PEER EDUCATION RESOURCE
GREEK COMMUNITY
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DISCUSSION NOTES
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Suggested activities

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Suggested activities

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Other Organisations
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REFERENCES
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Acknowledgements

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We are also grateful for the very helpful advice and feedback provided by members of the Community Reference Groups and the Project Steering Group during its development, as well as the contributions of community members and palliative care services.

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Odette Waanders
CEO, Palliative Care Victoria

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Introduction and overview

Why develop education modules especially for culturally and linguistically diverse communities?

Research shows that the overall use and awareness of palliative care services in culturally and linguistically diverse (CALD) communities is low. There are a number of reasons why this may be the case such as lack of access to and awareness of health services in general, lack of awareness about palliative care, and culturally specific factors including perceptions about death and illness, difficulties around discussions of dying, attitudes to receiving outside help and language and communication barriers.

The Peer Education Resource (PER) is one component of Palliative Care Victoria (PCV) and the Ethnic Communities Council of Victoria (ECCV) project, Culturally Responsive Palliative Care Community Education Program. This project aims to raise awareness about palliative care and improve communities’ access to culturally inclusive and responsive palliative care services.

This PER has been specifically designed to address the Greek community. Throughout the resource, information has been presented in a way that aims to take into account particular attitudes or concerns that people from the Greek community may share in relation to palliative care. Several common cultural perspectives have been identified in consultation with members of the Greek community, representatives of Greek organisations in Victoria and a survey of current literature.

It is important to recognise that there is as much individual diversity within cultures as there is diversity between cultures. The diversity and subtlety of the views of focus group members cannot be captured in this PER, but should be noted here. Ultimately, approaching people as individuals and as families is more important rather than relying on cultural stereotypes.

What are the aims of the PER and information sessions?

This PER intends to provide increased understanding and knowledge about palliative care through information, activities and case studies.

Delivering this PER will support people from the Greek community to be more aware of palliative care services in Victoria. In doing so, it is anticipated that information sessions will contribute to:

- Raising awareness of palliative care in the Greek community, particularly among the older population and those with life-limiting or chronic illness;
- Raising awareness of issues around death and dying and how to promote quality of life in the Greek community;
- Normalising discussion about death as a natural part of life in the Greek community.

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1 In this resource, 'CALD community' refers to any community which is culturally and linguistically diverse from the general Anglo-Australian community. The terms ‘CALD’ and ‘ethnic’ are used interchangeably to avoid repetition.
Who can use this resource?

*Palliative Care for Ethnic Communities* is for use by bilingual peer educators for the provision of culturally appropriate education and information in the Greek community about palliative care. The PER has been designed to be delivered in the first language of participants, however if an interpreter is required, it is important to consider the following things:

- Is the educator trained in working with an interpreter?
- Does the interpreter have an understanding of palliative care and appropriate terminology?
- Has adequate time been allocated for briefing the interpreter prior to the session? This should include clarifying their willingness to discuss sensitive issues.
- Has the length of the information delivery and discussion time been adjusted to take into account the additional time needed for interpreting?

(Adapted from ECCV, 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, 2013. p. 4).

What are the topics covered?

**This resource covers four main topics:**

1. An introduction to palliative care
2. Specific information about services and staff
3. Information for family members and others who have taken on a caring role for loved ones
4. Start talking about palliative care

How is this resource structured?

This PER provides a basic introduction to palliative care. It is based on a presentation and open discussion format that uses activities and scenarios to encourage discussion. It has been developed for the delivery of a single stand-alone session of 1.5 hours and one optional follow-up session of 1.5 hours. The PER is divided into four modules:

<table>
<thead>
<tr>
<th>Module</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Introduction to palliative care</td>
</tr>
<tr>
<td>2</td>
<td>Service specific information</td>
</tr>
<tr>
<td>3</td>
<td>Information for family and other carers</td>
</tr>
<tr>
<td>4</td>
<td>Start talking about palliative care</td>
</tr>
</tbody>
</table>

Each module provides case studies and activities for participants to increase their understanding of the information delivered.

While it is important to cover all the information and, in particular, the key messages, peer educators should feel comfortable deciding which activities may be relevant after learning about their participants specific needs. Facilitators can also modify the suggested activities based on the time available to deliver the education session.
Each module is structured in the following way:

<table>
<thead>
<tr>
<th>Aim</th>
<th>The aim of the module</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning objectives</td>
<td>The intended learning outcomes of the module</td>
</tr>
<tr>
<td>Discussion points</td>
<td>Questions which will be answered in each module</td>
</tr>
<tr>
<td>Discussion notes</td>
<td>Information related to each discussion point, should be used as a guide about what to cover in each module</td>
</tr>
<tr>
<td>Educators should consider</td>
<td>Things educators should be aware of when presenting the discussion notes. They may relate to sensitivities, terminology, differences etc. in culture and attitudes concerning palliative care related topics</td>
</tr>
<tr>
<td>Suggested activities</td>
<td>A list of interactive activities that can be used to convey the discussion notes or key messages</td>
</tr>
</tbody>
</table>

**Each session should:**

- If possible, be delivered in the groups’ first/preferred language.
- Cover the key messages.
- Be interactive and empowering.
- Provide participants with an opportunity to speak one-on-one with the educator after the session.
- Offer a follow up session to discuss the issues further.
- Provide individual participants with a handout of key messages and information about additional resources.
- Be designed and delivered to run for 1.5 hours or less.
- Be delivered by an educator with experience in public speaking, working with groups and facilitation.
- Be delivered by a well-informed educator. He/she does not need to be an expert on palliative care. But if unable to answer specific questions, it is important that educators are able to access information and provide it to participants at a later time.

(Adapted from ECCV, 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, 2013. p. 4).
Suggested session timetable

The time allocations suggested below are flexible and can be adjusted as the educator sees fit.

