



Culturally Responsive Palliative Care

Cultural perspectives and values
from ten culturally and linguistically
diverse communities in Victoria

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Introduction

Cultural perspectives and values from culturally and linguistically diverse communities in Victoria

Background to the Project

The Culturally Responsive Palliative Care Community Education Project formed part of Palliative Care Victoria's Cultural Responsiveness Strategy. The project was undertaken in partnership with the Ethnic Communities' Council of Victoria in 2013-2015 and with the Multicultural Centre for Women's Health (MCWH) in 2013-2014.

It involved community engagement and peer education to raise awareness of, and access to, palliative care services and focused on ten larger communities: Chinese, Maltese, Italian, Turkish and Vietnamese during 2013-15 and the Greek, Macedonian, Polish, Croatian and Arabic-speaking background communities in 2014-15.

In 2013-2015, 33 trained bilingual health educators delivered 150 community education sessions in eleven community languages to 4846 participants.

Further information about the Project, and links to the evidence base and summaries of the external evaluation of the Strategy are available [here](#).

Peer Education Resource

The bilingual peer educators delivered the information sessions using a Peer Education Resource that was tailored for each community in partnership with a Community Reference Group. In 2013-14, this process was coordinated by Maria Hatch and Dr Jasmin Chen from MCWH and in 2014-15 by Mike Kennedy from Palliative Care Victoria.

The first part of the Peer Education Resource contained background about the community and its cultural perspectives and values. These community summaries are set out below in this document and can also be accessed as individual PDF files.

A community reference group was established for each participating community and provided the project partners with invaluable advice and guidance in preparing the Peer Education Resource documents.

When referring to these documents, care needs to be taken to avoid cultural stereotyping and profiling. In undertaking this project, we learned multiple times that there is as much diversity *within* each ethnic community as there is between them, and that cultural perspectives and values are evolving and changing. However, this information may be useful in identifying some issues to be explored with clients or patients from culturally and linguistically diverse backgrounds to deliver culturally responsive person-centered care.

Arabic-Speaking Background Community Cultural Profiles

Discussing palliative care in the Arabic-speaking background communities

Talking about palliative care can be difficult for people from all cultures and communities. Although in Arabic-speaking background communities there is no specific taboo around talking about death, many people from Arabic-speaking background communities may be reluctant to speak about their personal experiences with illness and dying. Palliative care can produce negative feelings because of its association with illness, death and dying. These negative feelings can trigger difficult memories. When delivering information to participants about palliative care, it is important to be respectful of their feelings and their right to privacy.

As a peer educator, it is important to remember that learning is an active process through which people create meaning and develop understanding. The ways that participants react to new information depend on their ideas, opinions, knowledge, personal experiences, understanding of the world and their own learning style. Particularly around topics such as death and dying, participants will bring with them a whole set of cultural and social beliefs that will impact their learning experience. Education sessions are a good opportunity to raise awareness about palliative care but also to explore commonly held beliefs about health and illness and to dispel myths about palliative care.

Discussing illness, death and dying can often trigger strong emotions and feelings in people, especially if a participant has been personally impacted by it. Participants should be informed that:

- They do not need to contribute to discussion if they feel uncomfortable and are not forced to participate if they don't want to.
- They may take a break or leave the room if they feel like they need to.
- If they would like to share a story or experience they went through, they do not have to identify it as happening to them but they can say it happened to 'someone they know.'

Arabic-speaking background communities in Victoria and Australia

The Arabic-speaking background population in Victoria is very diverse in terms of religion, language, age and country of origin. It is made up of over 68,000 people of both Christian and Islamic denominations coming from different countries which are members of the Arab League of Nations where the official language is Arabic. Arabic was the sixth most common language other than English spoken at home in Victoria in the 2011 census.

Countries which are members of the Arab League of Nations

Algeria (125)	Lebanon (22)	Somalia (64)
Bahrain (119)	Libya (92)	Sudan (43)
Comoros	Mauritania	Syria (72)
Djibouti	Morocco (113)	Tunisia (134)
Egypt (27)	Oman (117)	United Arab Emirates (76)

Iraq (26)	Palestine (98)	Yemen (142)
Jordan (103)	Qatar (135)	
Kuwait (89)	Saudi Arabia (67)	

Note: The numbers in brackets are the ranking order in the top 150 overseas countries of birth for Victoria in the 2011 census.

The Arabic nation is Arabic speaking. There is great diversity in the ethnicity of the nation – the Arabic race is the largest group; other ethnicities are Kurd, Chaldean, Assyrian, African, Pharo and Armenian. There is diversity in religious practice as well. Thus migration from a particular Arabic League country may not indicate the migrant’s ethnicity, religion or language spoken at home. Some individuals think of their identity in nationalistic or sectarian terms. Although they speak Arabic and share Arab culture, some individuals may refer to their identity as Lebanese (national term), Chaldean or Coptic (religious term) or Kurdish (ethnic term).¹

For the purposes of this Peer Education Resource, it is not necessary to do a detailed breakdown of the distribution of the Arabic-speaking background population of Victoria by local government areas. Based on the countries of birth for Arabic-speaking background communities in Victoria (using data from the 2011 Census and countries in the top 50 Overseas counties of birth), there are significant Arabic-speaking background communities in Hume, Moreland, Whittlesea, Brimbank, Casey, Greater Dandenong, Darebin, Wyndham, Hobsons Bay and Manningham.²

About Arabic-speaking background communities in Victoria and Australia

People from an Arabic-speaking background in Australia came from various countries in the Middle-East and North Africa, mostly over the last 40 years. They migrated due to displacement by war and political upheaval, or a desire for professional or economic advancement.

Many are Muslims, for whom the religious perspective over-rides the cultural background, especially when issues of death and dying arise. Another group is the Coptic Orthodox. Most householders are qualified doctors, engineers, lawyers and teachers who migrated originally from Egypt and surrounding countries. A significant group of people from an Arabic-speaking background in Australia is from Lebanon. These people are from four religious groups: Muslim, Maronite, Orthodox and Druze. They have similar cultures in their way of living but have different ways of burying their dead.

Arabic-speaking background communities’ Cultural Perspectives and Values

Within any cultural group or community, individual views and values are shaped by many factors, including our age, gender, income, religion, sexuality, profession, education and political views, not to mention personal experiences. Individuals from the same culture do not all think alike or share the same value systems and opinions. Likewise, cultural values and attitudes can change over time and are never the same thing to everyone.

¹ South Eastern Region Migrant Resource Centre, “Arabic Cultural Profile – Older People”, 2010.

² Victorian Multicultural Commission, Community profiles 2011 Census, <http://www.multicultural.vic.gov.au/population-and-migration/victorias-diversity/community-profiles-2006-census>, accessed 27 August 2014.

For Arabic-speaking background communities, shifting cultural values can become more apparent through the migration experience and there can be great differences between the views and values of two generations within the same family. For older generation migrants in particular, some traditional views and attitudes may have been preserved despite changing attitudes and practices in their country of origin. In this sense, culture as it exists for Arabic-speaking background communities in Australia cannot necessarily be generalised from contemporary Arabic-speaking background culture or with Arabic-speaking background communities living in other parts of the world.

Nevertheless, certain beliefs can have more influence or resonance with a cultural group and can be recognised as commonly shared or understood within a community. Individuals from that group do not need to personally agree with those values to recognise their cultural importance.

Here are a number of commonly held Arabic-speaking background cultural perspectives and values that may have bearing on their response to a discussion about palliative care. Please keep in mind that these perspectives will not apply to everyone in the Arabic-speaking background communities and it is important not to make assumptions about people's values and beliefs.

Community and Religion

The main religion in most Arabic-speaking countries is Islam, the second being Christianity in various forms. Sunni and Shia are the two main streams of Islam. Another religion, the Druze, practiced mainly in Lebanon and Syria, originated from Islam.

The majority of Christian groups reside in the following Arabic-speaking countries: Lebanon, Jordan, Syria, Egypt, Palestine and Iraq. Christian Maronites (Catholic) and Christian Orthodox form 30 percent of the population in Lebanon. Coptic Orthodox is a minority group in Egypt and Chaldeans/Assyrians and Christian Orthodox are minority groups in Iraq. There was a small Jewish population in Egypt, Lebanon, Iraq and Morocco before the creation of Israel and the current conflict between Arabs and Israelis.³

Muslim patients and families

Though Islam is a single religion, it is important to recognise that Muslim people are not a single homogenous group. The cultural diversity of the Muslim community in Victoria makes it difficult for anyone to prejudge the expectations or needs of individual patients, for example, with regard to religious observance. When in doubt, it is always best to ask.⁴

Catholic patients and families

For Arabic-speaking background communities who are Catholics, religion is important for comfort. It is separate from everyday life and does not have an impact on decisions relating to illness. In some cases the priest may visit the family and act as a counsellor to help ease the stress on the family.⁵

Family

Generally speaking, the Arabic-speaking background communities are family-oriented and the male is the head of the family and makes decisions. It is expected that the children will care for

³ South Eastern Region Migrant Resource Centre, "Arabic Cultural Profile – Older People", 2010..

⁴ Islamic Council of Victoria, Muslims Australia, "Caring for Muslim Patients", 2010.

⁵ Alzheimer's Australia Victoria, *Perceptions of dementia in ethnic communities*, 2008.

the parents. The main carer initially is the spouse, supported by the family members. Traditionally, the son is expected to care for the parents, while the daughter is expected to care for the parents if she is not married. If the daughter is married, she is responsible for both her husband and his family. Even though the attitudes and expectations are changing for more traditional Arabic-speaking background communities, the expectation that children will care for their parents is deeply embedded, including in religious beliefs. For these communities, it is not acceptable for children to put their parents into nursing homes and this carries a lot of stigma and shame. A common belief is that if children are good they will care for their parents as this is what Allah wants of them. If they do not take care of their parents then, in turn, their children may not care for them when they grow old.⁶ Family honour is an important cultural value, and extremely important for people who migrated from a rural background.⁷

Attitudes to illness and pain management

People from Arabic-speaking backgrounds may use western medicine concurrently with herbal remedies or traditional healing practices. Doctors and qualified medical people are well accepted and respected by Arabic-speaking background community members. A medical diagnosis should be given to the closest family member, preferably the oldest son or daughter.

Gender issues can affect relationships with the wider community and should be considered when offering a service, matching where possible a client with a worker or interpreter of the same gender.

Elderly people may face difficulty reading health information and promotional materials in Arabic as many of them may not be literate in their first language. People may prefer to communicate through a personal contact who can speak the same dialect.⁸

Islamic teachings give mentally competent adult patients the full right to refuse current or future treatment. Many medical ethicists and Muslim scholars consider it equally appropriate to withhold or withdraw futile medical treatment. However, other Muslim scholars tend to be stricter about withdrawing rather than withholding treatment, even when both are considered medically futile.⁹

There are no taboos with regard to pain relief in Arabic-speaking background communities. For practicing Muslims, clinicians should check whether medications contain alcohol or ingredients made from pigs.¹⁰

The illicit use of opioids and other drugs that affect intellectual and cognitive functions is strictly prohibited in Islam. However, medically prescribed opioids are generally considered permissible because of necessity. Usually, patients and families accept the use of opioids for symptom control if the rationale is clearly explained to them. It is important to explain to the patient and family the possible side effects, as there may be significant concerns regarding drowsiness.

⁶ Alzheimer's Australia Victoria, *Perceptions of dementia in ethnic communities*, 2008.

⁷ South Eastern Region Migrant Resource Centre, "Arabic Cultural Profile – Older People", 2010..

⁸ South Eastern Region Migrant Resource Centre, "Arabic Cultural Profile – Older People", 2010.

⁹ Mohammad Zafir al-Shahri and Abdullah al-Khenaizan, "Palliative care for Muslim patients", *The Journal of Supportive Oncology*, Vol. 3, No. 6, Nov./Dec. 2005, pp.432-436.

¹⁰ Andrew Taylor and Margaret Box, *Multicultural Palliative Care Guidelines*, 1999.

In terminally ill patients, it may be difficult to maintain a state of equilibrium allowing for optimal symptom control and a normal level of consciousness. In these situations, the pros and cons should be clarified to the patient and family, who may prefer to endure a slightly higher degree of symptoms in order to maintain a higher level of consciousness.¹¹

Attitudes towards mental health

In Arabic-speaking background communities, mental illness is viewed in negative terms, with the resultant stigma impacting on the whole family. The communities are also characterised by their reluctance to seek professional assistance which can be attributed to a number of reasons including: stigma surrounding the person with the mental illness and their family members;; shame that the individual or family will experience; lack of awareness of mental health illnesses and mental health service providers; and traditional and cultural dependency on other sources of help such as family, religious leaders, traditional healers and Arabic-speaking doctors.¹²

Dementia is considered by many people from an Arabic-speaking background to be a normal part of ageing but is associated with mental illness. There is some reluctance in the Arabic-speaking background communities to admit to the illness and, because of the stigma, people with dementia may stay away from friends and community and become isolated. Some of the stigma is related to the word that is most commonly used in translations – “kharaf” – and in most cases the term is understood in negative terms and carries negative connotations.¹³

The main concern expressed in Arabic-speaking background communities around counselling is that they feel as if they are speaking to a ‘stranger’. Carers sometimes express a fear that they would be betraying their family members and treating them as a burden if they sought external assistance. It is therefore common that carers may resist support services and often pretend that they have more help than they actually do. Where counselling services are used, most people prefer face to face contact with someone who speaks their language and with whom they have built a relationship over some time.¹⁴

Attitudes towards care

Community care

As there is a strong preference for members of Arabic-speaking background communities to stay at home, they are likely to accept services that will help them to do so. There is, however, conflicting information as to how these services are best provided. Some people prefer the services to be provided by someone who is not from an Arabic-speaking background due to issues of privacy and shame. For others, Arabic-speaking background is necessary. Gender matching is an important requirement.¹⁵

¹¹ Mohammad Zafir al-Shahri and Abdullah al-Khenaizan, *ibid*.

¹² Patrycja Toczek, *Demystifying Mental Health in Ethnic Communities: Multicultural Mental Health Project Evaluation*, 2009, p.14.

¹³ Alzheimer’s Australia Victoria, *Perceptions of dementia in ethnic communities*, 2008.

¹⁴ Alzheimer’s Australia Victoria, *Perceptions of dementia in ethnic communities*, 2008.

¹⁵ Alzheimer’s Australia Victoria, *Perceptions of dementia in ethnic communities*, 2008.

Residential care

Placing family members in nursing homes is not an option for Arabic-speaking communities unless as a last resort. Most people perceive residential care negatively, and if they had to access it, would prefer an Arabic-speaking – specific facility. Some of these views may also be due to negative perceptions of this type of care in their country of origin and a combination of attitudes that it is not acceptable to place members of the family in such facilities.¹⁶

Attitudes towards death and dying

The news about a life-threatening illness or disease is usually first given to the family, to the closest family member to the patient. The next of kin will advise the immediate family, but perhaps advice will not be given to friends. Patients are often not told about a life-threatening illness or disease, as it is felt that to do so may exacerbate their condition. However, every family is different; if the patient wishes to know, the patient's wishes are paramount.

Family and friends are very important and are a great source of support for the patient, providing constant help and attendance. Allowance needs to be made for this in hospitals and hospices.¹⁷

Death is seen as something predestined by God and families may thus appear inappropriately calm and accepting by Western standards.

Preservation of life overrides all other matters. Islamic law permits withdrawal of futile and disproportionate treatment on the basis of consent from immediate family members who act on the professional advice of the physician in charge of the case. Once treatment has been intensified to save a patient's life, life-saving equipment cannot be turned off unless the physicians are certain about the inevitability of death.¹⁸

It is important for Muslims to recite the Qu'ran or prayers in front of the dying patient or in a room close by. For a patient who has just died, the face of the deceased person should be turned in the direction of Mecca. The whole body of the deceased person must be covered by a sheet and should be handled as little as possible. The body should be handled with the utmost respect by a person of the same sex. The body should not be washed as this will be done as part of a special religious ritual before burial. Muslim burials are performed as soon as possible after death, sometimes on the same day. Cremation is not permitted.¹⁹

Intergenerational Perspectives and the Migration Experience

The migration and settlement experience of Arabic-speaking background migrants varies greatly according to the social circumstances and the country from which they have come. In terms of total population numbers, Lebanon and Egypt continue to be the largest source countries of overseas born people from an Arabic-speaking background in Australia. Wars and other civil strife in the Middle East and North Africa affect the flow of migration to Australia and since 2006 there has been a flow of refugees coming to Australia from Iraq and Sudan.

¹⁶ Alzheimer's Australia Victoria, *Perceptions of dementia in ethnic communities*, 2008.

¹⁷ Andrew Taylor and Margaret Box, *Multicultural Palliative Care Guidelines*, 1999.

¹⁸ Islamic Council of Victoria, Muslims Australia, "Caring for Muslim Patients", 2010.

¹⁹ Islamic Council of Victoria, Muslims Australia, "Caring for Muslim Patients", 2010.

Migration from Lebanon:

- Lebanese migrants came in three waves: the first was before and after World War I due to economic factors, the second wave was the effect of World War II and the third wave was the immediate effect of the civil war in Lebanon in 1975.
- The majority of the two first waves were from Christian backgrounds with some from a Muslim background and some number from Druze (a sect that originated from Islamic religion one thousand years ago), while the majority of the third wave were from a Muslim background.
- Lebanese born and Lebanese descendants in Australia from all backgrounds now exceed 200,000. Early migrants worked in factories, as shopkeepers and in some professional positions, while a large number of recent migrants who came under the Family Reunion Program face unemployment problems. Skilled Lebanese migrants integrated well into the community and into professional work. Depending on their socio-economic background, some of the second generation young people from an Arabic-speaking background face issues that are common to Australian youth in addition to issues related to being part of a disadvantaged community.
- Arabic-speaking background migrants of the two first waves are reaching the retirement age now.

Migration from Egypt:

- Egyptian born migrants who settled here after the World War II between 1947 and 1971 were Coptic Christians with some Egyptians from European backgrounds (eg. Greeks).
- In a smaller numbers, Muslim Egyptians arrived in the 1970s and 1980s.
- Despite the fact that 90% of Egypt's population is Muslim, the majority of those who migrated here before 1976, and the more recent arrivals, are from Christian Coptic backgrounds and generally are well-educated.

Migration from Iraq:

- In recent times, Iraq has become the largest source of Arabic-speaking background migrants to Australia due to Iraq's involvement in the two Gulf wars and the recent "War on Terror".
- The majority of Iraqi migrants came under Humanitarian or Refugee Programs.
- The majority of the Iraqi population is from a Muslim background (Shia or Sunni), with smaller numbers being Kurds (Muslim Sunni), Chaldeans and Assyrians (Christian groups). However the majority of Iraqi migrants are Shia.
- The Iraqi people in Australia congregate along ethnic and religious lines rather than national lines.

Migration from Sudan:

- Over the last ten years Sudan has emerged as second to Iraq as a source of Arabic-speaking background arrivals.
- Victoria receives a disproportionate number of South Sudanese arrivals into Australia under the Refugee and Humanitarian Program.
- The percentage of Sudanese arriving under the Humanitarian Scheme is approximately 95%; the largest identified group amongst them is the Dinka.
- Other communities are the Nuer, Chollo, and sub-communities such as Equatorian and Nasir communities. Most Sudanese read and speak Arabic (Egyptian dialect), the official language of Sudan, in addition to their own tribal languages and dialects.

