance of appropriate communication.

Refer to Centre for Cultural Diversity in Ageing (2000b) supporting cultural diversity in residential care: working with Bilingual staff in aged care. Retrieve from: http://www. culturaldiversity.com.au

Care Planning: Family Members Contribution

Families should be considered as integral members of the care team when it comes to developing a care plan that is truly centred on the CALD person. This is particularly important during the transition from community to residential care to ensure the success of settling into a new environment for both the resident and their family. This will reduce the stress and guilt that often occurs when a loved one enters aged residential care. Knowing the CALD resident will mean combining cultural practices with Western practices from the outset.

11. Staff caring for CALD residents with dementia, continued

Cultural practices have important physical implications that can be challenging to address. For example, traditional African practice and dress code includes bare feet or open sandals. For residents with diabetes this practice can immediately come into conflict with best practice from a Western medicine perspective. How one dresses is a major aspect of cultural identity so this can have major issues for the family and recently admitted resident.

All CALD residents' care plans should demonstrate cultural competence, particularly in relation to behavioural health issues to meet the residents' and family needs.

✓ Best Practice Points

- Provide detailed information about what dementia is during the first visit so that the family has all the information they need. This could even be when the family is visiting the facility prior to admission.
- Establish the family's understanding of dementia.
- Explain that there may be differences in care provision systems compared to their country of origin.
- Determine cultural beliefs about medications and traditional health practices.
- Explain and reinforce a few principles of dementia care at each visit. Assess the level of understanding of the family members.
- Involve someone who can speak the same language and preferably from the same culture to enhance the understanding of the family's needs and preferences.
- Meet with family regularly.
- Ensure staff are aware of who the main decision-maker is in the family to avoid conflict and confusion.
- Encourage all family members to be involved with the care plan process.
- Take time to learn about traditional and ritual practices.
- Keep an open mind about the communication styles of the family.
- Explore attitudes and beliefs about behavioural manifestations of dementia – what does the family think is causing the behaviours; what do the behaviours mean to family members?
- Establish the family's understanding of dementia.
- Explain that there may be differences in care provision systems in a different country.

General Care Principles:
Principles of Culturally Competent Care for Individuals with Dementia

- Determine meanings of dementia, and related concepts in the person's culture of origin.
- Determine meaning of caregiving, gender roles, and role of elders in society in culture of origin.
- Attempt to ascertain type and degree of cultural adaptation of the individual with dementia and caregivers; may differ for older and younger family members.
- Determine cultural beliefs about medications and traditional healing practices.
- Identify challenges to maintaining food preferences such as: following a vegetarian diet, access to traditional foods used for celebrations, adjustment to/influence of standard western fast food diets (especially reliance on low-cost foods that may be high in added sugar, fat, and salt).
- Identify environmental issues that may impact on cultural practices, such as space constraints limiting use of a dedicated room for prayers.
- Explore attitudes and beliefs about the behavioural manifestations of dementia – what does the family think is causing the behaviours; what do the behaviours mean to family members?
- Keep an open mind about the communication style of the family. Ask more open-ended questions versus yes/no questions.
- Try to understand the priorities of the family in decision-making (for example, an appointment with a specialist may not mean any more to them than a routine appointment; providing information and education is important as there is chance the family might miss the specialist appointment).
- Collaborate with community organisations that provide support services that may be important to CALD residents and families.