<table>
<thead>
<tr>
<th>Module</th>
<th>Time allocation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction and icebreaker</td>
<td>5 minutes</td>
</tr>
<tr>
<td><strong>Module 1:</strong> Introduction to palliative care</td>
<td>20 minutes</td>
</tr>
<tr>
<td><strong>Module 2:</strong> Service specific information</td>
<td>15 minutes</td>
</tr>
<tr>
<td>Short break</td>
<td>5 minutes</td>
</tr>
<tr>
<td><strong>Module 3:</strong> Information for carers</td>
<td>20 minutes</td>
</tr>
<tr>
<td><strong>Module 4:</strong> Start talking about palliative care</td>
<td>15 minutes</td>
</tr>
<tr>
<td>Wrap up and conclusion</td>
<td>10 minutes</td>
</tr>
</tbody>
</table>

Follow up session of 1.5 hours

Educators will not be able to conduct all the suggested activities in the time allocated. A follow up session of 1.5 hours is recommended if participants feel that they require more information to understand the topics better. The case studies and suggested activities provided should be used as a guide to facilitate this follow up session.

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 2001, there were 252,217 Greek speakers in Australia, representing 1.2% of the entire population.²

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 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.

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.³ 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).⁴ 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.

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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).

**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.

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 Religion**

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 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.

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.

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.

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 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 dying

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.

Intergenerational Perspectives and the Migration Experience

Intergenerational misunderstandings and conflicting expectations are common to all families and communities. 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.

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**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.
A note about case studies

Learning comes from experiencing, thinking and reflecting. Telling stories can help participants to understand information, as well as to relate to a particular experience.

The case studies provided in each module are a good way to encourage group discussion, to allow participants to share their experiences with the group and to think through topics and issues that relate to palliative care.

Educators can change the names or the general circumstances of characters to make the case studies more appropriate to the group. Educators may also tell the story in their own words.

The case studies in this resource are fictional and they do not describe real people.

What resources are needed to run a session?

It is always helpful for participants if they can take information home in their own languages. As a peer educator it is important that you have prepared resources and handouts for participants prior to your session. Palliative Care Victoria has information brochures in the following languages:

<table>
<thead>
<tr>
<th>Arabic</th>
<th>Italian</th>
<th>Portuguese</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chinese</td>
<td>Japanese</td>
<td>Russian</td>
</tr>
<tr>
<td>Croatian</td>
<td>Khmer</td>
<td>Serbian</td>
</tr>
<tr>
<td>Dari</td>
<td>Korean</td>
<td>Spanish</td>
</tr>
<tr>
<td>Farsi</td>
<td>Macedonian</td>
<td>Turkish</td>
</tr>
<tr>
<td>French</td>
<td>Maltese</td>
<td>Vietnamese</td>
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<tr>
<td>Greek</td>
<td>Polish</td>
<td></td>
</tr>
</tbody>
</table>

Educators can access the information brochures online at: http://www.pcvlibrary.asn.au/display/mur/Information+in+community+languages.

If bulk copies of these brochures are required for sessions, they can be ordered from Palliative Care Australia and supplied at no cost. Some can be ordered online at www.palliativecare.org.au or educators can call Palliative Care Victoria on (03) 9662 9644.

Some activities require additional resources (which will be stated), which educators will need to prepare before their session. Additional handouts and questions can be found at the end of the resource and should also be prepared for participants prior to the session.

Peer educator checklist

- Seating arrangement
  It is important that the room has been set up in a way that is suitable for discussion. If possible avoid a lecture style format as this can feel too formal and intimidating for participants. U-shape or circle is ideal.
- Catering
Make sure that participants can access drinks/snacks when they need to.

✓ Resources
Butchers papers, sticky notes, markers or pens are available.

Ensure that any information sheets/handouts that need to be distributed have been prepared and are ready to hand out. Welcome, introduction and are ready to hand out.
Welcome, introduction and icebreakers

1. Welcome participants, introduce yourself, introduce the topic and modules and do the housekeeping.
2. Conduct an ‘icebreaker activity’ – one which allows participants to relax and get to know each other.

Suggested icebreaker activities

The following is a list of possible activities that the educator may choose to use as an icebreaker at the beginning of the session. The activities may be adapted as necessary, or educators may prefer to use their own activities.

1. Favourite holiday or festival
   (Approximately 5 minutes)

   Form small groups of people or pairs. Ask everyone to tell their group or partner what their favourite holiday or festival is and why.

2. Good or new
   (Approximately 5 minutes)

   Ask each person to share something good or new that they have experienced in the last 24 hours.

3. Unique characteristics
   (Approximately 5-10 minutes)

   Divide the groups into pairs and give participants a few minutes to interview each other. Then, each participant should introduce their partner by name and to share at least two unique characteristics about them.

4. Favourite things
   (Approximately 5-10 minutes)

   Divide the group into pairs and ask participants to tell each other their favourite food or name the animal they feel best describes them and why. If you want, this information can be shared with the group by asking participants to introduce their partner by telling the group what was discussed.

5. The magic wand
   (Approximately 5-10 minutes)

   Ask the participants what they would do if they just found a magic wand that allows them to change anything they want. How would they change themselves? They can change anything they want. How would they change themselves, their job etc.? Have the participants say why it is important to makes changes in general.

(Ice breakers adapted from Multicultural Mental Health Australia, Queensland Transcultural Mental Health Centre and the Commonwealth Department of Health and Ageing, Stepping out of the Shadows: Reducing Stigma in Multicultural Communities Training Package, Community Training Manual, 2008. p. 93-95.)
Module 1: Introduction to palliative care

Aim
The aim of this module is to provide a basic introduction to palliative care.