- The level of English proficiency is very low in general.²⁰

Intergenerational misunderstandings and conflicting expectations are common to all families and communities.²¹ Our history impacts greatly on the cultural context through which we see the world – both when we entered the world and where. Particularly for migrant communities, the differences in the experiences of one generation and another can be more pronounced, leading to more possibilities for conflict and misunderstanding.

For many first generation people from an Arabic-speaking background who have migrated to Australia, the experience of migration has given them a strong sense of independence and self-reliance in which they take great pride. It may also have been a source of stress, homesickness and isolation.

Particularly for many older members of the Arabic-speaking background communities, accepting help from external services could be felt as an admission of weakness or giving up personal independence. Service providers have also reported that there can be fears about accepting services, particularly if service providers are entering the home. Fears around being mistreated, confined, moved out of home and the cost of services can all be deterrents to accepting external support.

In turn, the second and subsequent generations growing up in Australia can feel conflicting cultural pressures and heavy family responsibilities. The children of migrants must often navigate between the competing cultural values and languages of their family and Australian society. Typically, while the older generation will idealise traditional values and practices, the younger generation will be more adaptive to dominant Australian values and customs.

Of the total Victorian population, 86.3 percent are Australian citizens. The relevant percentages of people born in Arab League of Nations countries vary by country: 87.8 percent for Lebanon-born, 86.5 percent for Egypt-born, 72 percent for Sudan-born and 67.4 percent for Iraq born.²²

There are also variable levels of English proficiency:²³

Country of birth	Lebanon %	Egypt %	Sudan %	Iraq %
Speaks English only	7.2	18.9	5	2.6
Speaks English very well or well	78.9	91.3	79.9	67.7

²⁰ South Eastern Region Migrant Resource Centre, "Arabic Cultural Profile – Older People", 2010.

²¹ Parts of this section were developed from Ethnic Communities' Council of Victoria (2009), *Respect and Dignity: Seniors, family relationships and what can go wrong*, A Greek community education resource kit around elder abuse prevention, p. 2.

²² Victorian Multicultural Commission, Community profiles 2011 Census, <http://www.multicultural.vic.gov.au/population-and-migration/victorias-diversity/community-profiles-2006-census>, accessed 27 August 2014.

²³ Victorian Multicultural Commission, Community profiles 2011 Census, <http://www.multicultural.vic.gov.au/population-and-migration/victorias-diversity/community-profiles-2006-census>, accessed 27 August 2014.

It is difficult from the available data sources to discern whether the ability to speak Arabic as a “second language” has declined in the second and subsequent generations. It is likely that the rates for fluency in Arabic vary across the Arabic-speaking background communities

A note about terminology

In the English language, words such as *grief*, *bereavement* and *illness* can have different meanings and connotations for different people. Similarly, people from ethnic backgrounds may have specific cultural values that they associate with these words. For example, some people might associate *illness* with karma or the supernatural, and discussions around possible treatment or intervention need to take this into account in order for them to be meaningful.

Words such as *grief*, *bereavement* and *illness* are used in this resource with the understanding that there will be different cultural meanings associated with them. Education sessions are intended to be delivered in participants’ first language, and therefore terms should be appropriately translated if applicable.

Educators should also be aware that in the health sector there are several terms used to describe terminal illness. Participants may have heard of some or all of the following:

- Incurable illness/condition
- Chronic and complex illness/condition
- Eventually fatal illness/condition
- Life-limiting illness/condition
- Terminal illness/condition

It is equally possible that participants have never heard these terms before and educators should consider clear and culturally appropriate ways of communicating ideas around death and illness before their session.

Chinese Community Cultural Profile

Discussing palliative care in the Chinese community

Talking about palliative care can be difficult for people from all cultures and communities. Although in the Chinese community, there is no specific taboo around talking about death, many Chinese people may be reluctant to speak about their personal experiences with illness and dying. Palliative care can produce negative feelings and trigger difficult memories. When delivering information to participants about palliative care, it is important to be respectful of their feelings and their right to privacy.

As a peer educator, it is also important to remember that learning is an active process through which people create meaning and develop understanding. The ways that participants react to new information depend on their ideas, opinions, knowledge, personal experiences, understanding of the world and their own learning style. Particularly around topics such as death and dying, participants will bring with them a whole set of cultural and social beliefs that will impact their learning experience. Education sessions are a good opportunity to raise awareness about palliative care but also to explore commonly held beliefs about health and illness and to dispel myths about palliative care.

Discussing illness, death and dying can often trigger strong emotions and feelings in people, especially if a participant has been personally impacted by it. Participants should be informed that:

- They do not need to contribute to discussion if they feel uncomfortable and are not forced to participate if they don't want to.
- They may take a break or leave the room if they feel like they need to.
- If they would like to share a story or experience they went through, they do not have to identify it as happening to them but they can say it happened to 'someone they know.'

About the Chinese Community in Australia

The Chinese speaking community is one of the largest and most diverse cultural groups in Australia, both culturally and linguistically, spanning many different countries of origin and regional dialects. The two most common 'Chinese' languages spoken in Australia are Cantonese and Mandarin and the experiences of these speaking groups will be focused on in this resource. Most Mandarin speakers living in Australia were born in China, Malaysia, Taiwan, Singapore, Indonesia, Vietnam or Hong Kong, with a significant number of Mandarin speakers born in Australia. Most Cantonese speakers who are living in Australia were born in China, Hong Kong, Malaysia, Vietnam, Singapore, Cambodia or Macau.²⁴

Chinese immigration to Australia began as early as 1818 but was seriously curtailed by the introduction of the White Australia Policy in 1901. The policy restricting the migration of non-Europeans was lifted in the 1970s, at which time the number of Cantonese speaking immigrants increased dramatically, peaking in 1989. In contrast, Mandarin speakers began arriving in the 1980s and immigration numbers have sharply increased in the last decade, from 8,670 in 2000 to 23,259 in 2010. In 2011 there were 336,409 Mandarin speakers in Australia, representing 1.6% of the entire Australian population, and 263,673 Cantonese speakers, representing 1.2% of

²⁴ SBS (2012). *SBS Census Explorer*. Accessed on February 28 2013 from <http://www.sbs.com.au/censusexplorer/>.

the entire population. Most of the Chinese speaking population is concentrated in Sydney and Melbourne.²⁵

Given their different patterns of immigration, most Cantonese speakers are Australian Citizens (79.3%) whilst around half of Mandarin speakers are not (49.8%). Although palliative care services can be relevant for any age group, both Cantonese and Mandarin communities have a significant emerging ageing population. Cantonese speaking seniors are more likely to have aged in Australia and to have citizenship than Mandarin speaking seniors who have often arrived in later life to live with their adult children.²⁶ A high proportion of Chinese speakers aged 65 years or over do not speak English well or not at all, with 76% of Mandarin speakers, 63% of Cantonese speakers and 62% of other Chinese language speakers experiencing a significant language barrier.²⁷ This is no indication of education however, given that the majority of the Chinese-speaking population has finished Year 12 or equivalent (87.1% of Mandarin speakers and 70.1% of Cantonese speakers).

There is great diversity within the Chinese speaking community, not least in relation to faith. A large number of Chinese speakers reported having no religion in the 2011 census (55.2% of Mandarin speakers and 42.5% of Cantonese speakers). However there are significant numbers of Chinese speakers who identify as Buddhists (19.6% of Mandarin speakers and 25.4% of Cantonese speakers) or who identify with some form or denomination of Christianity (approximately 14.3% of Mandarin speakers and 23.6% of Cantonese speakers).²⁸ Despite the wide diversity of spiritual perspectives, and depending on their individual views, some Chinese speakers may still observe particular religious traditions and attitudes as part of their cultural heritage.

Chinese Cultural Perspectives and Values

Within any cultural group or community, individual views and values are shaped by many factors including our age, gender, income, religion, sexuality, family background, profession, education and political views, not to mention personal experiences. Individuals from the same culture do not all think alike, or share the same value systems and opinions. Likewise, cultural values and attitudes can change over time and are never the same thing to everyone. For the Chinese speaking community in particular, shifting cultural values can become more apparent through the migration experience and there can be great difference between the views and values of two generations within the same family.

Nevertheless certain beliefs can have more influence or resonance with a cultural group and can be recognised as commonly shared or understood within a community. Individuals from that group do not need to personally agree with those values to recognise their cultural importance.

Here are a number of commonly held Chinese cultural perspectives and values that may have bearing on their response to a discussion about palliative care. Please keep in mind that these

²⁵ SBS (2012). SBS Census Explorer.

²⁶ SBS (2012). SBS Census Explorer.

²⁷ Australian Bureau of Statistics (2011). Table generated 28 February 2013 using English proficiency by age in five year groups and language spoken at home. www.abs.gov.au.

²⁸ SBS (2012). SBS Census Explorer.

perspectives will not apply to everyone in the Chinese speaking community and it is important not to make assumptions about people's values and beliefs.

Family and filial piety

Traditionally, family is highly valued in Chinese speaking cultures and care and respect for one's family is seen as a great and fundamental virtue. "Three (or sometimes five) generations under one roof" (sān dài tóng táng)²⁹ is a complimentary mainland Chinese saying used to describe a happy family and grandparents often play a key role in caring for their grandchildren (This can even be a reason for some older generation Chinese speakers to migrate to Australia).³⁰

In this sense, there is a strong expectation in traditional Chinese speaking communities that sons and daughters will respect and care for their elderly relatives. Filial piety is a highly valued and deeply ingrained cultural value that recently there have been attempts in China to legally enforce children's responsibility to care for their parents.³¹

Traditionally the responsibility of a parent's welfare falls primarily to the eldest son or daughter, who occupies a privileged position in the family. The role of the eldest son, in particular, is often valued as the head of the family and the one who will continue the family line, however day to day care, and domestic duties are still seen as the role of women in the family and are more likely to fall to the daughter(s), or daughter(s)-in-law. This can lead to tensions when, for example, parents are brought under the care of their son, but the responsibilities of daily care fall on the daughter-in-law.

While this is the traditional view, the responsibility of care depends greatly on individual circumstances. The expectations of older generation Chinese speakers in relation to family responsibility can conflict with the socio-economic pressures of younger generations, and vice versa. Nevertheless, most Chinese speaking families want to be highly involved in care and it may be important for educators to emphasise that palliative care services do not diminish family involvement in decision making or interfere with established caring roles. Because of the importance of family, many Chinese speakers will care for their loved ones at any cost, financial or personal, and it may be important for educators to make participants aware of the support that palliative care services provide to help carers in their role. Family members may feel guilt and shame that accepting palliative care is avoiding their filial responsibility and may even fear being stigmatised by the community if they access palliative care services for their loved one. If this is the case, it is important that educators emphasise that palliative care supports families to provide the best care with dignity and respect for their loved one.

Keeping face in the community

The importance of 'keeping' or 'saving face (mian/lian)' is acknowledged to a greater or lesser extent in some Chinese speaking communities. Saving face often relates to maintaining personal integrity, dignity and not bringing shame to one's family and, depending on the extent of their

²⁹ Chyi, Hau, and Shangyi Mao. "The Determinants of Happiness of China's Elderly Population." *Journal of Happiness Studies* 13.1 (2012), p. 167.

³⁰ Wong M. Bbkayi (Baby Plus 2). MCWH: Melbourne (2012), pp. 35-36.

³¹ Feng, V. "New filial piety law takes effect to much criticism in China" South China Morning post, Monday 3 July 2013, Accessed: 20 October 2013: <http://www.scmp.com/news/china/article/1273003/new-filial-piety-law-takes-effect-much-criticism-china>.

social networks in Australia or elsewhere, some Chinese speakers may feel pressure to meet social expectations that they perceive to exist in the wider Chinese speaking community. In relation to palliative care, social pressure to be dutiful to one's parents may create anxiety about accepting outside help. Carers may experience feelings of guilt or shame in relation to this issue and it may be important for educators to address these concerns and reassure participants that seeking support is not an admission of weakness or irresponsible behaviour.

Attitudes to illness and pain management

The Chinese community have high regard for the medical professions and will often place great value on the opinion of their doctor and doctors more generally. Particularly among the older generation, it would not be uncommon for Chinese speakers to have consulted Eastern medicine practitioners as well and to place great importance on the types of food they eat or drink, according to traditional Eastern philosophies of health. For some Chinese speakers, ways of describing health and illness can be quite specific to the concepts and philosophy of Eastern medicine. Some Buddhists, and some older generation Chinese speakers, may associate illness with karma and see enduring suffering as part of their spiritual journey. In some cases, and particularly amongst the older generation, this belief may affect some people's willingness to accept the idea of pain management if they feel that their suffering in some way atones for, or is a consequence of, actions in a past life. Some Chinese speakers may even feel that enduring suffering contributes to the future karma of their family.

While Chinese speakers often strongly value the opinions of their doctor, some Chinese speakers may be likely to take less than the recommended doses of prescribed medicines or to self-medicate. Educators may choose to raise this issue for discussion, if appropriate, and to emphasise to participants the importance of disclosing the use of other medicines to their doctor. It may be helpful to reassure participants that doctors will not stop them from using other herbs and medicines if they do not conflict with their prescribed medicines, but without this knowledge, other remedies can be harmful and damage their health.

It is not uncommon for families to try and keep the seriousness of an illness from their parent. This is not particular to the Chinese community, but can be motivated by the desire to keep their loved one free from worries and to ensure that they enjoy the time they have to the fullest.

Attitudes to Death and Dying

Broadly speaking, Chinese speaking cultures often have a history of taboos and superstitions around the discussion of death and dying, although this depends greatly on the individual, levels of education and whether people were raised in urban or rural environments. A lingering example is the traditional avoidance of the number four, which in both Cantonese and Mandarin, sounds similar for the word for death and is considered 'unlucky'. While superstitions such as these can be quite superficial, they indicate a strong cultural sensitivity around the issue and Chinese speakers may be reluctant or unwilling to discuss their experiences or views. Depending on their audience, educators may consider employing humour as a way of approaching the issue.

Chinese speakers confronting the death of a loved one are commonly unwilling to accept or acknowledge this possibility and will typically do anything possible to delay death. The importance of maintaining strong hope in the face of death often means that Chinese speakers will expect active or curative care to continue until the last possible minute. Although this attitude is not

particular to the Chinese speaking community alone, educators may wish to address it in relation to palliative care, which Chinese speakers may wrongly associate with giving up hope or inviting death. At the same time, it is important not to create unrealistic expectations about the role of palliative care, which does not seek to prolong life at any cost. In this regard, it may be worth emphasising the important role of palliative care services in relieving pain, without ruling out the possibility of recovery.

Despite any cultural reluctance to discuss death and dying, it is not uncommon for older Chinese speakers to have made plans for their final resting place and have clear ideas about the way they would like their affairs to be managed after their death. Particularly for those from a traditional Buddhist background, where and how one is buried can have great importance and older generation Chinese speakers may have made advanced preparations for this, with or without discussion with the family, to ensure that they will be taken care of after death.

In relation to death itself, it is difficult to generalise about whether or not Chinese speakers would prefer to die at home or not and depends greatly on the individual, the specific cultural or regional traditions of their home country and religious beliefs. Educators should be aware of the differences across Chinese speaking cultures, and may wish to raise this for discussion. Many Chinese speakers living in Australia will prioritise the level of care they or their loved one can receive during their illness and may prefer hospital or a hospice (particularly if it is ethno-specific) for that reason. Educators may want to reassure participants that some specialist palliative care nurses are available 24 hours a day if they choose to care for their loved one at home.

Attitudes towards Mental Health

Depending on their level of education and experience, there is strong stigma around mental illness amongst many Chinese speakers. This stigma may be more prevalent among older generation Chinese speakers, who are more likely to describe their mental health in terms of physical symptoms (eg. lethargy, tiredness). Some Buddhists, and some older generation Chinese speakers, may also connect mental illness with karma and see mental suffering as a test or consequence of actions in their life or past life. In general and as is the case in many cultures, Chinese speakers may feel reluctant to discuss personal issues relating to mental health outside their family circle, depending on the level of trust established with others and may be reluctant to consider counselling or other forms of support.

Many Chinese speakers living in Australia, particularly in the older generation, may lack social networks and support during the grieving process and can experience isolation and depression. Depending on their audience, educators may wish to emphasise that palliative care provides ongoing support for 12 months after someone has experienced the loss of a loved one.

Intergenerational Perspectives and the Migration Experience

Intergenerational misunderstandings and conflicting expectations are common to all families and communities.³² Our history impacts greatly on the cultural context through which we see the world – both when we entered the world and where. Particularly for migrant communities, the difference

³² 10 Parts of this section were developed from Ethnic Communities' Council of Victoria (2009), *Respect and Dignity: Seniors, family relationships and what can go wrong*, A Chinese community education resource kit around elder abuse prevention, p. 2.

in the experiences of one generation and another can be more pronounced, leading to more possibilities for conflict or misunderstanding.

Generally speaking, for first generation Chinese speaking migrants, the settlement process and lack of cultural continuity can be a difficult and isolating experience. This may be even more pronounced for older members of the community, or members of the community who do not speak English well or at all and who may be more socially and culturally isolated. In addition to this, many older generation Chinese speakers who migrate to Australia later in life may find themselves socially and financially dependent on their children, which can create additional pressures within families. A combination of these factors can erode communication and confidence levels and affect general health and mental well-being. Lack of language and limited literacy levels also contributes to lack of awareness and knowledge of available services, including where to go for help and how to get there while having to navigate through a complex and rigid system.

In turn, the second generation growing up in Australia can feel conflicting cultural pressures and family responsibilities. The children of migrants must often navigate between the competing cultural values and languages of their family and Australian society. Typically where the older generation will idealise traditional values and practices, the younger generation will be more adaptive to dominant Australian values and customs. This can create conflict and intergenerational divisions which can play out in relation to issues and expectations about care. Family dynamics are rapidly changing for many Chinese speakers, not only for those who have migrated to Australia, but in many countries of origin as well. Grandchildren increasingly adopt more Western attitudes and the divide between the traditional views and the Western views can sometimes be irreconcilable.

It is important for educators to be aware of intergenerational tensions and where appropriate, to encourage thoughtful and reflective discussion around these issues if they arise during a session

A note about terminology

In the English language, words such as *grief*, *bereavement* and *illness* can have different meanings and connotations for different people. Similarly, people from ethnic backgrounds may have specific cultural values that they associate with these words. For example, some people might associate *illness* with karma or the supernatural, and discussions around possible treatment or intervention need to take this into account in order for them to be meaningful.

Words such as *grief*, *bereavement* and *illness* are used in this resource with the understanding that there will be different cultural meanings associated with them. Education sessions are intended to be delivered in participants' first language, and therefore terms should be appropriately translated if applicable.

Educators should also be aware that in the health sector there are several terms used to describe terminal illness. Participants may have heard of some or all of the following:

- Incurable illness/condition
- Chronic and complex illness/condition
- Eventually fatal illness/condition
- Life-limiting illness/condition

Terminal illness/condition

It is equally possible that participants have never heard these terms before and educators should consider clear and culturally appropriate ways of communicating ideas around death and illness before their session.

