



# Culturally Responsive Palliative Care

## Macedonian Community Cultural Profile

2014



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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.

## 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.<sup>1</sup>

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.<sup>2</sup> 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).<sup>3</sup> 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.

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<sup>1</sup> 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.

<sup>2</sup> 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/communityprofiles/16-fyrom.pdf>

<sup>3</sup> 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 Religion<sup>4</sup>

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

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<sup>4</sup> 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.<sup>5</sup>

### 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.<sup>6</sup>

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.<sup>7</sup>

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,

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<sup>5</sup> Alzheimer’s Australia Victoria, “Perceptions of dementia in ethnic communities – Macedonian Cultural Profile”, 2008.

<sup>6</sup> MIC, “Macedonian Cultural Profile”, 2012.

<sup>7</sup> 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.<sup>8</sup> 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.<sup>9</sup>

### 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.<sup>10</sup>

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.

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<sup>8</sup> MCWA, "Death and Dying in the Macedonian Community", 2009.

<sup>9</sup> Alzheimer's Australia Victoria, "Perceptions of dementia in ethnic communities – Macedonian Cultural Profile", 2008

<sup>10</sup> Alzheimer's Australia Victoria, "Perceptions of dementia in ethnic communities – Macedonian Cultural Profile", 2008

## Attitudes towards death and dying<sup>11</sup>

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 Experience<sup>12</sup>

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.

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<sup>11</sup> MCWA, “Death and Dying in the Macedonian Community”, 2009.

<sup>12</sup> 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.