Learning objectives
By the end of this module, participants should be able to:

✓ Provide a basic definition of palliative care
✓ Identify who can benefit from palliative care and when
✓ Explain some of the benefits of palliative care

Discussion points
The discussion should address the following points:

• What is palliative care?
• Who can benefit from palliative care and when?
• What are some of the benefits of palliative care?

Discussion notes

What is palliative care?
Palliative care is all about looking after people with illnesses that can’t be cured, relieving their pain and supporting them and their families through difficult times.

There are several definitions of palliative care. The following definitions are from a number of well-known organisations:

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative Care Victoria (PCV)</td>
<td>‘Palliative care is specialist health care and practical support for those living with a terminal illness’</td>
</tr>
<tr>
<td>Palliative Care Australia’s (PCA)</td>
<td>‘Palliative care is care provided for people of all ages who have a life limiting illness, with little or no prospect of cure, and for whom the primary treatment goal is quality of life.’</td>
</tr>
<tr>
<td>The World Health Organisation (WHO)</td>
<td>‘an approach that improves quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.’</td>
</tr>
</tbody>
</table>
Many people have mistaken ideas about palliative care, so it’s important to understand what palliative care is not.

Palliative care is;

- not the end of all active treatment
- not confined to the last hours or days of life
- not the withdrawal of food and fluids
- not the ‘default’ position when all else fails
- not hastening death by use of drugs
- not artificially prolonging life

Educators should consider

Some participants may be familiar with the term ‘palliative care.’ For others, it will be a new concept. For those who have had little or no personal experience with a terminal illness, the idea of accessing palliative care services for themselves or for a loved one can be distressing. This is because palliative care is often associated with the end of life, even though it is not confined to the last days or weeks of life.

It is important to remember that individuals and family members will respond differently to palliative care, depending on their culture, values and spiritual or religious beliefs.

When delivering information related to ‘what is palliative care?’ focus on the fact is that palliative care aims to improve a person’s quality of life and relieve suffering by offering physical, social, cultural, spiritual and emotional support. The focus of care is on managing symptoms, providing comfort and helping to support the person who has the illness and their relatives. The palliative care team will always consider the cultural, spiritual and social values of the person with the illness, their carers and family members.

Palliative care has a positive and open approach toward death and dying. However, in many cultures it may be that death is a taboo topic and one that is difficult to discuss. It might be helpful to explain to participants that the palliative care team can work with people and their families to ensure that cultural and spiritual beliefs and values are respected and followed. This includes some people’s wishes to avoid discussions around death and dying or expectations of their religious representative to administer certain rituals.

Who can benefit from palliative care and when?

Palliative care is for anyone, including children with a life threatening illness, irrespective of culture, background, religion, or beliefs. This can be provided by the GP and other health care services. Individuals can be referred to palliative care at any stage after diagnosis to assist with complex care needs, including pain and symptom management, and to meet the holistic needs of the person and to support those caring for them. Palliative care can be provided as needed during and at the end stage of a life-limiting illness in combination with GP and other health and care services. Palliative care also supports carers throughout the illness and during the grieving process.

Palliative care can assist people with a range of conditions, including cancer and chronic illnesses such as heart disease, lung disease, motor neurone disease, advanced dementia
and kidney disease. Palliative care is provided based on the needs of the person. A person may live comfortably for months or years and not require palliative care for much of that time, or their illness may advance rapidly and palliative care will focus on their end-of-life care needs. The type and frequency of care given will depend on the individual’s changing needs and circumstances.

Families and carers can also receive support from palliative care services and this will be discussed in detail in Module 3.

Educators should consider

People from all cultures want the best for their family members, particularly in times of illness and uncertainty, but they may have different ideas about what engaging palliative care services might mean. Some people do not want to access palliative care for their loved one who is ill because they are worried it might be perceived by their loved one that they no longer care. If the educator feels that this is the case, it is important to encourage people to think about things from a different perspective. That is, if you want the best for your loved one, palliative care is crucial because it is about providing the best individualised care to the person with a life-threatening illness. It is in fact the opposite of not caring because it recognises the person who is unwell as a whole person with a right to dignity, comfort and support. Family members can look back on their palliative care experience with the knowledge that everything possible was done for their loved one.

Some people who are living with a life-limiting illness might be reluctant to consider palliative care because they think that others might perceive them as ‘giving up.’ (Individuals and families may feel that palliative care it is a sign of weakness because of its association with end of life). It is important to assure people that palliative aims to help patients have the best quality of life until death and to support their carers.

What are some of the benefits of palliative care?

Palliative care aims to help the person live as fully and comfortably as possible. Benefits of palliative care include:

- Pain control
- Treatment and management of common symptoms of serious illness such as fatigue, anxiety, shortness of breath, depression, nausea, weight loss
- Improvement in quality of life
- Addressing sources of social, emotional or spiritual distress
- Supporting carers and relatives, including providing respite, equipment and advice and emotional and bereavement support
Educators should consider

It is not uncommon for people to feel anxious or upset when faced with palliative care. Family members might feel like they are relinquishing control. Similarly, the person with the illness might feel like they are giving up their independence. The palliative care team works with the person with a life-limiting illness and their family to figure out the best way in moving forward. While the list above highlights some benefits, keep in mind that it will be different for everyone depending on their needs. Individuals can benefit from all of those things or they may benefit from just one or two of those things. For example, the person might only want help in managing pain and not be interested in the emotional or spiritual support that palliative care can offer. The list is not exhaustive and palliative care is flexible and responsive to an individual's needs.

Key messages

- Palliative care aims to improve a person’s quality of life and relieve suffering by offering physical, social, cultural, spiritual, emotional and practical support.
- Palliative care is not confined to end of life, and can be provided at any stage after diagnosis.
- Palliative care is for anyone with a terminal or life-threatening illness.
- Palliative care can assist people in different ways, depending on their needs. It is important for people to discuss any issues or concerns they have with palliative care staff.
- Palliative care does not mean that a person is giving up or that their family members don’t care.