Croatian Community Cultural Profile

Discussing palliative care in the Croatian Community

Talking about palliative care can be difficult for people from all cultures and communities. Although in the Croatian community there is no specific taboo around talking about death, many Croatian people may be reluctant to speak about their personal experiences with illness and dying. Palliative care can produce negative feelings because of its association with illness, death and dying. These negative feelings can trigger difficult memories. When delivering information to participants about palliative care, it is important to be respectful of their feelings and their right to privacy.

As a peer educator, it is important to remember that learning is an active process through which people create meaning and develop understanding. The ways that participants react to new information depend on their ideas, opinions, knowledge, personal experiences, understanding of the world and their own learning style. Particularly around topics such as death and dying, participants will bring with them a whole set of cultural and social beliefs that will impact their learning experience. Education sessions are a good opportunity to raise awareness about palliative care but also to explore commonly held beliefs about health and illness and to dispel myths about palliative care.

Discussing illness, death and dying can often trigger strong emotions and feelings in people, especially if a participant has been personally impacted by it. Participants should be informed that:

- They do not need to contribute to discussion if they feel uncomfortable and are not forced to participate if they don't want to.
- They may take a break or leave the room if they feel like they need to.
- If they would like to share a story or experience they went through, they do not have to identify it as happening to them but they can say it happened to 'someone they know.'

About the Croatian community in Victoria and Australia

Croatian migration to Australia dates back to the Australian gold rush in the 1850s, where they first settled in the Victorian goldfields. The next wave of migrants arrived prior to the first World War due to dissatisfaction with political developments at home. During this period, many Croatian migrants settled in Mildura.

Large numbers also migrated following the second World War, fleeing post-war political changes in Croatia. This group was mostly displaced persons, mainly political and economic migrants. These migrants were often well educated and had been in refugee camps.

The 1960s and 1970s were a period during which the regime of ex-Yugoslavia opened its borders to migration outside the country. While most of this migration was to Western Europe, many migrated to Australia. This was the largest wave of Croatian migration to Australia and included those who migrated for political, economic and ideological reasons as the result of high unemployment, difficult economic conditions and anti-Croatian sentiment in Yugoslavia. Most settled in industrial suburbs around Melbourne and its western suburbs as well as in country Victoria. A large Croatian community also was established in Geelong.

The Croatian migrants who arrived in the 1990s, many of them refugees, were mostly middle-aged, married and predominantly professionals. However, with 70 per cent of Australian residents

born in Croatia arriving before 1980, the level of immigration has dropped significantly in recent years and the Croatian population is ageing.³³

In the 2011 Census, Victoria and New South Wales had roughly equal concentrations of the Croatian community, with 17,248 people in Victoria, just over one third of the national total. 85 per cent of these people live in Melbourne. At the 2011 Census, 63 per cent of the Croatian population in Victoria were aged 55 or older with 25 per cent in the 65-74, and 13 per cent in the 75-84 age cohorts.

The Croatian language is thirteenth of the top twenty languages spoken at home in Victoria. 81.6 per cent of the Croatian population in Victoria assessed themselves at the 2011 Census as speaking English “very well” or “well” while 17.4 per cent assessed themselves as speaking English “not well” or “not at all”.

Croatian people in Victoria have a very high level of Australian citizenship (95.7 per cent at the 2011 Census compared to 85 per cent for the total Australian population). The Croatian population in Victoria are less geographically concentrated than many other culturally and linguistically diverse communities. Slightly more than half of the Croatian population in Victoria live in the Brimbank, Greater Geelong, Casey, Greater Dandenong, Hume, Melton, Whittlesea and Hobsons Bay Local Government Areas with only Brimbank (15.8 per cent) having more than 10 per cent of that population.³⁴

Croatian Cultural Perspectives and Values

Within any cultural group or community, individual views and values are shaped by many factors, including our age, gender, income, religion, sexuality, profession, education and political views, not to mention personal experiences. Individuals from the same culture do not all think alike or share the same value systems and opinions. Likewise, cultural values and attitudes can change over time and are never the same thing to everyone.

For the Croatian community, shifting cultural values can become more apparent through the migration experience and there can be great differences between the views and values of two generations within the same family. For older generation migrants in particular, some traditional views and attitudes may have been preserved despite changing attitudes and practices in Croatia. In this sense, despite close ties with Croatia, Croatian culture as it exists in Australia can not necessarily be generalised from contemporary Croatian culture or with Croatian communities living in other parts of the world.

Nevertheless, certain beliefs can have more influence or resonance with a cultural group and can be recognised as commonly shared or understood within a community. Individuals from that group do not need to personally agree with those values to recognise their cultural importance.

³³ This migration history was derived from the following sources: “Croatian Cultural Profile”, Diversicare Qld, 2011; “Croatian Cultural Profile”, Migrant Information Centre (Eastern Melbourne), May 2012; “Croatian Cultural Profile”, Sydney Multicultural Community Services, 2011; Silvana Pavlovski, “Croatian Community brochure”, Australian Croatian Community Services, 2010; “Croatian Resource Manual”, Australian Croatian Community Services, 2014.

³⁴ Office of Multicultural Affairs and Citizenship [Victoria], *Victorian Community Profiles: 2011 Census Croatia-Born*, 2013; Office of Multicultural Affairs and Citizenship [Victoria], “The Croatia-Born Community in Victoria: 2011 Census, Fact Sheet Number A-18”, 2013.

Here are a number of commonly held Croatian cultural perspectives and values that may have bearing on their response to a discussion about palliative care. Please keep in mind that these perspectives will not apply to everyone in the Croatian community and it is important not to make assumptions about people's values and beliefs.

Community and Religion

In the 2011 Census, the major religious affiliations amongst the Croatian in Victoria were Catholic (78.9 per cent) Serbian Orthodox (6.6 per cent) and Eastern Orthodox (3.1 per cent). 4.5 per cent stated "no religion", which was lower than that of the total Victorian population (20.4 per cent).³⁵

For Croatian Catholics, particularly those who are elderly, their daily life may be closely linked with the Catholic Church. There are Croatian Catholic Centres in Clifton Hill, Sunshine, Keysborough and Geelong.

Most young people are baptized and most marriages are conducted in a church. Most families observe Catholic rites of passage, including Baptism, First Communion, Confirmation and Marriage ceremonies in the church. When a family member dies, the usual rituals of Roman Catholicism prevail. It is also a custom for the relatives to wear black clothing as a symbol of mourning.

Croatian Catholics are especially devoted to the Virgin Mary and the Feast of Our Lady (first Sunday in May) is an important celebration to many elderly Croatians. All Saint's Day (1 November) was the only Catholic holiday that was celebrated by most of the ethnic groups in the former Yugoslavia and it is still a very important observance in the Croatian community. Families wash and prepare graves, and decorate them with candles, flowers and photographs.³⁶

Family

The Croatian community is quite family centred and the family is still the basis of the social structure. The extended family is still the norm and relatives remain quite close with both the mother's and the father's sides. The family provides its members with a social network and assistance in times of need. While the nuclear family is becoming increasingly popular, Croatians still prefer to look after their elderly parents rather than send them to a nursing home.³⁷

In Australia, children are often unable to meet these expectations, due to longer distances between family members and greater commitments of the children. This may cause considerable stress and conflict in the family.

Attitudes to illness and pain management

Generally, Croatian-born Australians value their health and seek medical attention when required, however preventative health measures may not always be adopted.

³⁵ Office of Multicultural Affairs and Citizenship [Victoria], *Victorian Community Profiles: 2011 Census Croatia-Born*, 2013.

³⁶ Sydney MCS, "Croatian Cultural Profile".

³⁷ Diversicare, "Croatian Cultural Profile", 2011.

Many elderly Croatian-born Australians have little or no knowledge of anatomy or how their bodies work and, due to English language difficulties, medical terms, procedures and illnesses may need to be explained clearly with the assistance of an interpreter or younger family member.

Traditionally, doctors and general practitioners are well respected and given great authority. Many people rely on their doctors for information, assistance and referrals. Most Croatians will follow the advice of doctors and comply with medical treatments. Some problems can occur with elderly Croatian people over-medicating or not complying with long-term use of their medications.³⁸

Herbal medicines, massage and faith healers were traditionally used in Croatia and some older Croatian people may prefer to turn to these treatments initially.

Croatian people tend to openly discuss their physical ailments and health conditions. For some elderly Croatian people, there may be a fear of admitting their illness and pain in case the doctor suggests residential care or support.

There are mixed attitudes amongst Croatians toward taking strong pain relieving medication such as morphine. Medicine is a normal part of life, but giving morphine is usually seen as a sign that 'the end is near' which can increase anxiety. Patients and families will usually accept the use of opioids for symptom control if the rationale is clearly explained to them. Palliative care services should use a qualified interpreter for this conversation with the patient and family.³⁹

Traditionally, in Croatia, the patient was almost never told about a diagnosis of a life-limiting illness and this information was given to their family. For many families, it is still preferable to share a serious diagnosis such as a terminal illness with loved ones, as opposed to the loved ones being told by a doctor. However, attitudes to this issue are changing. Every family is different and if the patient wishes to know, the patient's wishes are paramount. The family will usually be involved in decision-making about treatment.

Palliative care services are used to dealing sensitively with the patient's and family's wishes in relation to disclosure.

Most elderly Croatian people are unaware of palliative care and may be reluctant to talk about it. Palliative care was not available in Croatia prior to 1990.

Attitudes towards mental health

Many Croatians experienced trauma in the Second World War or in the more recent conflicts in Croatia. In some cases, this trauma has never been addressed. Many elderly Croatians experience depression and a high number suffer with paranoia due to language barriers, social isolation and the difficulties experienced in settling in to a new culture. Mental illness was traditionally associated with social stigma but this is changing.

There may be the view that medication is the only treatment and psychotherapy, group therapy, occupational therapy or counselling may be rejected.

³⁸ Diversicare, "Croatian Cultural Profile", 2011

³⁹ ACCS, "Croatian Resource Manual" 2014.

Because mental health issues carry a lot of stigma and are not openly discussed in the community, people suffering from mental illness or dementia will not discuss their problems openly in the community. The stigma attached to poor mental health or dementia can result in significant isolation for both the individual and their immediate family.⁴⁰

Counselling is often considered to be something that people accept when they are suffering from a mental illness so there may be the response that support from palliative care counsellors is not necessary because the person or family members are 'not crazy'. Counselling services are more likely to be used by subsequent generations of Croatian migrants. If they are to be used by the Croatian elderly, they would need to be provided in their language and in a face to face setting.⁴¹

Attitudes towards care

Family still remains the main support network for elderly members of the community but this is increasingly being supplemented by external services. There may be some reluctance to use family members to provide personal care – this is an intergenerational issue. Croatians are open to using community services to remain in their homes for as long as possible. This is especially the case as there is a growing realisation that the children are no longer able to care for their parents and this type of assistance is necessary to avoid going into a nursing home.⁴²

The gender of the care worker is also an issue and there is a strong preference for female workers due to the belief that cleaning, washing and domestic duties are 'women's jobs'. There are also gender issues in relation to the provision of personal care and it is inappropriate for a male worker to assist a female client with personal care.

Residential care is viewed negatively in the Croatian community. There are no Croatian-specific facilities in Victoria and there is a strong fear of isolation if the person is placed in a non-Croatian speaking facility. Because there were limited services for the aged in Croatia, residential care was rare and was seen as institutionalisation and not the right thing to do to a family member.⁴³

Attitudes towards death and dying

For many Croatians of the Catholic faith, death is a time to observe religious rituals and rites. Traditionally, a twenty-four hour vigil is held at the bedside of the dying person. One of the main rituals performed at the time of dying is the administering of the last rites. A Croatian priest is generally invited to pray with the relatives and anoint the dying person. The family may wish to bathe and dress the deceased person in clothes selected by the family before the body is moved to the funeral home.

In accordance with Roman Catholic tradition, most Croatians prefer to be buried. However, some Croatians request to be cremated and have their ashes returned to family plots in Croatia.⁴⁴

Mourners wear black clothes for forty days, but in some cases for a year, or life.

⁴⁰ MICE, "Croatian Cultural Profile", 2012.

⁴¹ Alzheimer's Australia Victoria, *Perceptions of dementia in ethnic communities*, 2008.

⁴² ACCS "Croatian Resource Manual", 2014.

⁴³ Alzheimer's Australia Victoria, *Perceptions of dementia in ethnic communities*, 2008.

⁴⁴ ACCS, "Croatian Resource Manual", 2014.

Intergenerational Perspectives and the Migration Experience

Intergenerational misunderstandings and conflicting expectations are common to all families and communities.⁴⁵ Our history impacts greatly on the cultural context through which we see the world – both when we entered the world and where. Particularly for migrant communities, the differences in the experiences of one generation and another can be more pronounced, leading to more possibilities for conflict and misunderstanding.

For many first generation Croatian people who have migrated to Australia, the experience of migration has given them a strong sense of independence and self-reliance in which they take great pride. It may also have been a source of stress, homesickness and isolation.

Particularly for many older members of the Croatian community, accepting help from external services could be felt as an admission of weakness or giving up personal independence. Service providers have also reported that there can be fears about accepting services, particularly if service providers are entering the home. Fears around being mistreated, confined, moved out of home and the cost of services can all be deterrents to accepting external support.

In turn, the second and subsequent generations growing up in Australia can feel conflicting cultural pressures and heavy family responsibilities. The children of migrants must often navigate between the competing cultural values and languages of their family and Australian society. Typically, while the older generation will idealise traditional values and practices, the younger generation will be more adaptive to dominant Australian values and customs.

Not surprisingly, given the tendency of Croatian migrants to assimilate more easily than many other migrant groups, the ability to speak Croatian as a “second language” has declined in the second and subsequent generations.

A note about terminology

In the English language, words such as *grief*, *bereavement* and *illness* can have different meanings and connotations for different people. Similarly, people from ethnic backgrounds may have specific cultural values that they associate with these words. For example, some people might associate *illness* with karma or the supernatural, and discussions around possible treatment or intervention need to take this into account in order for them to be meaningful.

Words such as *grief*, *bereavement* and *illness* are used in this resource with the understanding that there will be different cultural meanings associated with them. Education sessions are intended to be delivered in participants’ first language, and therefore terms should be appropriately translated if applicable.

Educators should also be aware that in the health sector there are several terms used to describe terminal illness. Participants may have heard of some or all of the following:

- Incurable illness/condition
- Chronic and complex illness/condition
- Eventually fatal illness/condition

⁴⁵ Parts of this section were developed from Ethnic Communities’ Council of Victoria (2009), *Respect and Dignity: Seniors, family relationships and what can go wrong*, A Greek community education resource kit around elder abuse prevention, p. 2.

Life-limiting illness/condition

Terminal illness/condition

It is equally possible that participants have never heard these terms before and educators should consider clear and culturally appropriate ways of communicating ideas around death and illness before their session.

Greek Community Cultural Profile

Discussing palliative care in the Greek Community

Talking about palliative care can be difficult for people from all cultures and communities. Although in the Greek community there is no specific taboo around talking about death, many Greek people may be reluctant to speak about their personal experiences with illness and dying. Palliative care can produce negative feelings because of its association with illness, death and dying. These negative feelings can trigger difficult memories. When delivering information to participants about palliative care, it is important to be respectful of their feelings and their right to privacy.

As a peer educator, it is important to remember that learning is an active process through which people create meaning and develop understanding. The ways that participants react to new information depend on their ideas, opinions, knowledge, personal experiences, understanding of the world and their own learning style. Particularly around topics such as death and dying, participants will bring with them a whole set of cultural and social beliefs that will impact their learning experience. Education sessions are a good opportunity to raise awareness about palliative care but also to explore commonly held beliefs about health and illness and to dispel myths about palliative care.

Discussing illness, death and dying can often trigger strong emotions and feelings in people, especially if a participant has been personally impacted by it. Participants should be informed that:

- They do not need to contribute to discussion if they feel uncomfortable and are not forced to participate if they don't want to.
- They may take a break or leave the room if they feel like they need to.
- If they would like to share a story or experience they went through, they do not have to identify it as happening to them but they can say it happened to 'someone they know.'

About the Greek community in Victoria and Australia

The Greek community is one of the most established cultural groups in Australia. Greeks have settled in Australia since the 1860s gold rushes. In 2011, there were 252,217 Greek speakers in Australia, representing 1.2% of the entire population.⁴⁶

The early 20th Century onwards saw the number of Greek people in Australia grow through chain migration. The expulsion of Greeks from Asia Minor (the then Ottoman Empire and now modern day Turkey) in 1922-23 and immigration quotas imposed by the United States in the early 1920s contributed to a large increase of migration of Greeks to Australia during this period.

Migration to Australia again increased after World War Two, a period of great hardship and civil division in Greece. The aftermath of WW2 and the Civil War plunged Greece into severe economic depression and bitter political conflict. Emigration was actively encouraged by the Greek Government struggling to rebuild the country. In 1952 migration of Greeks to Australia increased when the Australian Government provided assisted passage to tens of thousands of Greeks. The arrival of Greek Cypriots in Australia after the conflict in Cyprus in 1974 represented

⁴⁶ SBS (2012). *SBS Census Explorer: Greek*. Accessed on 16 June 2014 from <http://www.sbs.com.au/yourlanguage/greek/censusexplorer>.

the last large-scale migration of Greeks to Australia. However, since the global financial crisis and the downturn in the Greek economy, Net Overseas Migration from Greece (migration arrivals from Greece less migration departures to Greece) has increased over the past three years for which data is available from the Department of Immigration and Border Protection (2009-10 – 151, 2010-11 – 315, and 2011-12 – 1193) and it is likely that this trend will continue at least over the next few years.⁴⁷

The Greek community in Melbourne is one of the largest outside Greece. At the 2011 Census, Victoria had the largest concentration of the Greek community; 50% of the national total.⁴⁸ The population throughout Australia has been decreasing, due to ageing, some return migration and lack of new arrivals.

The Greek community has a very high level of Australian citizenship (96.8 per cent at the 2011 Census compared to 84.9 per cent for the total Australian population).⁴⁹ Notwithstanding the high level of citizenship and broad participation in all professional spheres from law to sports; Greeks have also sought to preserve their own cultural heritage. They have established churches, schools, media outlets, cultural associations and welfare and residential care services.

Half of the Greek-born population in Victoria live in the following local government areas: Darebin, Monash, Whittlesea, Moreland, Manningham, Kingston, Brimbank and Glen Eira (all having between 10 per cent and 4 per cent of the Greek population).⁵⁰

Greek Cultural Perspectives and Values

Within any cultural group or community, individual views and values are shaped by many factors, including our age, gender, income, religion, sexuality, profession, education and political views, not to mention personal experiences. Individuals from the same culture do not all think alike or share the same value systems and opinions. Likewise, cultural values and attitudes can change over time and are never the same thing to everyone.

For the Greek community, shifting cultural values can become more apparent through the migration experience and there can be great differences between the views and values of two generations within the same family. For older generation migrants in particular, some traditional views and attitudes may have been preserved despite changing attitudes and practices in Greece. In this sense, despite close ties with Greece, Greek culture as it exists in Australia can not necessarily be generalised from contemporary Greek culture or with Greek communities living in other parts of the world.

⁴⁷ Migrant Information Centre (Eastern Melbourne), "Greek Cultural Profile", 2010.