Example of Culturally-Sensitive Person-Centred Care Plan

Description of problem/ needs identified	Recommendations for culturally-sensitive care interventions	Rationale
Mr Kim's relatives may think that he is 'crazy' and they may not understand the dementia diagnosis.	Recognize that the family needs time to absorb information and to learn new skills (such as how to approach the behavioural manifestations of dementia and depression). Explain and reinforce a few principles of dementia care at each visit, assessing caregivers for their level of understanding and using a Korean interpreter whenever possible.	Cultural differences may impact on a family's perception of time. Involving someone with a Korean cultural background and who speaks Korean language may enhance understanding of the family's needs and preferences.
Mr Kim sometimes chooses footwear that is not ideal for his foot problems. The healthcare team must understand and appreciate accepting risk as a marker of personal agency.	Meet with the entire family and ask Mr Kim about why he prefers certain footwear. Involve Mr Kim's son Peter as well, as the women in the family who may provide some of the direct care, in explanation of the risks and benefits of various footwear choices. Suggest verbal cues that offer Mr Kim footwear alternatives that are comfortable to him.	Showing respect for traditional dress and beliefs is important in building trust with an individual with dementia and family caregivers. Removing the offending footwear might work, but could also increase agitation if Mr Kim tries to rummage around to find his "lost" shoes. Speaking with all members of the family, instead of just the person's spouse, may facilitate decision-making among the male and female members (in a patriarchal society, the male family members may need to be included, as well as women who may be providing some direct care).

Description of problem/ needs identified	Recommendations for culturally-sensitive care interventions	Rationale
Mr Kim is not able to communicate with clinic providers during appointments due to issues of language and culture. Mr Kim's son Peter may not be available to accompany Mr Kim to appointments because of working multiple jobs. (Caregivers are expected to accompany a family member to appointments. Usually family members accompany an elder in a Korean context. Continuity is a challenge when different family members accompany the person each time, and no one has complete information)	Encourage Mr Kim's son Peter and also other family members to accompany the resident on clinic visits. Explain the role of a medical interpreter; express the value of family input during medical appointments as well. Obtain a professional medical interpreter as well, if the family agrees.	In some cultures, women may not be encouraged to speak up (or at all) during clinic visits; therefore having only a daughter or daughter-in-law at a visit may not facilitate communication between the family and providers. Families from certain cultures may not wish to appear as though they are abdicating their role in caregiving for their parents. The medical interpreter can explain to Peter how valuable his input is, and clarify that the role of the interpreter is simply to assist the healthcare team in understanding all of the conversation.
Mr Kim does not always take his medication as prescribed	Take time to learn about traditional healing practices, such as making ritual offerings to dead ancestors. Demonstrate an appreciation for these practices and express how valuable both traditional practices and medication may be in treating the symptoms of dementia. Ask about other cultural practices, such as those related to food (e.g. ensuring that the family has been able to maintain their vegetarian diet) and physical environment (have they been able to dedicate a room for prayers and support other important religious activities).	Many non-pharmacological interventions are effective in managing the behavioral and psychological manifestations of distress that may accompany dementia. The comfort of these traditional healing practices may have an impact on the frequency or severity of his expressions of distress, on his depression and quality of life. They may also influence the well-being of his wife and other relatives as well.

12. Culturally and Linguistically Diverse Older People Assessment Processes

(adapted from Waitemata DHB CALD Older People Resource for Health Providers www.eCALD.com)

Type of Assessment	Assessment Tool
Physical assessment	Physical examinations by someone of the opposite sex are unacceptable in many cultures. Ask if the older person would like other family members to be present during physical examination. Throughout the assessment, inform the client of procedures and ask for permission to examine different areas of the body. Use an interpreter if required.
Cognitive and affective status	Symptoms' recognition meaning and ways of reporting are expressed differently by older people of different cultures (e.g., heavy heart may indicate depression among Chinese older people).
Culturally appropriate dementia assessment tools	The Rowland Universal Dementia Assessment Scale (RUDAS) is a short cognitive screening instrument designed to minimise the effect of cultural learning and language diversity on the assessment of baseline cognitive performance. The Montreal Cognitive Assessment (MOCA) tool is translated into 36 languages and dialects (Nasreddine, 2006) The MOCA is used for detection of Mild Cognitive impairment in multiple conditions including MCI/Alzheimer's disease, Vascular cognitive impairment, Parkinson and Fronto-temporal dementia.

✓ Best Practice Points

It may take longer to complete cognitive assessment with people with a CALD background. Therefore allow sufficient time. Consult with family members.

Seek advice from culturally appropriate staff that specialise in working with people from CALD backgrounds.