1. Activity: Brainstorming ‘palliative care’

(Approximately 10 minutes)

This is a good exercise to begin with as it will give the educator an understanding of the participants’ level of knowledge about palliative care and perhaps some of their concerns about accessing the service (whether cultural or otherwise).

Ask participants to think about and discuss what palliative care means to them. If you can, you may like to whiteboard some of the responses so you can refer to them later on.

Some possible questions:

- What do you know about palliative care?
- What do you think palliative care is about?
- Have you or has anyone you know had any experiences with palliative care? If you feel comfortable to do so, are you able to share some of these experiences?
2. Activity: Talking about health
(Approximately 10 minutes)

The aim of this activity is to convey the idea that good health is more than addressing physical needs.

Ask participants to partner up and have a chat about some of the differences in health services between their country of origin and Australia (educators might like to discuss this as a larger group if they feel that would work better).

Some possible questions:

- Who do you see now when you are feeling unwell?
- What does being healthy mean to you?
- What do you do to feel healthy?
- In your country of origin, what did you do when you were unwell?
- Have your attitudes to health changed since migrating to Australia? How?

3. Activity: Play video, ‘Some things are too important to be left unsaid’
(Approximately 4 minutes)

If educators have access to a computer and internet they may wish to play the video, Some things are too important to be left unsaid which can be accessed here: http://www.pcvlibrary.asn.au/display/mur/Videos+in+community+languages. It is a video about the importance of having conversations with loved ones and family about end of life care. The video is available in 22 languages including Arabic, Greek, Hindi, Italian, Cantonese, Mandarin, Spanish, Sudanese, Turkish and Vietnamese, as well as English.

Educators may wish to play the video at the beginning or at the end of the education session.
Module 2: Service specific information

Aim
The aim of this module is to provide basic information about who is involved in the delivery of palliative care services and where services can be obtained.

Learning objectives
By the end of this module, participants should be able to:
✓ Describe who is included in the palliative care team
✓ Explain where palliative care services can be provided
✓ Identify the cost of palliative care services

Discussion points
The discussion should address the following points:
• Who makes up the palliative care team?
• Where can palliative care services be obtained?
• Where can palliative care services be provided?
• What is the cost of palliative care services?

Discussion notes

Who makes up the palliative care team?
Many different people make up the palliative care team and who provides the care will depend on:
• the needs of the patient (including medical, practical, psychological, spiritual, cultural etc.)
• the resources and needs of the family and carers

A care team may include:
• general practitioner
• specialist palliative care doctor and nurse (physicians, specialists, nurses with advanced training in palliative medicine)
• specialist doctors – oncologists, cardiologists, neurologists, respiratory physicians (A doctor who specialises and practises a particular branch of medicine)
• nurses
• allied health professionals – pharmacists, occupational therapists, physiotherapists
• social workers
• art therapists and music therapists
• grief and bereavement counsellors
• pastoral care workers
• Palliative care volunteers
Palliative care volunteers work free of charge. They are trained to offer support to a person with a life limiting illness and those caring for them. Volunteers can assist the person who is ill and their carers and families in many ways including: giving the carer a break, driving the ill person to medical appointments, taking a record of the ill person’s life story, providing companionship or other forms of support.

Educators should consider

Some participants may never have heard of certain professions such as social workers and psychologists before. In fact, they may have come from countries and cultures where the notion of ‘therapy’ or ‘counselling’ is foreign. Often people from CALD backgrounds may prefer to keep issues or concerns to themselves or resolve issues within the context of the family.

People may express their distrust and anxiety towards having people from a different cultural background involved in their personal business, particularly when it concerns sensitive issues. It is important to encourage people to ask questions and spend some time discussing and dispelling the myths around shame and stigma in relation to seeking professional help. Reassure your participants that the needs of the patient and their families are respected and their wishes will guide decision-making and care planning. Furthermore, the palliative care team are bound by professional ethics and confidentiality.

Where can palliative care services be obtained?

A family doctor or GP may coordinate a person’s palliative care. It is best that individuals talk to their doctor first about their needs and it is a good idea to have their close family involved in this discussion. If English is difficult for them, their GP can organise a free qualified interpreter to be present during the discussion. This should be organised ahead of time.

The GP or the ill person or their family can also request assistance from a specialist palliative care service, which has a trained team specialised in assisting with pain and symptom management, as well as addressing social, psychological, emotional, cultural and spiritual needs associated with a life-limiting illness.

The following specialist palliative care services are available in Victoria:

- Community palliative care services provide care and support to patients and their carers in their home environment.
- Inpatient palliative care within a hospital aims to improve the management of symptoms, to provide care at the end of life, or to provide some respite for carers if a bed is available. Inpatient palliative care is usually for a short period of time.
- Hospices also provide inpatient care in a specially designated section of an inpatient facility. There are also several day hospices that provide respite and therapeutic activities for patients living at home.
- Consultancy services – provide specialised palliative care advice to other health professionals in hospital, aged care and primary care services.

The initial contact with a palliative care service can be made when the ill person is in hospital or when they are living at home in the community or in a care facility.
Anyone can make a referral to a community palliative care service but a referral is required for an inpatient or consultancy service. If in doubt, contact a community palliative care service to discuss the situation.

Palliative care services are available throughout Victoria. It is easy to find a palliative care service using the postcode or suburb search on the Palliative Care Victoria website: [www.pallcarevic.asn.au](http://www.pallcarevic.asn.au) (Victoria wide). You can also call Palliative Care Victoria on 9662 9644. An interpreter can be requested when making the call and this will be arranged.