⁴⁸ Office of Multicultural Affairs and Citizenship (Victoria) (2013). *Victorian Community Profiles: 2011 Census Greece-Born*. Accessed 16 June 2014 at <http://www.multicultural.vic.gov.au/images/stories/documents/2013/Censusfactsheetscommunityprofiles/communityprofiles/07-greece.pdf>

⁴⁹ SBS (2012). *SBS Census Explorer*.

⁵⁰ Office of Multicultural Affairs and Citizenship [Victoria], "The Greece-Born Community in Victoria: 2011 Census, Fact Sheet Number A-7", 2013.

Nevertheless, certain beliefs can have more influence or resonance with a cultural group and can be recognised as commonly shared or understood within a community. Individuals from that group do not need to personally agree with those values to recognise their cultural importance.

Here are a number of commonly held Greek cultural perspectives and values that may have bearing on their response to a discussion about palliative care. Please keep in mind that these perspectives will not apply to everyone in the Greek-speaking community and it is important not to make assumptions about people's values and beliefs.

Community and Religion⁵¹

Many Greek values are based on the individual in relation to the family, the local community and the wider society. Western notions of privacy, individuality, personal conscience and independent decision-making differ from the traditional Greek sense of the individual. The expectations of immediate and extended family as well as members of a person's broader community (village, neighbourhood and church congregation) determine the person's behaviour and responsibilities. Greek culture emphasizes the communal and public rather than the private sphere. For many Greek immigrants, especially the elderly, their identity is closely tied to their behaviour within the communal and public spheres. The values which stem from this understanding of the individual revolve around the ways in which a person behaves and presents to others.

The majority of Greeks belong to the Greek Orthodox Christian Church. 91 per cent of Greek people in Victoria identify as being Greek Orthodox (Victorian Multicultural Commission 2013). Most Greek celebrations and customs have their foundations in Greek Orthodoxy. Religion is a stronger influence with older Greeks than with the younger generation. Respecting the Greek belief system and spirituality is considered important in developing a good relationship.

Icons are significant religious symbols in Orthodoxy and Greek people pay honour to icons and usually have them in their homes. Icons and mirrors in the home are covered during the first few days of mourning as a sign of respect.

Fasting is an essential part of the Orthodox religion. Fasting from food means abstinence from meats, oil, and dairy products. It is customary to fast for 40 days prior to midnight on Easter Saturday. During Lent in the Easter period, Greeks spring-clean their homes and properties in preparation for Holy Week.

Family

Family relationships are very important to the Greek population. The family has a strong role in decision-making regarding the care of elderly people. A patriarchal social structure is the norm, where Greek fathers are the protector, provider and authority in the family and Greek mothers are expected to take care of their children and honour their husband.

Traditionally, the children and family members care for the elderly at home where possible. However it is no longer customary for Greek families in Australia to live together as an extended family unit and many elderly people live alone. There are some taboos around residential care

⁵¹ This section compiled with information from Diversicare, "Greek Cultural Profile", 2006; MIC, "Greek Cultural Profile", 2010; Greek Care, "Greek Culture and Tradition". www.greekcare.org.au/advice-and-information/greek-culture-and-tradition accessed on 2 September 2014.

which can be seen as degrading to the care recipient. However this is changing as Greek-specific aged care services have been developed that are culturally responsive and sensitive.

Women usually take on the role of caring for older Greek people and this can lead to isolation as they are willing to sacrifice their own needs to be a carer.

Attitudes to illness and pain management

Greek Australians tend to seek out doctors who understand their language and culture. In cases of terminal illness, there is a tendency to avoid telling the ill person that they are dying. A small number of older Greek people may still practice cupping and this produces round bruises. It is important not to mistake the resulting marks as a sign of abuse.⁵²

Greek people will access pain relieving medication and use it when needed. Patients and families will usually accept the use of opioids for symptom control if the rationale is clearly explained to them – that the purpose for the treatment is to relieve the person's suffering. Palliative care services should use a qualified interpreter for this conversation with the patient and family.

Attitudes towards mental health

Older members of the Greek community may regard disability as embarrassing and a cultural stigma is attached to mental illness in particular. Older Greek people tend to suffer more from depression and anxiety when they have migrated. Greek women are more at risk than Greek men. Older Greeks may be reluctant to access mental health services as there is a general lack of understanding of mental health issues. "Depression" is not understood to be a mental illness. Dementia is not easy to discuss.⁵³

Attitudes towards care

Considering that elderly Greeks still rely heavily on the family for assistance, there is still some reluctance to use external services. This is especially the case with services provided by mainstream organisations. However, there is a growing acceptance of community services that enable the person to stay at home for as long as possible. Greek-speaking workers are preferred but non-Greek speaking workers are also accepted. As dependency increases, it is usually the spouse who provides the care.⁵⁴

Residential care is seen only as a last resort, reserved for people who are alone and have no family members to take care of them. There is a prevailing perception that the person deteriorates much more rapidly when they are placed in residential care than when they are cared for at home.

It is however important to note that, once again, these attitudes may vary across different generations of Greek-speakers and some community members may feel comfortable in placing family members in care provided that they are satisfied with the quality of care provided.

The economic crisis in Greece is having a significant impact on the country's hospitals where budgets have been slashed by more than half with the effects flowing through to staffing ratios, the availability of pharmaceuticals and medical supplies. As a result families in Greece may be the main source of personal care for hospital inpatients and may expect to provide a similar service in

⁵² MIC, "Greek Cultural Profile", 2010.

⁵³ South Eastern Region Migrant Resource Centre, "Greek Cultural Profile – Older People", 2010.

⁵⁴ Alzheimer's Australia Victoria, "Perceptions of dementia in ethnic communities", 2008.

Australia. The community information sessions about palliative care should emphasise that, if the family does desire to care for the person with a life-limiting illness, palliative care can assist the family to care for the person at home.

Attitudes to death and dying⁵⁵

For most Greeks, the beliefs, rituals and traditions surrounding death and mourning are founded in the Greek Orthodox religion. For many, following the traditions practised in their homeland is important. Family members and loved ones often consult their local priest and other relatives to ensure that these traditions are followed appropriately.

For Greek migrants who arrived in Australia as children, knowledge of the traditions may come from early memories of funerals and memorials in their village or town. They may remember vigils in family homes where for 24 hours women would wail funeral dirges over the body of the deceased. Although this ritual is not followed by Greek Australians today, many traditional beliefs and customs remain important.

The notion of the eternal life of the soul and the integrity of the body underpins many of the traditions surrounding death and mourning. For example, traditionally cremation was forbidden as it represents the destruction of the eternal physical body. However, cremation is becoming more common although this would usually be done in accordance with a written request from the person that they be cremated.

Icons and mirrors in the home are covered during the first few days of mourning as a sign of respect. Following a death, a "kandilo" (a religious burner comprising oil, water and a floating wick) must remain lit for 40 days next to an icon and a photo of the deceased until the soul leaves this world. The wearing of black in mourning is still very prevalent, particularly by older women.

In the Orthodox tradition, funerals and memorial services are both significant. The most widely observed memorial service, *Mnimosyno*, is held on the Sunday closest to the fortieth day after the death. Memorial services may also be held three, six and nine months after the death and on the anniversary of the death. Just after those dates would be an appropriate time for palliative care services to make follow-up bereavement calls.

In the past, many Greek people were very sensitive about death and dying issues so it was very common that Greek families did not want the dying person to be told of their diagnosis and prognosis, believing that it would only burden the dying person further. Greek families preferred to be informed first of the diagnosis and then decide if the ill person should be told. In those cases it might be the eldest son who would tell his parents of the diagnosis. However, attitudes to this issue are changing and this issue should be discussed with the family to ascertain their views. Every family is different and if the patient wishes to know, the patient's wishes are paramount.

⁵⁵ Greek Care, "Death and Mourning", www.greekcare.org.au/advice-and-information/greek-culture-and-tradition/death-and-mourning, accessed 2 September 2014.

Intergenerational Perspectives and the Migration Experience

Intergenerational misunderstandings and conflicting expectations are common to all families and communities.⁵⁶ Our history impacts greatly on the cultural context through which we see the world – both when we entered the world and where. Particularly for migrant communities, the differences in the experiences of one generation and another can be more pronounced, leading to more possibilities for conflict and misunderstanding

The majority of Greek migration to Australia occurred in the 1950s, 1960s and 1970s. Most Greeks left their homeland for economic reasons, some for political reasons and others for educational opportunities. Many of those migrating were unskilled and had no knowledge of the English language. Many older Greek people have established their own small businesses. Second generation Greeks have much higher levels of education. The Greek community has a strong ability to maintain a bicultural identity after migration.

As a result of hard work most Greek migrants purchased their own home. Parents emphasized their children's education so they might take on more skilled occupations. Australia's multicultural policies also enhanced the lot of the second generation. There are significant contrasts between the first and second generation Greeks, for example, language, level of integration/assimilation and the ability to negotiate social institutions and social systems.

For many first generation Greek people who have migrated to Australia, the experience of migration has given them a strong sense of independence and self-reliance in which they take great pride. It may also have been a source of stress, homesickness and isolation.

In turn, the second and subsequent generations growing up in Australia can feel conflicting cultural pressures and heavy family responsibilities. The children of migrants must often navigate between the competing cultural values and languages of their family and Australian society. Typically, while the older generation will idealise traditional values and practices, the younger generation will be more adaptive to dominant Australian values and customs. For example, for many second generation Greek Australians, gender roles are less sharply drawn, especially in 'mixed' marriages. However, women have continued to be the primary care givers in the home for their elderly relatives and in-laws.

A note about terminology

In the English language, words such as *grief*, *bereavement* and *illness* can have different meanings and connotations for different people. Similarly, people from ethnic backgrounds may have specific cultural values that they associate with these words. For example, some people might associate *illness* with karma or the supernatural, and discussions around possible treatment or intervention need to take this into account in order for them to be meaningful.

Words such as *grief*, *bereavement* and *illness* are used in this resource with the understanding that there will be different cultural meanings associated with them. Education sessions are intended to be delivered in participants' first language, and therefore terms should be appropriately translated if applicable.

⁵⁶ Parts of this section were developed from Ethnic Communities' Council of Victoria (2009), *Respect and Dignity: Seniors, family relationships and what can go wrong*, A Greek community education resource kit around elder abuse prevention, p. 2.

Educators should also be aware that in the health sector there are several terms used to describe terminal illness. Participants may have heard of some or all of the following:

Incurable illness/condition

Chronic and complex illness/condition

Eventually fatal illness/condition

Life-limiting illness/condition

Terminal illness/condition

It is equally possible that participants have never heard these terms before and educators should consider clear and culturally appropriate ways of communicating ideas around death and illness before their session.

Italian Community Cultural Profile

Discussing palliative care in the Italian community

Talking about palliative care can be difficult for people from all cultures and communities. Although in the Italian community, there is no specific taboo around talking about death, many Italian people may be reluctant to speak about their personal experiences with illness and dying. Palliative care can produce negative feelings and trigger difficult memories. When delivering information to participants about palliative care, it is important to be respectful of their feelings and their right to privacy.

As a peer educator, it is also important to remember that learning is an active process through which people create meaning and develop understanding. The ways that participants react to new information depend on their ideas, opinions, knowledge, personal experiences, understanding of the world and their own learning style. Particularly around topics such as death and dying, participants will bring with them a whole set of cultural and social beliefs that will impact their learning experience. Education sessions are a good opportunity to raise awareness about palliative care but also to explore commonly held beliefs about health and illness and to dispel myths about palliative care.

Discussing illness, death and dying can often trigger strong emotions and feelings in people, especially if a participant has been personally impacted by it. Participants should be informed that:

- They do not need to contribute to discussion if they feel uncomfortable and are not forced to participate if they don't want to.
- They may take a break or leave the room if they feel like they need to.
- If they would like to share a story or experience they went through, they do not have to identify it as happening to them but they can say it happened to 'someone they know.'

About the Italian Community in Victoria and Australia

The Italian speaking community is one of the most established cultural groups in Australia. In 2011 there were 299,833 Italian speakers in Australia, representing 1.4% of the entire population.⁵⁷ Of that number, around 41% (124,858) Italian speakers live in Victoria.⁵⁸ 49.9% of Italian speakers were born in Italy, with the majority of Italian migrants coming from Sicily, Calabria, Veneto and Campania.

There is a long history of Italian migration to Australia, beginning in the late nineteenth century. However, the largest wave of migration from Italy occurred post World War II and in the following decades, with the number of Italian migrants rising from 33,632 in 1947 to 289,476 in 1971.⁵⁹ The majority of Italian migrants in this period came from rural and farming areas in Sicily, Calabria, Veneto and Campania. These areas were often economically poor and provided limited access to education.

⁵⁷ SBS. (2012). *SBS Census Explorer: Italiano*. Accessed on July 12 2013 from <http://www.sbs.com.au/yourlanguage/italian/censusexplorer>.

⁵⁸ ABS. (2011) *2011 Census of Population and Housing Expanded Community Profile based on place of usual residence: Victoria*, Cat. No. 2005.0.

⁵⁹ Parts of this section are taken directly from Co.As.It (2008). *A Profile of Italian Australian Culture for Aged Care Service Providers*, p.6.

The Italian-speaking community has a significant ageing demographic with 111,361 Italian speakers reported being 65 years or older in 2011.⁶⁰ In Victoria, 45,399 Italian speakers were over 65. For a variety of reasons, older Italians may not speak English well or at all, and may also speak standard Italian as their second language, preferring a regional or local dialect as their first language. Many Italians migrated before English proficiency was necessary to migrate to Australia and before English classes were provided or made easily accessible. In 2011, 19,466 Italian speakers in Victoria reported not speaking English well or at all.

Many Italian speakers living in Victoria, and older migrants in particular, have maintained strong links with their culture, language, heritage and community as an essential part of their sense of identity and wellbeing. Nationally, a large majority of Italian speakers identify themselves as being Roman Catholic (89.0%).⁶¹

Italian Cultural Perspectives and Values

Within any cultural group or community, individual views and values are shaped by many factors including our age, gender, income, religion, sexuality, profession, education and political views, not to mention personal experiences. Individuals from the same culture do not all think alike, or share the same value systems and opinions. Likewise, cultural values and attitudes can change over time and are never the same thing to everyone.

Nevertheless certain beliefs can have more influence or resonance with a cultural group and can be recognised as commonly shared or understood within a community. Individuals from that group do not need to personally agree with those values to recognise their cultural importance.

Particularly for those older generation Italians who migrated in the 50s and 60s, Italian Australians often strongly identify with the regional culture, heritage and language in which they grew up. Significant differences in cultural attitudes can exist between these regions, and can vary depending on levels of education and urban and rural settings. For older generation migrants in particular, some traditional views and attitudes may have been preserved despite changing attitudes and practices in their home country. In this sense, despite close ties with Italy, Italian culture as it exists in Australia can not necessarily be generalised from contemporary Italian culture or with Italian communities living in other parts of the world.

The following are a number of commonly held Italian Australian cultural perspectives and values that may have bearing on responses to a discussion about palliative care in this community. Please keep in mind that these perspectives will not apply to everyone in the Italian speaking community and it is important not to make assumptions about people's values and beliefs.

Community & Religion

Italians tend to be highly social and there is a strong sense of community amongst Italian speakers in Australia, with many well established community organisations that keep the Italian community connected. Religion, in particular, plays a strong social as well as spiritual role in the lives of many Italian Australians with a large majority of Italian speakers identifying themselves as Western or Roman Catholic. Even for nominal or non-practicing Catholics, traditional religious celebrations and rituals are central to Italian cultural life and there is an expectation that these would be

⁶⁰ SBS. (2012). *SBS Census Explorer*.

⁶¹ This category is usually referred to as Western Catholic in the 2011 Census.

observed (eg. weddings, funerals, christenings). Often religion becomes increasingly important to Italian Australians as they age and religious mass plays an important social role for Italian communities.

Family⁶²

Family plays a central role for Italian-Australians and tends to be involved at all stages of decision making and social life. Because of the value Italian communities place on family, it is often assumed that caring roles should be taken on by family members and there is an expectation among many older family members that the family will deal with most issues and that they do not need outside assistance or services.

Women in the family are traditionally expected to be the primary care givers, whether they be the wife, mother, daughter or daughter in-law. However, family involvement in daily life is often a constant and responsibility in caring for loved ones is shared to a greater or lesser extent. This can include extended family and uncles, aunts, cousins and family friends are often regular visitors. It may be important for educators to emphasise that palliative care services work with families to enable people with terminal illness to continue to enjoy their lives with as little interruption as possible. Family involvement is not diminished by the use of palliative care and there is no obligation involved in using services.

Attitudes to illness and pain management

The medical profession is highly regarded in the Italian community, and their opinion carries great authority. It is not uncommon for Italian speakers to have long established and trusted relationships with their GP and to share trusted GPs with family and friends.

While it is common for people in the Italian community to discuss their general health, serious illness is rarely discussed openly, and is often referred to in general terms (for example, as 'una brutta malattia' or "un brutto male").

It is not uncommon for families to downplay the seriousness of an illness with their parent or loved one, and to avoid discussing the nature of the illness directly with them. This is not particular to the Italian community, and can be motivated by the desire not to upset their loved one, to hope for their recovery, to avoid emotionally painful situations and to ensure that their loved one enjoys the time they have to the fullest and in comfort. Participants should be assured that the palliative care team have a lot of experience in negotiating similar situations with care and sensitivity, and will respect the wishes of the family and their loved one.

Attitudes towards mental health

There is a strong stigma around mental health issues in the Italian community in Australia and among many older generation Italians, counselling is a completely foreign concept. Because of their unfamiliarity with ideas about mental health, older generation Italians experiencing depression or other personal issues associated with grief, loss or the demands of caring may be unable to identify or express their need for support. While women in the community tend to have

⁶² Parts of this section are taken from Co.As.It. (2008) *Profile of Italian Australian Culture for Aged Care Service Providers*, Co.As.It. Sydney, It.So.Wel. Wollongong, St. Carthages Lismore.

strong support networks amongst their female friends, there is a strong culture amongst men of not speaking about their personal feelings and a tendency to avoid admitting weakness or vulnerability. Although attitudes are changing, many Italian speakers would be reluctant to consider counselling, and may be more likely to describe their emotional or mental state in terms of physical symptoms, such as nerves (*nerve*). In this regard, Italian Australians may be more likely to seek medication from a doctor to treat mental health issues. If appropriate, it may be worth discussing the stigma around mental illness and explaining the importance of mental health and wellbeing for carers and families in supporting their loved ones effectively.

Attitudes to Death and Dying

Being a predominantly Roman Catholic culture, Italians in Australia do not have specific taboos around discussing death and dying in abstract terms, and it is common for many older Italians to have made some arrangements for their final resting place such as investing in burial plots. Religion often plays an increasingly important role for many Italians as they age and observing traditional Catholic practices and rites is usually an important consideration for someone who is nearing the end of life.

The notion that the death of a loved one can leave an *impressione* where they died can sometimes lead to reluctance or anxiety about whether or not it is good for a loved one to die at home. While this attitude depends on the individual, it may be worth raising this issue with participants and the fact that dying at home was a very common traditional practice in Italy.