13. Supporting cultural diversity in residential care: Evaluation and planning

Providing a best practice, dementia-friendly CALD residential care environment requires that:

- Residents' individual needs and choices are person-centred.
- Barriers that hinder full participation of the resident are uncovered.
- Management and staff are adequately trained.
- A Continuing Improvement Plan is in place to monitor the implementation of Best Practice CALD initiatives.

This recommended evaluation and planning tool developed by the Centre of Cultural Diversity in Ageing in Australia will assist aged care providers to assess the level at which they are providing CALD services in an equitable and inclusive manner for residents.

Retrieved from https://www.culturaldiversity.com.au

NB: Although these tools have been developed to be used alongside the Residential Care Accreditation Standards in Australia they still have relevance for New Zealand.

Dementia Information in other Languages

Alzheimer's Australia

Languages include: Arabic, Armenian, Chinese, Croatian, Dutch, Finnish, German, Greek, Hindi, Hungarian, Indonesian, Italian, Japanese, Khmer, Korean, Laotian, Latvian, Macedonian, Malay, Maltese, Polish, Portuguese, Romanian, Russian, Serbian, Spanish, Tagalog, Turkish, Ukrainian, Vietnamese.

Perceptions of Dementia in Ethnic Communities

Alzheimer's Australia (Vic)

Culturally Appropriate Dementia Assessment Tools

Alzheimer's Australia (Vic)

Religions and Beliefs

BBC

This section of the BBC website looks at a range of religions and beliefs, and explores their history, holy days, ethics, practices, rites and rituals and more.

An Outline of Different Cultural Beliefs at the Time of Death

Loddon Mallee Regional Palliative Care Consortium

This resource looks at the different religious beliefs surrounding death and dying and what funeral or burial rituals may be undertaken.

Spirituality in Aged Care Project – Final Evaluation Report, April 2011

Irene Nolan and Terry Mills, Healthcare Chaplaincy Council of Victoria Inc. (HCCV), Bendigo Health, 2011.

Multilingual Palliative Care Resources

Palliative Care Australia

Palliative Care Australia has released three of its most popular consumer resources in 21 languages: What is palliative care?, Facts about morphine, and Asking questions can help. These fact sheets are available in the following languages: Arabic, Chinese – simplified, Croatian, Dari, Farsi, French, Greek, Italian, Japanese, Khmer, Korean, Macedonian, Maltese, Polish, Portuguese, Russian, Serbian, Spanish, Traditional Chinese, Turkish, Vietnamese.

An Outline of Different Cultural Beliefs at the Time of Death

Loddon Mallee Regional Palliative Care Consortium

This resource looks at the different religious beliefs surrounding death and dying and what funeral or burial rituals may be undertaken.

Perceptions of Dementia in Ethnic Communities

Alzheimer's Australia (Vic)

Dying, Death and Grieving – A Cultural Perspective: Conference Report

Australian Multicultural Foundation, 2002.

The Family Caregiver Alliance resources in Chinese, Korean and Vietnamese

https://caregiver.org/fact-sheets

Multicultural Media: Radio Stations (Auckland based)

AM Stations		
531	Radio 531pi	Pacific Island radio
603	Radio Waatea 603AM	Māori radio and news Bilingual Māori and English
1386	Radio Tarana	Contemporary Indian radio
936	AM936 Chinese Radio	Chinese radio
990	Apna 990AM	Indian radio

FM Stations		
104.2	Chinese Radio FM 104.2	Chinese radio FM
06.2	Humm FM	Hindi radio
90.6	FM90.6 New Zealand Chinese Radio	Chinese radio

Newspapers

Mandarin Pages

Newspaper in Mandarin aimed at the Chinese population in New Zealand

http://www.mpages.co.nz

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Appendix 1: Template for Person Centred Care Assessment and Summary of Findings

Social and physical environment	Life History and experience	Personality

Physical health	Summary	Interventions	Cognitive impairment

Medication		Feelings (how do they appear?)	Mental health

Behaviour (what do they do?)			