There is also the National Palliative Care Service Directory where people can search for palliative care services across Australia: [http://pallcare.gky.com.au](http://pallcare.gky.com.au). If people require specific information in their own languages Palliative Care Victoria has resources in 23 different community languages. This can also be accessed through the Palliative Care Victoria website: ([http://www.pcvlibrary.asn.au/display/mur/Information+in+community+languages](http://www.pcvlibrary.asn.au/display/mur/Information+in+community+languages))

**Where can palliative care services be provided?**

Care can be provided in:

- the home
- a hospital
- a care facility, such as residential aged care

It is important to keep in mind that where a person is treated may depend on other factors such as:

- The nature of the illness
- How much support is available from the person’s family and community
- Whether there is a family member or friend who can provide care
- The preference of the ill person and their family
- The availability of inpatient beds

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**Educators should consider**

Many people prefer to receive the care they need during a life limiting illness at home, where they normally live. They may live with other family members, alone or in a care facility (such as residential aged care) that has become their home.

Some families may never have had people other than relatives and close friends inside their home. Therefore, the idea of inviting the palliative care team into their home may be very difficult.

The palliative care team is aware of potential sensitivities and will work with individuals and families to provide culturally appropriate care and to respect their needs and preferences.
What is the cost of palliative care services?

Most palliative care services in Victoria are funded by government. However, there may be some charges that will not be covered by the government such as specific medications not covered by the Pharmaceutical Benefits Scheme, equipment costs, or having a nursing staff to provide round the clock care at home.

Some hospitals offer specialist palliative care services for private patients who have private health insurance. It is important to check with individual health insurers as palliative care is not covered by many health insurers.

Educators should consider

Some people will be worried about the cost of palliative care services so it is important to emphasise that the service itself will generally come at no cost. There can be additional costs (such as equipment hire) however, and a palliative care staff member can advise people about these and what financial assistance may be available.

Key messages

- Many people make up the palliative care team including GPs, nurses, allied health staff, specialist palliative care doctors and trained volunteers.
- The palliative care team can assist people and their families in a variety of ways.
- Palliative care services are available all around Victoria and no referral is required to access a community palliative care service; a referral is needed to be admitted to a hospice (or inpatient palliative care service) and this can be through the GP or the community palliative care service.
- Palliative care can be provided in a range of settings including in the home, in a hospital or in an aged care facility.
- Palliative care services are generally free however, there may be additional costs associated which are not covered by government.
Suggested activities

1. Case study

(Approximately 10 minutes)

The following case study can be read out or retold in the educator’s own words to demonstrate one family’s particular experience of accessing palliative care services.

Eleni’s story - as told by her daughter Despina

My mother Eleni was 67 years old when we decided to use palliative care. She suffered from type 2 diabetes for many years, and more recently with kidney disease, but in general, she lived a pretty independent life with my father and me. I was still living at home because I was studying. My sister, my brother and their families came to visit every Sunday after going to church.

Then quite suddenly mum was rushed to hospital with pneumonia. She didn’t appear to be improving with antibiotics and after having a conversation with her doctor, we were told that it would be unlikely that mum would get better. The only thing they could do for her at this stage was to manage her pain and help make her comfortable. They said the best thing to do was to make the most of the time we had left with her and that we should think about accessing palliative care. Mum didn’t speak English very well and we knew that she hated being in hospital. She told me once that hospital frightened her and that when the time came she wanted to die at home.

It was hard for all of us to think about using palliative care and even more difficult to talk about it with my father. He wanted mum to be at home, but he didn’t think we needed any extra help since I was there. I’m the youngest and my sisters both have children, so it seemed logical that I would be looking after mum. But I felt really worried that I wouldn’t be able to cope. Initially I just called the palliative care number to ask for advice, but after I spoke with them it sounded like they could help a lot and I also discovered that their services were free. I chatted about it with Dad and my sisters and we decided to call and see what services they could offer.

Our palliative care nurse, Diana was wonderful. She made sure I understood everything that mum needed. Dad’s English is not too bad, but I wasn’t sure if he was going to understand everything. Since my Greek is conversational, Diana arranged for an interpreter to come along on the first day, just to make sure. She explained my mother’s condition, and what palliative care could offer mum and the family. As well as nursing, there were counsellors, doctors and other staff who could help us come to terms with mum’s situation, and who would also be available after mum’s death. Diana did a physical assessment of mum, asked whether there were any other issues besides pain. She explained all the medications, and how they should be taken.

After that, she arranged regular telephone calls and visits by the palliative care team to make sure my mum and all of us who were caring for her were OK. It was also a comfort knowing I could receive advice anytime of the day and night. One night mum’s breathing was really bad and a nurse ended up coming out just to check on her. Six weeks after mum died, the palliative care service phoned to check on how we were all doing and said they would call again in another six weeks or so. I realised that palliative care was more than just nursing. We got support as a family before and after mum died and being able to talk with Diana made me feel more comfortable in being able to support mum’s wishes. We couldn’t have cared for mum as well as we did without the palliative care service. I feel blessed that they supported me and take solace in the fact that mum was at home surrounded by family and friends until the end.
2. Activity: Asking for help
(Around 10 minutes)

This activity explores some of the ways we seek help in our everyday lives. The aim of the activity is to show that there are people/services available that can help us feel better or make things easier for us. This might help participants draw a comparison with palliative care and the benefits that it can provide for them and their loved ones.

Ask participants to have a chat about where they seek help.

Some possible questions:
- Who can you call on if you are feeling stressed or need help with managing caring responsibilities? Here in Australia and in your country of origin? Is it sufficient for your needs?
- Have you ever used any other services available in your community in case you need help? If yes, what is your experience of using these services? If not, why not?
Module 3: Information for family and other carers

Aims
The aim of this module is to provide basic information to carers who are giving support to a person who needs palliative care.

*The term ‘family and other carers’ is used to differentiate between professional carers in the palliative care team and an informal carer who is a relative or friend of the person with the illness.