Intergenerational Perspectives and the Migration Experience

Intergenerational misunderstandings and conflicting expectations are common to all families and communities.⁶³ Our history impacts greatly on the cultural context through which we see the world – both when we entered the world and where. Particularly for migrant communities, the difference in the experiences of one generation and another can be more pronounced, leading to more possibilities for conflict or misunderstanding.

For many first generation Italians who have migrated to Australia, the experience of migration has given them a strong sense of independence and self-reliance in which they take great pride. It may also have been a source of stress, homesickness and isolation. Many older generation Italian Australians express great nostalgia for their past, and idealise the lifestyle and traditional values of their home country and regional community.

Particularly for older members of the Italian community, accepting help from external services could be felt as an admission of weakness or giving up personal independence. Service providers have also reported that there can be fears about accepting services, particularly if service providers are entering the home.⁶⁴ Fears around being mistreated, confined or the cost of services can all act as deterrents to accepting external support.

In turn, the second generation Italians growing up in Australia can feel conflicting cultural pressures and heavy family responsibilities. The children of migrants must often navigate between

⁶³ Parts of this section were developed from Ethnic Communities' Council of Victoria (2009), *Respect and Dignity: Seniors, family relationships and what can go wrong*, A Chinese community education resource kit around elder abuse prevention, p. 2.

⁶⁴ Co.As.It (2008). *A Profile of Italian Australian Culture for Aged Care Service Providers*, p.3.

the competing cultural values and languages of their family and Australian society. Typically where the older generation will idealise traditional values and practices, the younger generation will be more adaptive to dominant Australian values and customs. Many older generation migrants who may not speak English well or at all, and who may have poor literacy in Italian, depend greatly on family to access information and services, and families can feel enormous duty to their loved ones and guilt if they feel they are not meeting their responsibility.

The generation of Italian migrants who arrived in the 50s and 60s are the first large population of Italian Australians to have reached older age, and are for that reason probably less familiar with services and processes related to ageing and end-of-life care.

A note about terminology

In the English language, words such as *grief*, *bereavement* and *illness* can have different meanings and connotations for different people. Similarly, people from ethnic backgrounds may have specific cultural values that they associate with these words. For example, some people might associate *illness* with karma or the supernatural, and discussions around possible treatment or intervention need to take this into account in order for them to be meaningful.

Words such as *grief*, *bereavement* and *illness* are used in this resource with the understanding that there will be different cultural meanings associated with them. Education sessions are intended to be delivered in participants' first language, and therefore terms should be appropriately translated if applicable.

Educators should also be aware that in the health sector there are several terms used to describe terminal illness. Participants may have heard of some or all of the following:

- Incurable illness/condition
- Chronic and complex illness/condition
- Eventually fatal illness/condition
- Life-limiting illness/condition
- Terminal illness/condition

It is equally possible that participants have never heard these terms before and educators should consider clear and culturally appropriate ways of communicating ideas around death and illness before their session.

Macedonian Cultural Community Profile

Discussing palliative care in the Macedonian Community

Talking about palliative care can be difficult for people from all cultures and communities. Although in the Macedonian community there is no specific taboo around talking about death, many Macedonian people may be reluctant to speak about their personal experiences with illness and dying. Palliative care can produce negative feelings because of its association with illness, death and dying. These negative feelings can trigger difficult memories. When delivering information to participants about palliative care, it is important to be respectful of their feelings and their right to privacy.

As a peer educator, it is important to remember that learning is an active process through which people create meaning and develop understanding. The ways that participants react to new information depend on their ideas, opinions, knowledge, personal experiences, understanding of the world and their own learning style. Particularly around topics such as death and dying, participants will bring with them a whole set of cultural and social beliefs that will impact their learning experience. Education sessions are a good opportunity to raise awareness about palliative care but also to explore commonly held beliefs about health and illness and to dispel myths about palliative care.

Discussing illness, death and dying can often trigger strong emotions and feelings in people, especially if a participant has been personally impacted by it. Participants should be informed that:

- They do not need to contribute to discussion if they feel uncomfortable and are not forced to participate if they don't want to.
- They may take a break or leave the room if they feel like they need to.
- If they would like to share a story or experience they went through, they do not have to identify it as happening to them but they can say it happened to 'someone they know.'

About the Macedonian community in Victoria and Australia

Macedonian migration to Australia dates back to the 1890s, but the number of arrivals at that time was small and they were mainly Macedonian men working away from home due to poverty and deteriorating conditions in Macedonia. Most were from villages with very little education and they worked in the mining industry or as manual labourers. It was not until the 1920s and late 1940s that the numbers increased. Macedonians migrated to Australia mainly as Displaced Persons during the Greek Civil War (1944-1949).

Further migration occurred during the late 1960s and early 1970s when Macedonians came to Australia either sponsored by their families or as economic migrants and were slightly better educated. Macedonians continued to migrate to Australia during the late 1980s and 1990s due to the lack of political stability in former Yugoslavia. Many of these migrants were skilled professionals.

Most of the Macedonian immigrants come from the former Yugoslav Republic of Macedonia (now Republic of Macedonia) with smaller numbers coming from northern Greece (Aegean Macedonia), Bulgaria and Albania. The main language spoken by the Macedonian community in

Australia is Macedonian although there are a number of specific dialects depending from which part of the country they arrived.⁶⁵

The Macedonian language is one of the top ten languages spoken at home in Victoria and is the eighth largest in terms of people with low English proficiency based on data from the ABS 2011 Census. According to the Australian Institute of Health and Welfare, between 2011 and 2026, the number of Macedonian-speakers is expected to increase by 55 per cent while the number of Macedonian-speakers who are 80 and over is expected to increase by 130%. Macedonians who arrived in the first three waves of migration generally have lower levels of English proficiency. Not all people who identify as Macedonian can read Macedonian and older Macedonians may have low literacy levels in both English and Macedonian.

At the 2011 Census, Victoria had the largest concentration of the Macedonian community; with almost half of the national total.⁶⁶ The population throughout Australia has been decreasing, due to ageing, some return migration and lack of new arrivals.

Macedonians have a very high level of Australian citizenship (95.6 per cent at the 2011 Census compared to 84.9 per cent for the total Australian population).⁶⁷ Three-quarters of the Macedonian population in Victoria live in the following local government areas: Whittlesea, Brimbank, Darebin, Greater Dandenong, Melton, Hobsons Bay and Greater Geelong.

Macedonian Cultural Perspectives and Values

Within any cultural group or community, individual views and values are shaped by many factors, including our age, gender, income, religion, sexuality, profession, education and political views, not to mention personal experiences. Individuals from the same culture do not all think alike or share the same value systems and opinions. Likewise, cultural values and attitudes can change over time and are never the same thing to everyone.

For the Macedonian community, shifting cultural values can become more apparent through the migration experience and there can be great differences between the views and values of two generations within the same family. For older generation migrants in particular, some traditional views and attitudes may have been preserved despite changing attitudes and practices in Macedonia. In this sense, despite close ties with Macedonia, Macedonian culture as it exists in Australia cannot necessarily be generalised from contemporary Macedonian culture or with Macedonian communities living in other parts of the world.

Nevertheless, certain beliefs can have more influence or resonance with a cultural group and can be recognised as commonly shared or understood within a community. Individuals from that group do not need to personally agree with those values to recognise their cultural importance.

⁶⁵ Macedonian Community Welfare Association (MCWA), Community Profile Information Kit – The Migration and Settlement Experience, <http://www.mcwa.org.au/publications/community-profile-information-kit>, accessed 26 June 2014.

⁶⁶ Office of Multicultural Affairs and Citizenship (Victoria) (2013). *Victorian Community Profiles: 2011 Census Former Yugoslav Republic of Macedonia (FYROM)-Born*. Accessed 26 June 2014 at <http://www.multicultural.vic.gov.au/images/stories/documents/2013/Censusfactsheetscommunityprofiles/cmmprofiles/16-fyrom.pdf>

⁶⁷ SBS (2012). *SBS Census Explorer*.

Here are a number of commonly held Macedonian cultural perspectives and values that may have a bearing on their response to a discussion about palliative care. Please keep in mind that these perspectives will not apply to everyone in the Macedonian community and it is important not to make assumptions about people's values and beliefs.

Community and Religion⁶⁸

Religion still plays a significant role in the Macedonian community but it is usually kept separate from other aspects of life and therefore may not play a major role for the palliative care patient. For older Macedonians whose experience may have been life in a communist country, their religion is culturally ingrained. Church groups and networks may be particularly important to the older generation who were instrumental in establishing the church in Australia. Macedonians are predominantly Macedonian Orthodox, Eastern Orthodox or Greek Orthodox) with small numbers being Muslim or belonging to Roman Catholic, Presbyterian or Baptist churches. Religion is a stronger influence with older Macedonians than with the younger generation.

Fasting is part of the Orthodox religion and some Macedonians observe fasting periods. Fasting means abstinence from meats, oil, and dairy products. It is customary to fast for 40 days prior to midnight on Easter Saturday. During Lent in the Easter period, Orthodox Macedonians spring-clean their homes and properties in preparation for Holy Week.

Highly ritualistic religious practices are used to mark major occasions such as births, marriages and deaths. The religious practices for the dead are highly ritualised and rich in symbolism. As with many other communities, the importance of religion varies in the Macedonian community. Some people go to Church to pray and observe customs and traditions and would not seek assistance through priests, while for others religion is an active part of many aspects of their life.

Family

There are variations in the attitudes towards the elderly and roles of the family members in the Macedonian community. Older Macedonian migrants who came to Australia in the earlier waves of Macedonian immigration may not have had experience of their parents ageing. Traditionally, older people are highly respected and are incorporated into decision-making structures and asked to mediate disagreements. Elderly Macedonians who migrated to Australia still have high expectations from their children and expect children to care for them. Traditionally in Macedonia it is the responsibility of the family to care for their older family members. They perceive this as their children's obligations because they came to Australia to provide a better life for them and if their sons and daughters don't take care of the parents in time of need it may be viewed as betrayal. Some elderly Macedonians feel a burden to their family but would still prefer to stay in their homes.

In contrast, the attitudes of second generation Macedonians whose values are mixed with Australian values may find it difficult to care for their parents due to work and their own family commitments. There is a tendency for children to feel guilty if they are unable to care for their parents and this is may be accentuated by the guilt that is placed on them by the parents. There

⁶⁸ Information in this section was collated from Migrant Information Centre (Eastern Melbourne), Macedonian Cultural Profile, 2012; and Macedonian Community Welfare Association (MCWA), Community Profile Information Kit – Religion, <http://www.mcwa.org.au/publications/community-profile-information-kit>, accessed 26 June 2014.

may also be an expectation that older parents will mind their grandchildren once they retire and this role often falls to the grandmother.

Overwhelmingly, in cases of married couples, the main carer is the spouse. Spouses commonly care for as long as they are able. Families remain the main support networks for elderly Macedonians and there is reluctance to seek help outside the extended family.⁶⁹

Attitudes to illness and pain management

Generally, Macedonians have a fatalistic attitude to illness, believing it is “meant to happen”. For more traditional members of the community, illness may be seen as punishment for mistakes of the past or even be considered a curse that has been placed upon them by someone else, attributing the cause of the illness to the evil eye, a curse or witchcraft. In these cases, there may be some reliance on spiritual guidance.

The Macedonian community holds doctors and medical professionals in high regard and will use modern medicine for treatments. Herbal remedies or spiritual healers may also be used together with prescribed medication. Some members of the community have a fatalistic view of illnesses that have no cure, and this may limit the possibilities of early intervention or health promotion. Some community members would discuss their concerns with their community workers as well.⁷⁰

Macedonian people will access pain relieving medication and use it when needed. There may be limited understanding of the role of opiates in pain relief but patients and families will usually accept the use of opioids for symptom control if the rationale is clearly explained to them – that the purpose for the treatment is to relieve the person’s suffering. Palliative care services should use a qualified interpreter for this conversation with the patient and family.

Dementia is not easy to discuss as it is seen as embarrassing and there is still some stigma attached, although this is slowly changing as community understanding of dementia increases. Dementia is often diagnosed late in the Macedonian community as people tend to deny the symptoms and do not actively seek information if they have concerns. Where possible, and once the symptoms reach critical point, they will see a family doctor.⁷¹

There is a lack of Macedonian-speaking medical practitioners and some members of the community will see non-Macedonian speaking doctors even if there is no interpreter present. This raises concerns around effective communication with the patient and the level of understanding of their illness.

In the past, many Macedonian people were very sensitive about death and dying issues so it was very common that Macedonian families did not want the dying person to be told of their diagnosis and prognosis, believing that it would only burden the dying person further. Macedonian families preferred to be informed first of the diagnosis and then decide if the ill person should be told. In those cases it might be the eldest son who would tell his parents of the diagnosis. However,

⁶⁹ Alzheimer’s Australia Victoria, “Perceptions of dementia in ethnic communities – Macedonian Cultural Profile”, 2008.

⁷⁰ MIC, “Macedonian Cultural Profile”, 2012.

⁷¹ Alzheimer’s Australia Victoria, “Perceptions of dementia in ethnic communities – Macedonian Cultural Profile”, 2008.

attitudes to this issue are changing and this question should be discussed with the family to ascertain their views.⁷² Every family is different and if the patient wishes to know, the patient's wishes are paramount.

Attitudes towards mental health

Older members of the Macedonian community may regard disability as embarrassing and a cultural stigma is attached to mental illness in particular. Mental illness and disability are not discussed openly within the community.

As there is a strong preference to deal with issues in private, there is some reluctance to use counselling services. Counselling, as a service, or even the term itself, does not tend to be recognised as most people consider psychologists and psychiatrists as the specialists who provide this type of service. It may be used for depression but it not common. If this type of service is to be used, it would have to be done in face-to-face contact with a person who speaks Macedonian or with an interpreter.⁷³

Attitudes towards care

As the concept of extended families dissolves, and with growing recognition that families are unable to provide adequate care for their elderly, the growing community acceptance of care services being provided outside the family network will also encompass this type of care provision for palliative care. The services are usually accepted once neither member of a couple can perform certain chores or if a person is living on their own had has no family members to assist. There are still issues with access to services but home-based services are more accepted, mainly because they provide the opportunity for the person to remain in their own home. It is important to note that services such as home care, lawn mowing and transport may be accepted but there are often considerable issues with personal care because it is seen as embarrassing to have someone else help with such a personal task. In terms of the workers' backgrounds, Macedonians tend to prefer services in their own language.⁷⁴

There is a still some reluctance in the Macedonian community to being placed in residential care. Residential care is perceived negatively in the community and there is a lack of acceptance of even respite care in a residential facility. There are no Macedonian-specific nursing homes in Victoria which further prevents the community from accessing this type of care for fear of being isolated and unable to speak to someone in their own language.

Most carers would continue caring for their spouse to the end of their life. Residential care is considered mainly once one of the couple dies and the other one is unable to care for themselves. It is also still considered shameful to place your family members in a nursing home and some elderly people feel that this is a way of their family getting rid of them because they are a burden.

People consider that the person has a better quality of life at home and that this should be the place where they are cared for even if this is sometimes difficult to do.

⁷² MCWA, "Death and Dying in the Macedonian Community", 2009.

⁷³ Alzheimer's Australia Victoria, "Perceptions of dementia in ethnic communities – Macedonian Cultural Profile", 2008

⁷⁴ Alzheimer's Australia Victoria, "Perceptions of dementia in ethnic communities – Macedonian Cultural Profile", 2008

Attitudes towards death and dying⁷⁵

Someone of the Orthodox faith will want a priest to administer the last rites and provide them with their final communion. Cremation is not permitted.

Icons and mirrors in the home are covered during the first few days of mourning as a sign of respect in the Orthodox tradition. Following a death, a “kandili” (a religious burner comprising oil, water and a floating wick) must remain lit for 40 days next to an icon and a photo of the deceased until the soul leaves this world. The wearing of black in mourning is still very prevalent, particularly by older women.

Intergenerational Perspectives and the Migration Experience⁷⁶

Over the past 100 years, Macedonian migration has mirrored and coincided with the political unrest and economic hardship that has devastated much of the region of Macedonia. Over the past century the ongoing political instability of the Balkans has resulted in the emigration of many Macedonians from their homeland either through forced displacement or through voluntary migration due to economic hardship or lack of life opportunities in their country of origin.

Pechalba, or working away from home as an itinerant worker, has always been a common Macedonian practice arising out of poverty and the need for a solution to it. As the political and social conditions in Macedonia deteriorated over time, *pechalba* became commonplace and, in a sense, a rite of passage for many Macedonian men.

In the case of Victoria, the early settlers congregated in the inner urban areas of Fitzroy, Collingwood, Preston, Richmond and the Werribee farms on Melbourne’s fringe. These often closed and close-knit communities resembled and reflected the way of life in their homeland and acted as a base from which the chain migration process was initiated.

The chain pattern of Macedonian migration prior to the 1970s saw, in some cases, the re-establishment of villages and village communities in pockets across Melbourne and Victoria. These rather cloistered communities were particularly evident in the farming enclaves of Werribee and Shepparton but also existed in the early clustered settlement areas of Fitzroy, Collingwood, Northcote and Preston. These rural and urban areas of settlement in many cases became the locus of the “imaginary village” in Melbourne.

The social context Macedonians were migrating from was radically different to those from Aegean Macedonia. The migrants came from a relatively more urbanised society where the ethnicity of the Macedonians was respected and recognised, and where daily life, such as education, business and commerce was conducted in the Macedonian language. Macedonians from the Republic of Macedonia also settled in the inner urban area of Melbourne such as Northcote, Preston, Fitzroy, Footscray and Yarraville and later moved out to the outer suburbs of Thomastown, Lalor, Epping, Sunshine and St. Albans.

⁷⁵ MCWA, “Death and Dying in the Macedonian Community”, 2009.

⁷⁶ Adapted from the MCWA Community Profile Information Kit at <http://www.mcwa.org.au/community-profile-information-kit/>, accessed 26 June 2014; and Ethnic Communities’ Council of Victoria (2009), *Respect and Dignity: Seniors, family relationships and what can go wrong*, A Greek community education resource kit around elder abuse prevention, p. 2.

During the 1990s, the break up of Yugoslavia and the outbreak of war in Croatia and Bosnia-Herzegovina, the war in Kosovo, and more recently in Western Macedonia itself, has destabilised the Balkans both politically and economically. The political instability of the region, coupled with the historical interdependency of the former republics of Yugoslavia has made the political and economic transition of Macedonia to a market economy a very difficult one. The impacts of the economic struggles facing Macedonia remain to be seen, although current trends suggest that people will continue to leave where possible for the opportunity of a better life elsewhere.

First generation migrants who brought their parents out to Australia under the family re-unification scheme tend to have a traditional, respectful attitude towards the elderly as keepers of the culture and language, and as elders in the community. Second (and other) generation Macedonians who have more vigorously attempted to assimilate and cast off markers of their “Macedonian-ness” are less likely to engage with the elderly of the community, or even in their own families. These are, of course, generalisations; there exist variations and permutations within generations and even within individuals in their responses to the elderly and the ageing in the Macedonian community.

A note about terminology

In the English language, words such as *grief*, *bereavement* and *illness* can have different meanings and connotations for different people. Similarly, people from ethnic backgrounds may have specific cultural values that they associate with these words. For example, some people might associate *illness* with karma or the supernatural, and discussions around possible treatment or intervention need to take this into account in order for them to be meaningful.

Words such as *grief*, *bereavement* and *illness* are used in this resource with the understanding that there will be different cultural meanings associated with them. Education sessions are intended to be delivered in participants’ first language, and therefore terms should be appropriately translated if applicable.

Educators should also be aware that in the health sector there are several terms used to describe terminal illness. Participants may have heard of some or all of the following:

- Incurable illness/condition
- Chronic and complex illness/condition
- Eventually fatal illness/condition
- Life-limiting illness/condition
- Terminal illness/condition

It is equally possible that participants have never heard these terms before and educators should consider clear and culturally appropriate ways of communicating ideas around death and illness before their session.

Maltese Community Cultural Profile

Discussing palliative care in the Maltese community

Talking about palliative care can be difficult for people from all cultures and communities. Although in the Maltese community, there is no specific taboo around talking about death, many Maltese people may be reluctant to speak about their personal experiences with illness and dying. Palliative care can produce negative feelings and trigger difficult memories. When delivering information to participants about palliative care, it is important to be respectful of their feelings and their right to privacy.

As a peer educator, it is also important to remember that learning is an active process through which people create meaning and develop understanding. The ways that participants react to new information depend on their ideas, opinions, knowledge, personal experiences, understanding of the world and their own learning style. Particularly around topics such as death and dying, participants will bring with them a whole set of cultural and social beliefs that will impact their learning experience. Education sessions are a good opportunity to raise awareness about palliative care but also to explore commonly held beliefs about health and illness and to dispel myths about palliative care.

Discussing illness, death and dying can often trigger strong emotions and feelings in people, especially if a participant has been personally impacted by it. Participants should be informed that:

- They do not need to contribute to discussion if they feel uncomfortable and are not forced to participate if they don't want to.
- They may take a break or leave the room if they feel like they need to.
- If they would like to share a story or experience they went through, they do not have to identify it as happening to them but they can say it happened to 'someone they know.'

About the Maltese Community in Australia

The Maltese community in Australia has a significantly ageing population, and is composed mainly of migrants who arrived in the mid-fifties or early sixties, their children and grandchildren. Most Maltese speakers were born in Malta (68.5%), followed by Australia (27.2%). There were two significant intakes of Maltese migrants in 1954 and again in 1963-4, however migration of Maltese speakers to Australia has dwindled significantly in the last ten years. Perhaps because of this, the largest age demographic recorded for Maltese speakers in 2011 was 60-64 years for both men and women.

The 2011 census recorded 41,274 Malta-born people in Australia with the largest population in Victoria followed by New South Wales. According to the census, the main languages spoken at home by Malta-born people in Australia were Maltese (23 559), English (16 789) and Italian (397). Of the 24 486 Malta-born who spoke a language other than English at home, 88.1 per cent spoke English very well or well, and 10.4 per cent spoke English not well or not at all.⁷⁷

Because Malta was a British colony until 1964, there is sometimes a perception that most Malta-born speakers are also fluent in English because they were raised in a bi-lingual environment. This

⁷⁷ Department of Immigration and Citizenship. (2011) *Community Information Summary: Malta-born*. Accessed on July 12 2013 from http://www.immi.gov.au/media/publications/statistics/comm-summ/_pdf/malta.pdf.

perception may be perpetuated by some older generation Maltese speakers, who may describe themselves as having English proficiency. In consultation with the community in Victoria, it seems unlikely that English proficiency is as high as reported among the older generation from Malta. It is possible that many of the first generation Maltese speakers who arrived in Australia during the mass migration period are more inclined to say they speak English because of their colonial heritage as 'British subjects'. Many Maltese speakers migrated before English proficiency was necessary to migrate to Australia and before English classes were provided or made easily accessible. It may also be that many older generation Maltese Australians had poor access to education, with 20.6% of Maltese speakers reporting that they had finished their Year 12 studies (or equivalent) in 2011.

Nationally, a significant majority of Maltese speakers identify themselves as being Western Catholic (95.4%). Religion is central to the cultural identity of many Maltese Australians, and plays a strong social and spiritual role in the community.

Maltese Cultural Perspectives and Values

Within any cultural group or community, individual views and values are shaped by many factors including our age, gender, income, religion, sexuality, profession, education and political views, not to mention personal experiences. Individuals from the same culture do not all think alike, or share the same value systems and opinions. Likewise, cultural values and attitudes can change over time and are never the same thing to everyone.

Nevertheless certain beliefs can have more influence or resonance with a cultural group and can be recognised as commonly shared or understood within a community. Individuals from that group do not need to personally agree with those values to recognise their cultural importance.

Maltese speakers, who migrated in the 50s and 60s, often strongly identify with the regional culture, heritage and language in which they grew up. For older generation migrants in particular, some traditional views and attitudes may have been preserved despite changing attitudes and practices in their home country. In this sense, despite close ties with Malta, Maltese culture as it exists in Australia can not necessarily be generalised from contemporary Maltese culture or with Maltese communities living in other parts of the world.

The following are a number of commonly held Maltese Australian cultural perspectives and values that may have bearing on responses to a discussion about palliative care in that community. Please keep in mind that these perspectives will not apply to everyone in the Maltese speaking community. It is important not to make assumptions about people's values and beliefs.

Community & Religion

Religion is paramount in the life of many Maltese Australians, and is very much a part of daily and social life, particularly for the older generation. A large majority of Maltese speakers identify themselves as Western or Roman Catholic and even nominal or non-practicing Catholics often identify closely with Roman Catholic values and observe traditional religious celebrations and rituals which are central to Maltese cultural life. Often religion becomes increasingly important to Maltese Australians as they age and religious mass plays an important social role for Maltese communities.

Because the Maltese community is closely connected, there are occasions when individuals or families may feel protective of their privacy, particularly in situations related to health or hardship. This can even make people reluctant to engage interpreting services for fear that they know the interpreter socially. Educators may want to keep discussions away from personal experiences, and to emphasise that palliative care services are bound by similar rules of conduct and privacy to GPs and professional counsellors.

Family

Family is central to the life of Maltese-Australians and involves a closely knit extended family. Grandmothers often play an important role in caring for children and while children leave the family home when they marry, it is relatively uncommon for a child to leave the home to live alone. As well as being very close, Maltese families tend to be insular and will often try to solve problems within the family, without seeking external help from friends or outside sources. Particularly because the community itself is quite closely connected, families can be quite protective of their privacy, particularly in relation to sensitive or personal issues. Depending on their level of education and English proficiency, many older generation Maltese speakers rely completely on their family to make decisions.

Because of the value Maltese communities place on family, it is often assumed that caring roles will be taken on by family members and in particular women in the family, who are traditionally expected to be the primary care givers, and responsible for domestic matters. It may be important for educators to emphasise that palliative care services work with families to enable people with terminal illness to continue to enjoy their lives with as little interruption as possible. Family involvement is not diminished by the use of palliative care and there is no obligation involved in using services.

Attitudes to illness and pain management

The medical profession is highly regarded in the Maltese community, and their opinion carries great authority. It is not uncommon for Maltese speakers to have long established and trusted relationships with their GP.

There is some stigma around serious illness for some Maltese speakers, and a common Maltese reaction is to reflect on their spiritual life and even wonder why it should be God's will and if they are being punished or tested. In these situations, faith will play an undiminished and deeply important role but families may choose not to share news of serious illness with friends in the wider community. Cancer and mental illness are both particularly taboo for the Maltese community and often carry strongly negative associations.

It is not uncommon for families to downplay the seriousness of an illness with their parent or loved one, and to avoid discussing the nature of the illness directly with them. This is not particular to the Maltese community, and can be motivated by the desire not to upset their loved one, to hope for their recovery, to avoid emotionally painful situations and to ensure that their loved one enjoys the time they have to the fullest and in comfort. Participants should be assured that the palliative care team have a lot of experience in negotiating similar situations with care and sensitivity, and will respect the wishes of the family and their loved one.

Attitudes towards mental health

As in many cultures, there is a strong stigma around mental health issues in the Maltese community in Australia and many older generation Maltese speakers will be unfamiliar with the concept of counselling. Because of their unfamiliarity with ideas about mental health, older generation Maltese speakers experiencing depression or other personal issues associated with grief, loss or the demands of caring may be unable to identify or express their need for support. While women in the community tend to have close support networks amongst their female friends, there is a strong culture amongst men of not speaking about their personal feelings and a tendency to avoid admitting weakness or vulnerability.

Although attitudes are changing, many Maltese speakers would be reluctant to consider counselling, and may even be concerned about community perceptions if they attended an information session which suggested they were interested in mental health. If appropriate, it may be worth discussing the stigma around mental illness and explaining the importance of mental health and wellbeing for carers and families in supporting their loved one effectively. It may also be worth discussing palliative care's commitment to respecting the wishes of the person who is ill and their families, including issues relating to privacy.

Attitudes to Death and Dying

Being a predominantly Roman Catholic culture, Maltese people in Australia do not have specific taboos around discussing death and dying; however as in most cultures, it is not often a common or comfortable topic of conversation. Although attitudes to death tend to depend on the individual, the idea of making arrangements or pre-paying for your own funeral is unpopular among many Maltese people who do not wish to tempt fate. Religion often plays an increasingly important role for many Maltese people as they age and observing traditional Catholic practices and rites is usually an important consideration for someone who is nearing the end of life.

There is a tendency among some Maltese women to remove themselves entirely from social life for a prolonged period after the death of their husband. This behaviour is more common among older generation women and women from a more traditional or rural background, however it can be a deeply isolating experience. In addition to this, couples that have maintained traditional gender roles in their relationship may struggle with independence. Widows in particular, may have very little experience of managing household finances while widowers may be overwhelmed by domestic duties. It may be beneficial to let participants know, if appropriate, that palliative care services can provide continuing counselling and spiritual support to people who have lost a loved one for a year or more.

Intergenerational Perspectives and the Migration Experience

Intergenerational misunderstandings and conflicting expectations are common to all families and communities.⁷⁸ Our history impacts greatly on the cultural context through which we see the world – both when we entered the world and where. Particularly for migrant communities, the difference in the experiences of one generation and another can be more pronounced, leading to further possibilities for conflict or misunderstanding.

⁷⁸ Parts of this section were developed from Ethnic Communities' Council of Victoria (2009), *Respect and Dignity: Seniors, family relationships and what can go wrong*, A Greek community education resource kit around elder abuse prevention, p. 2.

3 Parts of this section developed from Ethnic Communities' Council of Victoria (2009), *Respect and Dignity: Seniors, family relationships and what can go wrong*, A Greek community education resource kit around elder abuse prevention, p. 2.

For many first generation Maltese migrants, the lack of cultural continuity may have been a bewildering and isolating experience. This may be even more pronounced for older members of the community, or members of the community who do not speak English well or at all and who may be more socially and culturally isolated. Some Maltese speakers are also known to 'mix languages,' and speak a hybrid of English and Maltese which can be difficult to understand for both speaker and listener. Many older generation Maltese Australians express great nostalgia for their past, and idealise the lifestyle and traditional values of their home country and rural lifestyle, regardless of changes that may have occurred in contemporary Malta.

In turn, the second and third generation growing up in Australia can feel conflicting cultural pressures and heavy family responsibilities. The children of migrants must often navigate between the competing cultural values and languages of their family and Australian society. Typically where the older generation will idealise traditional values and practices, the younger generation will be more adaptive to dominant Australian values and customs. Many older generation migrants who may not speak English well or at all, and who may have poor literacy in Maltese, depend greatly on family to access information and services. As a result, families can feel enormous duty to their loved ones and feel guilt if they think they are not meeting their responsibility.

In many ways, the experience of caring for older family members is new to Maltese Australians, which may make it even less likely that the community is aware of palliative care services. The generation of Maltese migrants who arrived in the 50s and 60s are the first large population of Maltese Australians to have reached older age, and they may not have experiences of supporting their parents or grandparents and perhaps less familiar with services and processes related to ageing and end-of-life care.

Depending on your audience it is worthwhile being aware of intergenerational tensions and where appropriate, encouraging thoughtful and reflective discussion around these issues if they arise in the course of your session.

Polish Community Cultural Profile

Discussing palliative care in the Polish Community

Talking about palliative care can be difficult for people from all cultures and communities. Although in the Polish community there is no specific taboo around talking about death, many Polish people may be reluctant to speak about their personal experiences with illness and dying. Palliative care can produce negative feelings because of its association with illness, death and dying. These negative feelings can trigger difficult memories. When delivering information to participants about palliative care, it is important to be respectful of their feelings and their right to privacy.

As a peer educator, it is important to remember that learning is an active process through which people create meaning and develop understanding. The ways that participants react to new information depend on their ideas, opinions, knowledge, personal experiences, understanding of the world and their own learning style. Particularly around topics such as death and dying, participants will bring with them a whole set of cultural and social beliefs that will impact their learning experience. Education sessions are a good opportunity to raise awareness about palliative care but also to explore commonly held beliefs about health and illness and to dispel myths about palliative care.

Discussing illness, death and dying can often trigger strong emotions and feelings in people, especially if a participant has been personally impacted by it. Participants should be informed that:

- They do not need to contribute to discussion if they feel uncomfortable and are not forced to participate if they don't want to.
- They may take a break or leave the room if they feel like they need to.
- If they would like to share a story or experience they went through, they do not have to identify it as happening to them but they can say it happened to 'someone they know.'

About the Polish community in Victoria and Australia

Polish migration to Australia dates back to the Australian gold rush in the 1850s, but the largest numbers of Polish migrants came to Australia after World War II. The first wave of Polish migrants included 65,000 displaced persons who immigrated between 1947 and 1952. Many were employed on the Snowy Mountains Hydro-Electric Scheme in NSW.

In the early 1980s, a second wave of migrants arrived from Poland. This wave was known as the Solidarity wave. The Polish government had declared martial law due to demands for political reform from an independent trade union movement called Solidarity. During this period, 15,000 new Polish migrants arrived. These migrants were different from the previous wave as they were mostly young, educated and married.⁷⁹

⁷⁹ Stefan Markowski, "Polish Migration to Australia", *Humanities Research*, Vol. XV, No.1, 2009, http://press.anu.edu.au/hri/2009_01/mobile_devices/ch06s04.html accessed 30 June 2014.

The improvement in living conditions in Poland and more stringent migration criteria in Australia have significantly reduced the levels of Polish migration to Australia.

In the 2011 Census, Victoria had the largest concentration of the Polish community, 16,387 people, with just over one third of the national total. 92.5 per cent of these people live in Melbourne. The Polish population in Australia peaked at the 1991 Census. Since then, the improvement in living conditions in Poland and its eventual membership of the European Union in 2004 have significantly reduced the levels of Polish migration to Australia.

At the 2011 Census, 62 per cent of the Polish population in Victoria were aged 55 or older with 12 per cent in each of the 65-74, 75-84 and 85-94 age cohorts.

The Polish language is one of the top twenty languages spoken at home in Victoria. The main languages spoken at home by the Polish population in Australia are Polish (71 per cent), English (24 per cent) and German (1 per cent). 87.8 per cent of the Polish population in Victoria assessed themselves at the 2011 Census as speaking English “very well” or “well” while 11 per cent assessed themselves as speaking English “not well” or “not at all”.⁸⁰

Polish people in Victoria have a very high level of Australian citizenship (91.3 per cent at the 2011 Census compared to 85 per cent for the total Australian population). The Polish population in Victoria are less geographically concentrated than many other culturally and linguistically diverse communities. Slightly more than half of the Polish population in Victoria live in the Glen Eira, Brimbank, Casey, Greater Dandenong, Monash, Kingston, Knox, Port Phillip, and Stonnington Local Government Areas with only Glen Eira (11.3 per cent) having more than 10 per cent of that population.⁸¹

Polish Cultural Perspectives and Values

Within any cultural group or community, individual views and values are shaped by many factors, including our age, gender, income, religion, sexuality, profession, education and political views, not to mention personal experiences. Individuals from the same culture do not all think alike or share the same value systems and opinions. Likewise, cultural values and attitudes can change over time and are never the same thing to everyone.

For the Polish community, shifting cultural values can become more apparent through the migration experience and there can be great differences between the views and values of two generations within the same family. For older generation migrants in particular, some traditional views and attitudes may have been preserved despite changing attitudes and practices in Poland. In this sense, despite close ties with Poland, Polish culture as it exists in Australia can not necessarily be generalised from contemporary Polish culture or with Polish communities living in other parts of the world.

⁸⁰ Office of Multicultural Affairs and Citizenship (Victoria), “The Poland Born Community in Victoria: 2011 Census”, Fact Sheet Number A-21, 2013.

⁸¹ Office of Multicultural Affairs and Citizenship (Victoria), “Victorian Community Profiles: 2011 Census Poland-Born”, 2013.

Nevertheless, certain beliefs can have more influence or resonance with a cultural group and can be recognised as commonly shared or understood within a community. Individuals from that group do not need to personally agree with those values to recognise their cultural importance.

Here are a number of commonly held Polish cultural perspectives and values that may have bearing on their response to a discussion about palliative care. Please keep in mind that these perspectives will not apply to everyone in the Polish-speaking community and it is important not to make assumptions about people's values and beliefs.

Community and Religion

In the 2011 Census, the major religious affiliations amongst Polish people in Victoria were Catholic (68.4 per cent) and Judaism (10.2 per cent). 9.2 per cent stated "no religion", which was lower than that of the total Victorian population (20.4 per cent).

For Polish Catholics, particularly those who are elderly, their daily life may be closely linked with the Catholic Church. Many Polish people may belong to a church, even if they are not regular attendees. In Melbourne there are Catholic parishes with Polish congregations and/or Polish priests in Bells Park, Keysborough, Richmond, St Albans and Sunshine.

Some Polish people believe in the special properties of prayer books, rosary beads and religious medals. Pictures of Pope John Paul II, the Virgin Mary and various saints can be found in many Polish homes and some people carry them in their wallets.⁸²

Family

A successful family life is very important to Polish people. The father is generally the head of the family where often both parents work. The traditional family model is the nuclear family (father, mother and two children).

Traditional family values and loyalty are strong in most Polish households. The elderly play an active role in helping adult children in their daily routine with families. Although the extended family is also very important, many aged Polish people may not have extended families as many Polish migrants immediately after the Second World War immigrated to Australia with only their spouse, or alone. Younger Polish people who immigrated later are now bringing out their elderly parents who may have limited English.⁸³

When caring for a person with a life-limiting illness, the role of the family is very important and there is often a moral obligation to provide as much care as possible. There is often an expectation that the person will stay and be cared for at home, regardless of their health status. There is a strong attachment to the home and a reluctance to go into residential care. The main carers are usually women and most often spouses. Culturally, it is the duty of the spouse to care for their husband or wife and they often feel shame about accepting services. This often results in increased stress and ill health in carers.⁸⁴ As there is a tendency for families to be isolated from the community, carers themselves have little social interaction with other members of

⁸² South Eastern Region Migrant Resource Centre, "Polish Cultural Profile – older people", 2010.

⁸³ Diversicare, "Polish Culture Profile", 2006.

⁸⁴ Australian Multicultural Community Services, "Polish Community IN Victoria – Attitude to medical care", www.polishcommunity.org.au/index.php/about-polish-culture?id=28, accessed 30 June 2014.

the community. It is important to emphasise that palliative care services can support the person with a life limiting illness *and* their carers at home.