Learning objectives
By the end of this module participants should be able to:

- Identify who a family or other carer is
- Identify when and why a family member or friend or neighbour might provide care
- Describe some ways palliative care services can support family and other carers

Discussion points
The discussion should address the following points:

- Who is a carer?
- When and why might someone become a carer?
- How does palliative care support family and other carers?

Discussion notes

Who is a family carer?
A carer provides informal care to someone who is in need of support. Typically, an informal carer or family carer is a family member or a friend of the person needing care due to life-limiting or incurable illness.

While several family members can be involved in supporting and providing care to the individual, in most cases, there will be one person who is seen as the main carer.

When and why does someone become a carer?
A person becomes a carer when a family member or friend requires support to remain living at home.

Sometimes people live with a life-limiting illness for many years. Many people are fortunate to have someone who has already taken up a caring type role during the pre-palliative stage of their illness. Often these people see themselves as the ‘carer’ (even though they might not describe identify as one) before the decision to access palliative care is made.

The decision of taking on the caring role can be based on many factors, including: the desire to care for a loved one, the belief that no one else is available, cultural expectations within the community, and/or a commitment to reciprocate the care that parents once provided their children.
Being a full time carer can feel overwhelming and daunting at times. The important thing for carers to remember is that they are not alone. There are different people, organisations and services that they can call on for help.

**Educators should consider**

In some ethnic communities, it is common for a partner or close relative to be in a caring role for some time before palliative care is needed. Some people will not consider themselves a ‘carer’ but simply as someone who is supporting their loved one through their illness. In cultures with strong family or community bonds, family members will look after any family member who becomes unwell and will do so at any cost – financial or physical. In this sense, caring is not a role that one undertakes but a desire that one has to look after a loved one. Others may take on the care giver role because they feel they should or because their members of their community may expect them to. This is particularly true for women who may find themselves ‘thrown into’ a caring role due to traditional role expectations and responsibilities. Whatever the situation, it is crucial that family carers have all their options explained to them.

**How does palliative care support carers?**

Caring for a family member who is living with a terminal illness can be a very challenging time. This is why one of the important features of palliative care is that patients and their carers are the focus of care.

Carers and their families may experience stress and anxiety associated with:

- Uncertainty or unclear about the course of their family member’s illness
- Questions about how to best care for their family member and make sure that they have the services they need
- Financial concerns and changes in paid employment
- A perceived lack of support from family and friends

Carers may also feel guilty or upset when they prioritise their needs over the person they are caring for. It is important for carers to remember that their wellbeing is crucial in being able to support their relative through their illness.

Some of the ways a palliative care team can help carers:

- Teach a carer different ways to help their relative
- Provide a carer with advice related to seeking financial assistance or other practical assistance related to medications etc.
- Undertake tasks that might make the carer feel uncomfortable i.e. administering of medication
- Provide support to the carer if they need a rest or break
- Offer support and answer questions that individuals and their families have about end of life
- Can work with individuals and their carers within the context of their culture
Educators should consider

Some people may be intimidated by palliative care nurses or others coming into their homes. This might be the case especially for people with low English proficiency. The palliative care team are respectful of the sensitivities that people may have and families can specify how involved they want the palliative care team to be. Remember that the palliative care team are very experienced in answering challenging questions and trained in providing assistance in different situations.

Key messages

✓ A family carer is someone who takes on the responsibility of looking after someone who is ill.
✓ Often people will be in a caring role well before palliative care is accessed.
✓ Some people will take on the role willingly, while for others it will be seen more as an obligation.
✓ Being a carer can be difficult and demanding. This is why family carers are also the focus of the palliative care team.
✓ Palliative care supports family carers in a number of different ways.

Suggested activities

1. Activity: Who does the caring?
   (Approximately 10 minutes)

Ask participants to partner up and have a chat about who does the caring in their families (educators might like to discuss this as a larger group if they feel that would work better).

Some possible questions:

• What does caring mean to you?
• Who does the caring in your family? Why?
• What kinds of things does a carer do?
• Have you ever cared for someone with special needs? What did it involve? How did you feel?
• Have you ever been in a caring role for someone with a life-limiting illness? What did it involve? How did you feel?
2. Case study: When caring gets too much
(Approximately 10 minutes)

The aim of the activity is to shift the discourse from providing care/managing caring responsibilities to highlight the fact carers are not alone. There are support services available in the community, including palliative care services.

The following case study can be read out or retold in the educator’s own words to explore issues around caring for someone with a life-limiting illness.

Maria has been caring for her husband Vasilis since he was diagnosed with emphysema eleven years ago. Recently Vasilis’s breathing has become worse. He is always tired and he cannot walk far without becoming breathless. Lately he has been too tired to bathe himself. Maria also feels very tired and lately has become unwell and is struggling to provide the extra care that Vasilis needs.

Maria thinks that more treatment or medicine for Vasilis might help, but Vasilis doesn’t speak English well so he is reluctant to ask his doctor.

Their daughter Anna comes every week to help around the house and to take her father for doctors’ appointments and hospital visits but she has her own family to look after. Anna is becoming increasingly worried about her parents because she can see that her father probably needs more help that her mum can give him. Anna does not know what to do.

Questions to explore:

- What are some of the issues of concern in this story? Has this ever happened to anyone you know? What did they do?
- How might Maria feel about the situation? How might Vasilis feel about the situation? How might Anna feel about the situation?
- What are some of the ways this family can manage this situation?
- How would you manage this situation? What are the ways you would have managed this situation in your country of origin? *
- Where could Maria, Vasilis or Anna get more support?