Attitudes to illness and pain management

Research with the Victorian Polish community in the 2000s confirmed that most Polish elderly prefer to stay in their own homes for as long as possible, regardless of their health status and financial circumstances. Statistics show that older people from a Polish background often resist seeking help until crisis point is reached. This is a result of unwillingness to lose their independence and self-sufficiency as well as a notion of embarrassment connected to the necessity of seeking help from outsiders.

Traditionally, doctors and other health professionals are given great authority in various aspects of life and are well respected in the Polish community. Polish people are polite to authority figures and, not wanting to offend a doctor, may not ask for clarification on clinical issues. Polish people typically follow medical orders carefully and submit to various kinds of medical treatment including tests, operations and medication. On the other hand, alternative ways of treatment are also sought alongside mainstream medical advice, often without informing the medical practitioner. Herbal medicine and pharmaceuticals are sometimes privately imported from Poland.⁸⁵

Due to the language barrier, Polish people usually seek out Polish-speaking medical practitioners but may change doctors if they believe they are not getting better fast enough. They may also discuss their health concerns with their community worker, if they have one. Ethnic organisations and ethnic workers are often the first point of contact for information and referral. The case workers in ethnic organisations can be a useful source of assistance and advice if their clients are referred to a palliative care service and can build on trust and existing relationships.

Polish people will access pain relieving medication and use it when needed. Patients and families will usually accept the use of opioids for symptom control if the rationale is clearly explained to them.⁸⁶ Palliative care services should use a qualified interpreter for this conversation with the patient and family.

In the past, some family members may have preferred to keep the details of a diagnosis away from the person diagnosed with a life-limiting illness, reasoning that full disclosure will cause them to lose their will to live and give up on any possible treatment. However, attitudes to this issue are changing. Every family is different and if the patient wishes to know, the patient's wishes are paramount.

Palliative care was not provided in Poland until after 1990 so it is unlikely that elderly Polish people will be aware that such a service exists or what it entails.

Attitudes towards care

Family still remains the main support network for elderly members of the community but this is increasingly being supplemented by external services. Polish elderly are still reluctant to use

⁸⁵ Australian Multicultural Community Services, "Polish Community IN Victoria – Attitude to medical care", www.polishcommunity.org.au/index.php/about-polish-culture?id=28, accessed 30 June 2014.

⁸⁶ Andrew Taylor and Margaret Box, *Multicultural Palliative Care Guidelines*, Palliative Care Australia, 1999.

mainstream services due to lack of knowledge of the service system and unfamiliarity with service providers. Many access services through ethno-specific organisations and may then be referred on with the involvement of the ethno-specific workers.

Due to past experiences, Polish elderly have a strong fear of authority and also fear invasion of privacy which may prevent them from accepting services. It is therefore important to know and understand each person's past experiences and try to maintain their independence as far as possible.

Once services are introduced, they are generally well-accepted but they need to be provided by bilingual workers. The gender of care workers may be an issue on occasions, with female workers sometimes considered inappropriate for a male client. Careful selection and matching of carers and workers with clients is essential.

The expectation that the family will care for its family members still prevails in the Polish community and it is seen as shameful to place your parents or family members into residential care. The perception is that decline is very rapid once the person is placed in the residential care facility. Some members of the community feel quite adamant about staying in their own homes. The overall perception is that people will die quickly in residential care due to loneliness, depression, isolation and lack of communication.⁸⁷

Attitudes towards mental health

In the Polish community there is still some stigma attached to mental illness and this issue is not discussed openly in the community. Some Polish people may look for a physical cause of disease before considering a mental illness. There may be some discussion with people outside the immediate family about the fact that a family member is living with dementia, for example, with a church-based community who know the person and are familiar with their circumstances. If mental health issues do exist, home visits are preferred rather than clinic visits.⁸⁸

For those who use or would use counselling, it is mostly for issues around depression and Post Traumatic Stress Disorder. Most people feel more comfortable talking to family members or ethnic community workers than to professional counsellors. If counselling is used, it would need to be face-to-face with a Polish-speaker. Telephone counselling services are difficult to access due to the complicated process of accessing interpreters in order to access the service. This type of service is also seen as too impersonal.⁸⁹

As there is a strong preference to deal with issues in private, there is some reluctance to use counselling services. Counselling, as a service, or even the term itself, does not tend to be recognised as most people consider psychologists and psychiatrists as the specialists who provide this type of service. It may be used for depression but it not common. If this type of service is to be used, it would have to be done in face-to-face contact with a person who speaks Polish or with an interpreter.

⁸⁷ Alzheimer's Australia Victoria, "Perceptions of dementia in ethnic communities", 2008.

⁸⁸ Polish Community Council of Victoria, "Working with the Polish Community, n.d.

⁸⁹ Alzheimer's Australia Victoria, "Perceptions of dementia in ethnic communities", 2008.

Attitudes towards death and dying⁹⁰

Given the importance of the family and family connections, family members and friends will stay with the dying person so that he/she does not feel abandoned. For Polish Catholics, religious rituals include the administration of Holy Communion and the Last Rites.

Funeral customs are determined by the Church and the wishes of the family. After burial, mourners are invited for a wake or *stypa* where drinks and food are served in memory of the person. Most Polish people have a stoic acceptance of death as part of the life process, and a strong sense of loyalty and respect for their loved ones.

Relatives also wear black clothing on the day of the burial. The spouse may choose to wear black clothes for up to a year (the year of mourning). Graves of loved ones are visited for years to come, particularly on All Saints Day – 1 November – when flowers and candles are placed on the graves.

Cremation or burial will be a personal choice based more on religious beliefs than cultural norms.

Intergenerational Perspectives and the Migration Experience

Intergenerational misunderstandings and conflicting expectations are common to all families and communities.⁹¹ Our history impacts greatly on the cultural context through which we see the world – both when we entered the world and where. Particularly for migrant communities, the differences in the experiences of one generation and another can be more pronounced, leading to more possibilities for conflict and misunderstanding.

For many first generation Polish people who have migrated to Australia, the experience of migration has given them a strong sense of independence and self-reliance in which they take great pride. It may also have been a source of stress, homesickness and isolation.

Particularly for many older members of the Polish community, accepting help from external services could be felt as an admission of weakness or giving up personal independence. Service providers have also reported that there can be fears about accepting services, particularly if service providers are entering the home. Fears around being mistreated, confined, moved out of home and the cost of services can all be deterrents to accepting external support.

In turn, the second and subsequent generations growing up in Australia can feel conflicting cultural pressures and heavy family responsibilities. The children of migrants must often navigate between the competing cultural values and languages of their family and Australian society. Typically, while the older generation will idealise traditional values and practices, the younger generation will be more adaptive to dominant Australian values and customs.

⁹⁰ Diversicare, "Polish Culture Profile", 2006; Australian Multicultural Community Services, "Polish Community in Victoria – Burial and rituals associated with death", www.polishcommunity.org.au/index.php/about-polish-culture?id=26, accessed 30 June 2014.

⁹¹ Parts of this section were developed from Ethnic Communities' Council of Victoria (2009), *Respect and Dignity: Seniors, family relationships and what can go wrong*, A Greek community education resource kit around elder abuse prevention, p. 2.

Not surprisingly, given the tendency of Polish migrants to assimilate more easily than many other migrant groups, the ability to speak Polish as a “second language” has declined in the second and subsequent generations.

A note about terminology

In all cultures, the words you use to describe or explain something can have different meanings to different people. In the English language, for example, each person will bring different experiences and associations to their understanding of words such as *grief*, *death* and *illness*. Grief will mean something different to someone who has experienced it, just as death will mean something different to Catholics than to atheists. In both cases, it is important to recognise that your audience may respond differently to the words you use, depending on their personal associations and experiences.

Many of the words and explanations in this resource are written with the understanding that translating them into Maltese will involve a different set of meanings and cultural associations. Education sessions are intended to be delivered in participants’ first language, and therefore the way in which you translate material should be considered carefully.

Educators may struggle when explaining the term Palliative Care to participants who are not familiar with the service. ‘*Kura Palljativa*’ is an increasingly understood idea in Malta, which has excellent palliative care services, pioneered by the Malta Hospice Movement in 1989. However the term ‘*kura palljativa*’ is still not necessarily an informative term for individuals who have not encountered it before. Sessions should explain palliative care in a way that makes participants comfortable with the term and confident of how to access palliative care if necessary. In the end it will be up to the educator to choose what terminology feels best for them or their group, but they may find it helpful to read through and follow the suggested terminology used on the handouts translated in the back of this guide.

Educators should also be aware that in the health sector there are several terms used to describe terminal illness. Participants may have heard of some or all of the following:

- Incurable illness/condition
- Chronic and complex illness/condition
- Eventually fatal illness/condition
- Life-limiting illness/condition
- Terminal illness/condition

It is equally possible that participants have never heard these terms before and educators should consider clear and culturally appropriate ways of communicating ideas around death and illness before their session.

Turkish Community Cultural Profile

Discussing palliative care in the Turkish community

Talking about palliative care can be difficult for people from all cultures and communities.

Although in the Turkish community, there is no specific taboo around talking about death, many Turkish people may be reluctant to speak about their personal experiences with illness and dying. Palliative care can produce negative feelings and trigger difficult memories. When delivering information to participants about palliative care, it is important to be respectful of their feelings and their right to privacy.

As a peer educator, it is also important to remember that learning is an active process through which people create meaning and develop understanding. The ways that participants react to new information depend on their ideas, opinions, knowledge, personal experiences, understanding of the world and their own learning style. Particularly around topics such as death and dying, participants will bring with them a whole set of cultural and social beliefs that will impact their learning experience.

Education sessions are a good opportunity to raise awareness about palliative care but also to explore commonly held beliefs about health and illness and to dispel myths about palliative care.

Discussing illness, death and dying can often trigger strong emotions and feelings in people, especially if a participant has been personally impacted by it. Participants should be informed that:

- They do not need to contribute to discussion if they feel uncomfortable and will not be forced to participate if they don't want to.
- They may take a break or leave the room if they feel like they need to.
- If they would like to share a story or experience they went through, they do not have to identify it as happening to them but they can say it happened to 'someone they know.'

About the Turkish Community in Australia

The Turkish speaking community in Australia is well established, being largely made up of families who have been living in Australia for longer than a decade.⁹² According to the 2011 Census there are approximately 59,623 Turkish speakers in Australia, representing 0.3% of the entire population.⁹³ Most Turkish speakers are Australian citizens (90.5%) and the majority of the population is concentrated in Sydney and Melbourne.

The Turkish community was the first large Muslim population to settle in Australia. In 2011, 87.6% of Turkish speakers still identified as Muslim, with 6.8% identifying as having no religion.

The Turkish speaking population is an increasingly ageing demographic. 86.7% of all Turkish speakers living in Australia recorded that both parents were born overseas and 66.5% of Turkish speakers reported that they did not speak English well or not at all. The ageing population of Turkish speakers who arrived in the 1960s are particularly likely to not speak English well or at all, and to have low literacy and education levels. This is even more likely to be the case for older

⁹² Australian Turkish Association Inc. (2009) *Turkey community profile and its implication for service delivery*. Accessed on 1 September 2013 from <http://www.austurkish.org.au/history.html>.

⁹³ SBS Census Explorer (2013) *Turkish*. Accessed on 1 September 2013 from <http://www.sbs.com.au/yourlanguage/turkish/censusexplorer/page/in/english>.

women, who may traditionally have been discouraged from pursuing their education, although attitudes to women and education have changed decisively for most Turkish speaking migrant families today.⁹⁴

Turkish Cultural Perspectives and Values

Within any cultural group or community, individual views and values are shaped by many factors including our age, gender, income, religion, sexuality, profession, education and political views, not to mention personal experiences. Individuals from the same culture do not all think alike, or share the same value systems and opinions. Likewise, cultural values and attitudes can change over time and are never the same thing to everyone.

Nevertheless certain beliefs can have more influence or resonance with a cultural group and can be recognised as commonly shared or understood within a community. Individuals from that group do not need to personally agree with those values to recognise their cultural importance.

Studies looking at the Turkish Community in Australia have found that place of birth, 'mother-tongue', and religion are often symbolic markers of Turkish ethnicity.⁹⁵ More generally, notions of family loyalty, the social organisation of marriage and traditional segregation of gender roles have shaped Turkish youth identities in Australia.⁹⁶ The following are a number of commonly held Turkish cultural perspectives and values that may have bearing on responses to a discussion about palliative care in that community. Please keep in mind that these perspectives will not apply to everyone in the Turkish speaking community and it is important not to make assumptions about people's values and beliefs.⁹⁷

Community & Religion

There is a strong sense of community amongst Turkish speakers in Australia. Geographical concentration in particular cities and areas has kept the Turkish language and other cultural traditions alive and well across generations living in Australia.⁹⁸ Because of these strong networks, Turkish speakers may be reluctant to seek services or support outside their community, without having established relationships of trust (for example, with their General Practitioner).

This reluctance may be more profound for the majority of Turkish speakers who practice Islam. Many Turkish speakers in Australia strongly identify being Muslim with their Turkish identity⁹⁹ and may not feel that service providers are aware or respectful of customary Muslim codes of conduct and ethics, particularly concerning gender roles and accepted rules of association. The importance of faith for both practicing and nominal Muslims in matters concerning their health can be heard in the Turkish expression, "God first and then the doctor." Turkish speakers of Muslim faith strongly believe that their life is in God's hands, and many will turn to their faith in

⁹⁴ Australian Turkish Association Inc. (2009).

⁹⁵ Elley J & Inglis C. (1995) Ethnicity and gender: The two worlds of Australian Turkish youth. *Ethnic minority youth in Australia*, 193-202.

⁹⁶ Zevallos, Zuleyka. (2008) 'You Have to be Anglo and Not Look Like Me': identity and belonging among young women of Turkish and Latin American backgrounds in Melbourne, Australia. *Australian Geographer*: 39(1), p. 24.

⁹⁷ Parts of the following section are taken or closely adapted from Australian Turkish Association Inc. (2009). *Turkey community profile and its implication for service delivery*.

⁹⁸ Windle J. (2009) 'Soft' and 'Hard' Landings: the Experience of School under Contrasting Institutional Arrangements in Australia and France. *Turks Abroad: Settlers, Citizens, Transnationals*: 11(2), 174-194.

⁹⁹ Zevallos. (2008) p. 27.

times of trial as a source of ongoing hope. Whilst being mindful that not all Turkish speakers are Muslims, it is important to emphasise that the Palliative Care team is respectful of individuals' personal beliefs and will be happy to work with a family's religious leader or spiritual counsellor, and their wider religious community, as well as with their trusted GP and other treating medical professionals. Religious leaders often play a supportive role for the family even after their loved one has died, as do some Palliative Care services, which can continue to offer some support to carers and family for 12 months after bereavement.

Family

Family is a central source of support for individuals in the Turkish speaking community. Traditionally, great value is placed on family loyalty and it is expected that the family would undertake primary responsibility in caring for their loved ones. The dynamics of Turkish speaking families varies greatly depending on many factors including religion, education, and family background in rural or urban settings. In traditional families, the eldest son is often the decision maker, while the day to day duties of care traditionally fall to female family members.

Families often feel a strong moral obligation to care for their loved ones at home and would be reluctant to place them in a hospice, palliative care or aged care facility. Families may feel significant social pressure from the wider Turkish community, which may perceive sending their loved ones away as abandonment of their responsibilities. Equally, amongst more conservative members of the community, inviting a stranger into the home to manage care may also be negatively perceived. Because of these community perceptions, Turkish speakers may feel reluctant to seek help from sources outside their immediate circles of family and friends and may cause feelings of anxiety or shame. It is important for educators to acknowledge the stigma around this issue and, where possible, to discuss the importance of changing community perceptions about the use palliative care, which enhances, rather than replaces the quality of care provided by the family.

Gender segregation

Traditional segregation of genders, relating to rules of association between men and women, is practiced to a greater or lesser extent within the entire Turkish community in Australia. While gender segregation is based in religious observance for those of traditional Muslim faith, it is a cultural expectation which extends to the Turkish community in general, and unmonitored interaction between men and women is discouraged. For this reason, there is a strong cultural preference that personal care should be provided by someone of the same sex, with the exception of husbands and wives. Particularly for practicing Muslims, this may bear on an individual's willingness to consider using palliative care services if there is uncertainty about whether care provided by professionals would be gender specific.

There are many implications of gender segregation and gender roles which have relevance to the discussion of palliative care, and depending on the audience, educators may want to consider conducting gender specific education sessions in order to address the particular needs and quite separate roles of men and women in the Turkish community.

Gender roles and decision making

Traditionally, gender roles are quite strictly defined for both men and women in the Turkish community, although they apply more to the older generation and may not apply to everyone.

Beyond the rules of association between men and women, there is a strong division of labour in traditional Turkish families, in which men are responsible for financial and family decision making and women are responsible for the organisation and upkeep of the household, and would be assumed to be the main – and sometimes the sole – care provider in their families. Because of this, in a situation where a man became seriously ill, his wife would see caring as a natural extension of her duties and may not see the situation as one which requires additional support. In a situation where a woman was seriously ill, her husband would commonly require far more additional support in his role as carer. Educators should consider these different perspectives when discussing palliative care, depending on their audience.

As in many cultures and parts of the world, traditional gender expectations may disadvantage women from a Turkish speaking background who are, particularly in the older generation, less likely to have received education than their male peers.¹⁰⁰ Although Turkish-speaking families raising their children in Australia place great value on girls' education, this may be an important consideration when presenting information and resources to older generation women in particular, depending on their background.¹⁰¹ More generally, the focus for most women who learn about palliative care will be on the practical aspects of caring itself.

For men in the Turkish community, their role is traditionally more powerful than that of women, but in this sense carries heavy responsibility. While the role of the mother is revered in traditional Turkish culture, men have the last word and husbands are traditionally understood to be the leaders of the family. For this reason, when addressing Turkish speaking men, it may be worth emphasising the important role palliative care can play in providing health information so that families can make informed decisions about their loved one. The palliative care team is expert in all aspects of care relating to terminal illness, including avenues of financial assistance and advice on advanced care planning, including referral to expert legal advice in matters which arise in bereavement.

Please keep in mind that expectations of gender and gendered perspectives will not apply to everyone in the Turkish speaking community and will apply differently for older and younger generations. It is important not to make assumptions about people's roles and attitudes.

Attitudes to illness and Pain Management

The medical profession is highly regarded in the Turkish community, and their opinion often carries great authority. It is not uncommon for Turkish speakers to have long established and trusted relationships with their GP.

Whether or not someone from the Turkish speaking community is comfortable talking about health and illness depends on the individual and circumstances. Men are traditionally less likely to discuss their personal health issues with others (except very close friends), and may be reluctant to draw attention to anything that they may perceive to indicate personal weakness. In general, women tend to have stronger support networks, and are more able to discuss their health together,

¹⁰⁰ For example, in 2008 in Turkey 84% of all illiterate people were women. See Istanbul BIA News Centre. (25 August 2010). *4.7 million illiterate women in Turkey*. Bianet. Accessed on 20 September 2013 from <http://bianet.org/english/gender/124367-4-7-million-illiterate-women-in-turkey>.