* Bilingual peer educators should assess the group in deciding whether to ask the second question here. It is designed to promote a discussion about how things in Australia might be different from in participants’ country of origin and how these differences might affect the choices people are able to make – for example for people from a village background in their country of origin, there may be a network of neighbours, extended family members etc who would/could provide care. This type of support may not be available in Australia.
Module 4: Start talking about palliative care

Aims

The aim of this module is to provide participants with an understanding of the different cultural issues that may be relevant to people and their families when engaging with palliative care services. Broadly speaking, it also aims to empower participants to talk about the prospect of engaging palliative care services should the situation arise, for themselves or for a family member.

Learning objectives

By the end of this module participants should be able to:

- Think about their own cultural aspects around death and dying and initiate conversations about palliative care in their communities
- Understand that behaviours associated with grief are individual and sometimes culturally bound
- Identify some key strategies that might assist individuals and families navigate cultural barriers within palliative care
- Identify some ways that palliative care can support individuals and family through end of life

Discussion points

The discussion should address the following points:

- Why is it important to talk about palliative care?
- What are some other cultural aspects to think about?

Discussion notes

Why is it important to talk about palliative care?

Talking about palliative care helps to address fears and anxieties and to share information about what is most important to the person with a life-limiting illness, including their needs and preferences. Some people may be hesitant to talk to others (particularly to non-family members) about end of life because they see it as their own private business or they might not be willing to admit that death is approaching. The fear and taboo nature around talking about death might be why some people feel that it is culturally inappropriate to engage palliative care services in the first instance.

People may feel that health professionals do not understand the particular aspects of their culture in relation to death and dying. It is worth reminding participants that they can assist the palliative care staff to understand their preferred cultural, religious or spiritual practices by talking with staff, or by writing down their thoughts. This can help staff to understand what the person and their family is hoping for and avoid causing offence. If a person has any concerns about certain issues, they should speak to someone on the team, preferably in the early stages of palliative care. Patient and their families are viewed by the palliative care
team as the source of knowledge about their cultural needs and practices and they appreciate it when you share this information.

**Educators should consider**

Judging from participants’ level of engagement and reactions from information already delivered, by this stage of the session, the educator should have a good idea about how to best approach this module. Keep in mind that at this stage, discussions about death and dying should have already been touched upon. Educators should consider the following and decide which activities will best convey this information.

**Taboo topics**

In many cultures, words such as cancer, death and dying are avoided because they are seen as ‘bad luck’ or very threatening. Some people might refer to cancer as the ‘cursed disease’ or the ‘bad disease’ because the term ‘cancer’ invokes fear because of its association with death, pain and suffering. This may cause family members to keep information from the person who is ill about their health status or terminal prognosis because they want to protect them.

**Grief**

When people experience loss, it is usually followed by a period of grief. Grief can also occur before loss is experienced. It is a normal and natural response, and there is no set timeline or pattern that it follows. There is no one way to grieve, and people will experience grief differently, even if they are from the same culture. Broadly speaking, some cultures want to express their grief in private, while others may be much more open with their emotions. In some cultures, a vocal display of grief is expected as it demonstrates that the person was extremely loved. Cultural responses to grief may also be different depending on a person’s gender.

Often in times of great challenges and uncertainty, people turn to cultural beliefs and practices that are the most familiar and comforting to them. Within cultures, individuals will have different ways of practicing and respecting their culture. It is important not to assume that people from the same cultural background will feel the same way or react in the same way.

**Talk to palliative care staff about your cultural beliefs**

Palliative care staff are used to working with people from different cultural backgrounds and are often familiar with different cultural practices around end of life. Generally speaking, they understand that different cultures will have different ways of coping with the challenges that come with palliative care, including discussions around death and dying.

The palliative care team will aim to respect the family’s way of grieving and will be available for any support that they may need. The palliative care volunteer may spend time with the carer or they may refer family members to a counselling service or bereavement support group if it is culturally appropriate.

If there has been openness between the family and palliative care staff, then the staff will have a better understanding of a person’s culture and belief system. They will be more aware of the mourning ceremonies and traditions of the family, which can also provide comfort to the family.
Some other cultural aspects to think about

Here is a list of other cultural issues that people might want to discuss with the palliative care team, in order to avoid confusion and discomfort. Please be aware that accredited interpreter services are available and this can be arranged through the palliative care team, if and when required.

- The patient and family’s perspective on health and suffering
- Western health care practices and use of alternative traditional practices
- The role of spiritual and religious beliefs and practices
- The role of the family, including who acts as the family spokesperson
- How the patient and family communicate
- Family expectations regarding communication about diagnosis/prognosis with the patient
- Patient’s own role in problem solving and decision making
- Collective decision making
- Perception of status of health professionals - who has the power?
- Facts about morphine and other opioids

Educators should consider

This list might not be relevant for everyone and participants will have their own ideas and suggestions to contribute. This will be based on previous experience and interaction with Australia’s health system and their own cultural perspectives.

Key messages

- In many cultures, death and dying are seen as taboo topics.
- People will have different ways of practicing and respecting their culture, even within culture.
- The palliative care team aims to provide care that respects and responds to the person and their family’s cultural and spiritual values and practices.
- People can assist palliative care staff by talking to staff about their cultural values and beliefs.
- Everyone experiences grief differently, even if they are from the same culture. There is no right or wrong way to grieve.
- Palliative care can support people and their families through end of life and bereavement.
- Interpreter services are available if required.
Suggested activities

1. Activity: ‘Think of a time’
   (Approximately 5 minutes)

Improving a person’s quality of life during an ongoing illness can mean different things to different people. There are however some common factors across most cultures and communities that can support a person to have the best quality of life during this time.

This is a good exercise to explore why palliative care is important for people with a life-limiting illness. It can also demonstrate that people have different cultural experiences that will impact their needs when they are unwell. It is important to re-iterate that when people are unwell and they ask for help, this does not mean that they are giving up or they no longer care.