¹⁰¹ This should also be a consideration for many older generation men, again depending on their background.

however sensitive issues, gender-specific health issues and sexual and reproductive issues are usually inappropriate to discuss in mixed company. Educators should be sensitive to these differences and may try to make the discussion general rather than personal.

It is not uncommon for families to downplay the seriousness of an illness with their parent or loved one, avoid discussing the nature of the illness or to question the definitive nature of a prognosis.¹⁰² This is not particular to the Turkish community, and can be motivated by the desire to not upset their loved one, to hope for their recovery, to avoid emotionally painful situations and to ensure that their loved one enjoys the time they have to the fullest and in comfort. Individuals may feel like they are enacting a necessary tragicomedy, in which both parties are aware but unwilling to fully acknowledge the situation to one another. Participants should be assured that the palliative care team have a lot of experience in negotiating similar situations with care and sensitivity, and will respect the wishes of the family and their loved one.

According to Islamic belief, the relief of suffering is highly virtuous, and many Turkish speakers are very comfortable with the prescription of pain relief medications. Some practicing Muslims may have concerns about the content or use of opioids and other drugs for pain relief. For some Muslims it is important to maintain a level of consciousness as close to normal as possible towards the very end of life, however this view depends on the individual.¹⁰³ Equally, for some Muslims the use of gelatine or alcohol in certain drugs may be of concern. If it becomes relevant to the discussion, educators may want to assure participant's that the palliative care team is sensitive to cultural and religious beliefs around this issue and will discuss pain medications and medication levels closely with family if requested. Family and individuals maintain control of decision making about what pain medications are appropriate.

Attitudes towards Mental Health

There is a strong stigma around mental health issues in the Turkish community in Australia, to the extent that people who are diagnosed with a mental illness may not disclose it to their immediate family. This stigma extends to depression and may impact negatively on carers who experience stress, who are most often women, and who may not be able to identify or express their need for support. Equally, men in the Turkish community are looked to as the 'rock' of the family and may feel unable to acknowledge stress, depression or emotional vulnerability because of this expectation. While women in the community tend to have stronger support networks amongst their female friends, there is a strong culture amongst men of not speaking about their personal feelings. Although attitudes are changing, many Turkish speakers would be reluctant to consider counselling beyond seeking spiritual guidance from their religious leader, unless their trusted GP made a referral. It may be worth discussing these issues in detail if the opportunity arises, and explaining the importance of mental health and wellbeing for carers and families in supporting their loved one effectively. Educators may want to discuss the connections between mental health and physical health and the importance of seeing mental health as part of the health of the whole person.

¹⁰² Zafir al-Shahri M & al-Khenaizan A. (2005). *Palliative Care for Islamic Patients*. Journal of Supportive Oncology: 3(6), 432-6.

¹⁰³ Zafir al-Shahri M & al-Khenaizan A. (2005).

Attitudes to Death and Dying

Philosophically and religiously, there is acceptance within Turkish culture of the reality and necessity of death and dying. The Turkish community do not have specific traditions and rituals around dying, but consider the end of life to be a time of making peace with others and one's self. (There are considerations around burial after death which the palliative care team is very likely to be aware of, or can be explained to them.) Nevertheless, the focus of conversation around palliative care should be around comfort and quality of life, treating symptoms including the management of pain and support for carers. Particularly for Muslims, some Turkish speakers may have concerns around the chemical affects or ingredients of certain drugs used in pain management. If educators feel this is the case, it may be worth discussing these concerns with participants. Again, it is important for Turkish speakers who are practicing Muslims to be reassured that the palliative care team will respect and support any spiritual beliefs or religious practices of the family.

Intergenerational Relationships and the Migration Experience

Intergenerational misunderstandings and conflicting expectations are common to all families and communities.¹⁰⁴ Our history impacts greatly on the cultural context through which we see the world – both when we entered the world and where. Particularly for migrant communities, the difference in the experiences of one generation and another can be more pronounced, leading to more possibilities for conflict or misunderstanding.

Generally speaking, for first generation Turkish speaking migrants, the settlement process and lack of cultural continuity has been a difficult and isolating experience. This may be even more pronounced for older members of the community, or members of the community who do not speak English well or at all and who may be more socially and culturally isolated. For many older generation Turkish speakers in the Turkish community, their cultural and linguistic isolation from wider Australian culture has seriously impaired their communication and confidence levels, leading to increased isolation, depression, anxiety and the deterioration of their general health and mental well-being. Lack of language and limited literacy levels also contribute to lack of awareness and knowledge of available services, including where to go for help and how to get there while having to navigate through a complex and rigid system. Older people with low literacy levels may also find it difficult to relate to written information even in their own community language.

In turn, younger Turkish speakers, second and third generations growing up in Australia can feel conflicting cultural pressures and heavy family responsibilities. The children of migrants must often navigate between the competing cultural values and languages of their family and Australian society. Typically where the older generation will idealise traditional values and practices, the younger generation will be more adaptive to dominant Australian values and customs.

Depending on your audience it is worthwhile being aware of intergenerational tensions and where appropriate, encouraging thoughtful and reflective discussion around these issues if they arise during your session.

¹⁰⁴ Parts of this section were adapted from Ethnic Communities Council of Victoria. (2013). *Dignity and respect in ageing, the role of the family and what can go wrong. A Greek community education resource kit around elder abuse prevention*, p. 2.

A note about terminology

In all cultures, the words used to describe or explain something can have different meanings to different people. In the English language, for example, each person will bring different experiences and associations to their understanding of words such as *grief*, *death* and *illness*. Grief will mean something different to someone who has experienced it, just as death will mean something different to Muslims than to atheists. In both cases, it is important to recognise that your audience may respond differently to the words you use, depending on their personal associations and experiences.

Many of the words and explanations in this resource are written with the understanding that translating them into Turkish will involve a different set of meanings and cultural associations. Education sessions are intended to be delivered in participants' first language, and therefore the way in which you translate material should be considered carefully.

Educators may struggle when translating the term 'palliative care' into Turkish, as it is a relatively recent concept in Turkey and other home countries for Turkish speakers. Although palliative care concepts are gaining momentum in Turkish speaking countries, they have been slow to disseminate more widely, and often focus on pain management (algology) or fall under the broader term "supportive care".¹⁰⁵ Nevertheless, 'Palyatif bakım' is being increasingly discussed in Turkish speaking countries, at least within the medical profession, and educators may prefer this term, despite the fact that it is not necessarily informative for individuals who have not encountered it before. Sessions should explain palliative care in a way that makes participants comfortable with the term and confident of how to access palliative care if necessary. In the end it will be up to the educator to choose what terminology feels best for them or their group, but they may find it helpful to read through and follow the suggested terminology used on the handouts translated in the back of this guide.

Educators should also be aware that in the health sector there are several terms used to describe terminal illness. Participants may have heard of some or all of the following:

- Incurable illness/condition
- Chronic and complex illness/condition
- Eventually fatal illness/condition
- Life-limiting illness/condition
- Terminal illness/condition

It is equally possible that participants have never heard these terms before and educators should consider clear and culturally appropriate ways of communicating ideas around death and illness before their session.

¹⁰⁵ See International Observatory on End of Life Care. (2005). *Country Report: Turkey*. Accessed on 20 September 2013 from http://eolc-observatory.net/global_analysis/pdf/turkey_country_report.pdf.

Vietnamese Community Cultural Profile

Discussing palliative care in Vietnamese communities

Talking about palliative care can be difficult for people from all cultures and communities.

Although in the Vietnamese community, there is no specific taboo around talking about death, many Vietnamese people may be reluctant to speak about their personal experiences with illness and dying. Palliative care can produce negative feelings and trigger difficult memories. When delivering information to participants about palliative care, it is important to be respectful of their feelings and their right to privacy.

As a peer educator, it is also important to remember that learning is an active process through which people create meaning and develop understanding. The ways that participants react to new information depend on their ideas, opinions, knowledge, personal experiences, understanding of the world and their own learning style. Particularly around topics such as death and dying, participants will bring with them a whole set of cultural and social beliefs that will impact their learning experience. Education sessions are a good opportunity to raise awareness about palliative care but also to explore commonly held beliefs about health and illness and to dispel myths about palliative care.

Discussing illness, death and dying can often trigger strong emotions and feelings in people, especially if a participant has been personally impacted by it. Participants should be informed that:

- They do not need to contribute to discussion if they feel uncomfortable and are not forced to participate if they don't want to.
- They may take a break or leave the room if they feel like they need to.
- If they would like to share a story or experience they went through, they do not have to identify it as happening to them but they can say it happened to 'someone they know.'

About the Vietnamese Community in Australia

The Vietnamese were the first large group of Asian migrants to settle in Australia after the end of the White Australia policy and are the fourth largest overseas-born population from a non-English speaking background.¹⁰⁶ In 2011, there were 233,390 Vietnamese speakers recorded in Australia, making up 1.1% of the entire population.¹⁰⁷ Most Vietnamese speakers in Australia were born in Vietnam (63.6%), followed by Australia (31.1%). The community is also distinctive as Australia's largest refugee community, although this identity is changing with a new wave of international student migration and many second generation Vietnamese speakers.

In the immediate post-Vietnam war period, Vietnamese refugees arrived in three broad waves. The first group was made up of mostly young, well-educated and wealthy Catholics who faced severe reprisals from the new government in Vietnam and fled in 1975. The second wave of refugees, beginning in 1976, was a much more diverse group and included those who had escaped to refugee camps outside Vietnam. This group included people with different ethnicities, nationalities, religions and languages. Collectively, refugees in this wave were less educated, less literate and

¹⁰⁶ ABS. (2013) Cultural Diversity in Australia: Reflecting a Nation: Stories from the 2011 Census, 2012-2013. Accessed 12 June 2013:

<http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/2071.0main+features902012-2013>.

¹⁰⁷ SBS Census Explorer. (2013) *Vietnamese*. Accessed 2 August 2013 from

<http://www.sbs.com.au/yourlanguage/vietnamese/censusexplorer/page/in/english>.

came from more rural settings. This group also included the arrival of 'boat people', travelling to Australia directly. The third group, arriving in 1978, were mostly owners of private businesses expelled by the new Vietnamese Government or small traders described as 'economic refugees'.¹⁰⁸ From 1982 onwards many more refugees arrived under the Family Reunion Program. Many Vietnamese refugees experienced trauma and torture before and during their escape. For that reason, many first generation Vietnamese Australians are still traumatised and have strong feelings of antagonism towards the Vietnamese government. This attitude is changing with successive generations, but is still the case for many older generation Vietnamese speakers.¹⁰⁹

According to the 2011 Census, 5.3% of the Vietnamese population living in Australia are 65 years or older. 93.8% of Vietnamese speakers who completed the census recorded that both parents were born overseas. 85.2% were Australian citizens and 61.7% of Vietnamese speakers recorded that they have finished their Year 12 studies (or equivalent).

In 2011, most Vietnamese speakers identified as either Buddhist (52.6%) or Western Catholic (27.4%) with 12.8% identifying as having no religion. Because religion in Vietnam is closely bound up with Vietnamese history and culture, some Vietnamese speakers may observe religious traditions and rituals despite classifying themselves as non-religious.

Vietnamese Cultural Perspectives and Values

Within any cultural group or community, individual views and values are shaped by many factors including our age, gender, income, religion, sexuality, profession, education and political views, not to mention personal experiences. Individuals from the same culture do not all think alike, or share the same value systems and opinions. Likewise, cultural values and attitudes can change over time and are never the same thing to everyone.

Nevertheless certain beliefs can have more influence or resonance with a cultural group and can be recognised as commonly shared or understood within a community. Individuals from that group do not need to personally agree with those values to recognise their cultural importance.

The following are a number of commonly held Vietnamese cultural perspectives and values that may have bearing on their response to a discussion about palliative care. Please keep in mind that these perspectives will not apply to everyone in the Vietnamese speaking community and it is important not to make assumptions about people's values and beliefs. There are many nuances within these categories and they can never replace engaging with the individual views of participants.

There is no history of formal palliative care in Vietnam and although the Vietnamese government began a palliative care initiative in Vietnam in 2005, few older generation Vietnamese migrants are connected to their home country.

¹⁰⁸ Ben-Moshe D & Pyke J. (2012). *The Vietnamese Diaspora in Australia: Current and Potential Links with the Homeland*. Report of an Australian Research Council Linkage Project, p. 18; Racism No Way! (2013). *Australian Communities: Vietnamese Australians*. Teaching Resources Fact Sheet. NSW Government, Education and Communities. Accessed on 4 September 2013: <http://www.racismnoway.com.au/teaching-resources/factsheets/76.html>.

¹⁰⁹ Ben-Moshe D & Pyke J. (2012). p. 10, 21.

Family

A strong and closely connected family life is highly valued in Vietnamese communities and traditionally, the good of the family is thought to outweigh the needs of the individual, although this may be better understood as a tendency for Vietnamese people to prioritise their family's feelings over their own. Particularly among the older generation, there is an expectation that children will care for their elders and households are commonly made up of extended family. Day to day primary care and domestic duties are more likely to fall to the women in the family: wives, daughter(s) or daughter(s)-in-law. When talking about palliative care, educators may choose to emphasise the important ways that palliative care services can support families to provide the best possible care for their loved one at home.

Respect for one's elders and decision making

Traditionally, Vietnamese culture is quite strictly hierarchical, and one's parents remain decision makers for their children throughout their lives and regardless of their age. Given this, many older generation Vietnamese speakers may either exercise their authority in relation to their family or, if they are unwell, defer decision making to the eldest son (or eldest daughter). The eldest son, in particular, is traditionally seen as the head of the family and the one who will continue the family line. However all families are different and depending on the individual situation, whoever is providing direct care to the person who is unwell may play an important role in decision making. Even if one family member has the final word, they will consider the views of other members of the family in the process.

All children want the best for their parents and sometimes conflict can arise about the best way to care for loved ones and fulfil their final wishes. Educators may want to emphasise the important role palliative care can play in providing health information so that families can make informed decisions about their loved one.

Attitudes to illness

Vietnamese speakers who practice Buddhism may, on some level, connect illness with karma. In some cases, and particularly amongst the older generation, this belief may affect some people's willingness to accept the idea of pain management if they feel that their suffering in some way atones for, or is a consequence of, actions in a past life. Likewise, some Vietnamese speakers who are devoutly Catholic may feel that suffering is connected to atonement for sins. Depending on participants' views, any discussion around pain management or intervention may need to take this into account in order for the conversation to be meaningful, while reassuring participants that the palliative care team is sensitive to cultural and religious beliefs. It may also be worth discussing the role of morphine as a carefully monitored form of pain management, and not as a signal that the person who is ill is close to death.

In some instances, belief in karma can create a perceived stigma around a person's illness, because of its possible connection to actions in a past life, this life, or in relation to the discontent of ancestors. It is important to recognise that these attitudes are not the same for all Vietnamese Buddhists, and that older generations tend to be more religious than younger generations.

It is not uncommon for families to try and keep the seriousness of an illness from their parent. This is not particular to the Vietnamese community, but can be motivated by the desire to keep their

loved free from worries (particularly worries that would make them feel that the family could not cope without them), and to ensure that they enjoy the time they have to the fullest.

Attitudes to Death and Dying

Vietnamese people traditionally prefer to die at home, if possible. The thought that accepting palliative care might remove them from the home could be distressing so it is important to make the community aware that often services can be provided to allow loved ones who are unwell to remain at home. It is also important to explain that families do not lose control of the decision making process, or involvement in the day to day care of their loved one, even if they cannot remain at home. Palliative care services can help families to understand their rights and can provide accurate information to help people to make informed decisions about their or their loved one's health.

Vietnamese Buddhists believe that a body should not be moved for 8 hours after death. This may potentially influence their decision to use palliative care services, particularly inpatient services. Depending on the audience, educators may want to raise this issue or explain that palliative care services are very experienced in providing person-centred care. They respect people's individual beliefs and will observe family's wishes.

Privacy Issues

Vietnamese people prefer same sex carers if possible. Privacy and dignity are important cultural values and it should be emphasised that, if possible, personal preferences will be respected.

Intergenerational Perspectives and the Migration Experience

Intergenerational misunderstandings and conflicting expectations are common to all families and communities.¹¹⁰ Our history impacts greatly on the cultural context through which we see the world – both when we entered the world and where. Particularly for migrant communities, the difference in the experiences of one generation and another can be more pronounced, leading to more possibilities for conflict or misunderstanding.

Generally speaking, for first generation migrants, the lack of cultural continuity can be a bewildering and isolating experience. This may be even more pronounced for older members of the community, or members of the community who do not speak English well or at all and who may be more socially and culturally isolated, and often financially and socially dependent on their children.¹¹¹ In turn, the second generation growing up in Australia can feel conflicting cultural pressures and heavy family responsibilities. The children of migrants must often navigate between the competing cultural values and languages of their family and Australian society. Typically where the older generation will idealise traditional values and practices, the younger generation will be more adaptive to dominant Australian values and customs.

Depending on your audience it is worthwhile being aware of intergenerational tensions and where appropriate, encouraging thoughtful and reflective discussion around these issues if they arise in the course of your session.

¹¹⁰ Parts of this section were developed from Ethnic Communities' Council of Victoria. (2013). *Respect and Dignity: Seniors, family relationships and what can go wrong. A Chinese community education resource kit around elder abuse prevention*, p. 2.

¹¹¹ Ben-Moshe D & Pyke J. (2012). p. 10.

A note about terminology

In all cultures, the words you use to describe or explain something can have different meanings to different people. In the English language, for example, each person will bring different experiences and associations to their understanding of words such as *grief*, *death* and *illness*. Grief will mean something different to someone who has experienced it, just as death will mean something different to Buddhists than it does to Catholics. In both cases, it is important to recognise that your audience may respond differently to the words you use, depending on their personal associations and experiences. Many of the words and explanations in this resource are written with the understanding that translating them into Vietnamese will involve a different set of meanings and cultural associations. Education sessions are intended to be delivered in participants' first language, and therefore the way in which you translate material should be considered carefully.

Educators may struggle when translating the term 'palliative care' into Vietnamese, as there is no simple equivalent. For example, *cuối đời* is a good term to gently convey the end of life, but it may not capture the idea that palliative care can be accessed at any age. Other suggestions include:

1. Dịch Vụ Chăm Sóc Đặc Biệt cho người bệnh ở giai đoạn cuối / bệnh hiểm nghèo và thân nhân của họ (*A special service for people on terminally illness/with life threatening illness and their family members*)
2. Dịch Vụ Chăm Sóc cho người bệnh ở giai đoạn cuối (*Service for people who are on terminal illness*)
3. Dịch vụ săn sóc đặc biệt cho người mắc bệnh nan y và gia đình (*Palliative care is a special care for people with terminal illness and family*)

Sessions should explain palliative care in a way that makes participants comfortable with the term and confident of how to access palliative care if necessary. In the end it will be up to the educator to choose what terminology feels best for them or their group, but they may find it helpful to read through and follow the suggested terminology used on the handouts translated in the back of this guide.

Educators should also be aware that in the health sector there are several terms used to describe terminal illness. Participants may have heard of some or all of the following:

- Incurable illness/condition
- Chronic and complex illness/condition
- Eventually fatal illness/condition
- Life-limiting illness/condition
- Terminal illness/condition

It is equally possible that participants have never heard these terms before and educators should consider clear and culturally appropriate ways of communicating ideas around death and illness before their session.