Ask participants to think of a time when they were sick (some participants might prefer to talk about a time when a family member or friend was unwell, rather than when they were). If it appropriate, ask participants to discuss in pairs or groups of three. Educators may like participants to come back and share their discussions with the main group.

Some possible questions:

- Can you think of a time when you were sick? How did you feel?
- What did you need to help make you feel better?
- Did anyone help you?
- How did you feel about asking for help?

2. Activity: ‘Mourning in my culture’
   (Approximately 5 minutes)

This activity explores different cultural customs and values related to grieving and mourning. It can be done in small groups or if educators feel that participants are comfortable with one another, issues can be discussed in one large group.

Ask participants to discuss their cultural customs around death and explore the value of these customs.

Some possible questions:

- What are the customs, beliefs and practices around death in your culture or faith group?
- Which of these are helpful and why?
- Are any unhelpful and why?
- How could a palliative care team give support to the grieving family in this setting?
3. Activity: Conclusion and debriefing
(Approximately 5 minutes)

This is a good activity to wrap up content and to make sure that participants have understood the key messages of the session. Educators might like to break participants up into small groups and if appropriate.

Ask the participants to briefly make a verbal list of 2 or 3 of the key points of the session.

Ask the participants how this session helped their understanding of palliative care. Maybe they learnt something new or changed their opinion of palliative care because of this session.

Make sure:

- Participants have enough time to discuss their learning experience and provide space to explore some ideas further (this might need to be done in a follow up session).
- This does not turn into a negative or unproductive activity.
- The session ends on a positive note and thank participants for their time and engagement.
Further information

It is always helpful for participants if they can take information home in their own languages. As a peer educator it is important that you have prepared resources and handout for your participants prior to your session. The following information can be reworked into an information handout or educators might prefer to spend a few minutes at the end of the session explaining where participants can go for more information.

Where can I go for more information?

**Palliative Care Victoria**

**Information and referral service**

Palliative Care Victoria provides an information and referral service. Telephone 9962 9644 during business hours (9 am to 5 pm Monday to Friday). A telephone interpreter service can be arranged – please indicate the language required.

**Palliative Care Service Location**

You can search for a palliative care service using the suburb or postcode search available on the Palliative Care Victoria website: [www.pallcarevic.asn.au](http://www.pallcarevic.asn.au)

**Information in community languages**

There are many useful resources in the multicultural section of Palliative Care Victoria’s online library – [www.pcvlibrary.asn.au](http://www.pcvlibrary.asn.au) – go to the multicultural section and select culturally and linguistically diverse communities. You can also search using one of 23 community languages and download brochures in 21 community languages or watch short videos in 23 community languages.

**Other Organisations**

It is also important to be aware of different organisations who are working with culturally and linguistically diverse communities so you can refer your participants to them.

**Relevant websites:**

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<tr>
<th>Organisation</th>
<th>Description</th>
<th>Website</th>
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<tr>
<td>Australian Multicultural Foundation</td>
<td>Promotes awareness, respect and understanding of cultural diversity in Australia and its contribution to our community. Its activities include training, research, projects, events and publications.</td>
<td><a href="http://amf.net.au/">http://amf.net.au/</a></td>
</tr>
<tr>
<td>Cancer Council Victoria</td>
<td>Provides cancer information and resources in community languages. You can also talk confidentially to a Cancer Council Nurse with the assistance of an interpreter in your community language. Call 13 14 50 Monday to Friday 9 am to 5 pm, state the language you need, wait on line for an interpreter (up to 3 minutes) and ask the interpreter to contact the Cancer Council on 13 11 20.</td>
<td><a href="http://www.cancervic.org.au/other_languages">http://www.cancervic.org.au/other_languages</a></td>
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<tr>
<td>Organisation</td>
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<tr>
<td>Centre for Cultural Diversity in Ageing</td>
<td>A Victorian based organisation that primarily supports the aged care sector and addresses the needs of elderly people from CALD backgrounds. They provide training, consultancy and translation services to the aged care sector. They also support CALD communities to better understand the aged care services.</td>
<td><a href="http://www.culturaldiversity.com.au/">http://www.culturaldiversity.com.au/</a></td>
</tr>
<tr>
<td>Centre for Culture, Ethnicity and Health</td>
<td>Provides specialist information, training and support on cultural diversity and wellbeing.</td>
<td><a href="http://www.ceh.org.au">www.ceh.org.au</a></td>
</tr>
</tbody>
</table>

(Taken from Palliative Care Victoria, [http://www.pallcarevic.asn.au/multicultural/cald-communities/cald-websites-resources/](http://www.pallcarevic.asn.au/multicultural/cald-communities/cald-websites-resources/))

### Additional questions

It is important to be aware of places where people can learn more about palliative care and where people can go to feel supported. These include GPs, nurses and palliative care agencies. People can also talk to their local ethno-specific agency if they need help accessing information in their own languages.
References


Palliative Care Victoria. 2007. About Palliative Care: Some frequently asked questions about palliative care in Victoria.


Cancer Council NSW. 2009. Understanding Palliative Care: A guide for people with cancer, their families and friends.

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.
Handouts

Handouts in the relevant community languages are available for participants. These are tailored to each community based on feedback.

They include the following information topics:

**Frequently asked questions about palliative care**

- What if I do not speak English well?
- Who can I ask for more information?
- If I use palliative care, can I still see my GP?
- If I use palliative care, do I have to leave my home?
- If I use palliative care, who will know about my illness?
- Can I stop palliative care once I start it?
- Can I choose if my palliative carer is male or female?
- When should I consider palliative care for myself or a loved one?
- What practical support can palliative care offer?
- Does palliative care use morphine for pain?

**Some things to remember**

- What is palliative care?
- How does palliative care work?
- How does palliative care help carers and families?
- Talking about palliative care
- Where can I go for more information?