

Multicultural Palliative Care Guidelines



Andrew Taylor and Margaret Box

Palliative Care Australia

Funded by:

- The Commonwealth of Australia, Department of Health and Aged Care
Palliative Care Australia gratefully acknowledges the financial assistance of the Commonwealth Department of Health and Aged Care. However the views expressed may not represent the views of the Commonwealth.
- The Palliative Care Council of South Australia
- Palliative Care Victoria

© Copyright 1999 Palliative Care Australia

ISBN: 0-646-38432-5

Disclaimer:

The information contained in this book is for general guidance only. It is a compilation of views that do not encompass all views of the various language, cultural and religious groups mentioned. The authors, contributors, Palliative Care Australia and the Commonwealth can accept no liability for errors or omissions in this book.

The authors urge you to treat each person as an individual, seeking to understand their particular needs.

Limited additional copies of this book are available on a cost recovery basis for \$7.00 each, from:

Palliative Care Council of South Australia
202 Greenhill Road
EASTWOOD
SOUTH AUSTRALIA 5063

Contents

| | |
|-------------------------------------|-----|
| Acknowledgments | 4 |
| Preface | 5 |
| Palliative Care is ... | 6 |
| The project | 8 |
| Traditionally ... | 9 |
| Australians today | etc |
| Religion | |
| The way forward | |
| Practice guidelines | |
| Statistics - The 20 language groups | |
| Map Comments | |
| Maps | |

- Adelaide
- Brisbane
- Canberra
- Darwin
- Hobart
- Melbourne
- Perth
- Sydney

Language groups

- Arabic
- Bosnian
- Chinese
- Croatian
- Greek
- Hindi
- Italian
- Japanese
- Khmer
- Korean
- Macedonian
- Maltese
- Persian
- Polish
- Portuguese
- Russian
- Serbian
- Spanish
- Turkish
- Vietnamese

Bibliography

Palliative Care Australia and member organisations

Acknowledgments

The authors wish to thank all those who have assisted this project, without whose cooperation and willing assistance, this book would not have been possible:

Community Consultants

Jasmin Abdic, Father Antoun Abourjeili, Athan Anagnostou, Saad Andrawos, Franca Antonello, Luigi Astegno, Inaam Baraket, Azaz Baroudi, Lucero Barreto, Inder Bhagwanani, Pui Fong Castrey, Sabina Chang, Dorota Cipusev, Dr Tony Cocchiaro, Dr Le Cong, Bonnie Costa (Leung), Dr Daniella Costa, Demis Croucas, Olga Dinef, Olga Djuric, Lillian & John Falzon, Michael & Eileen Feldman, Reiko Furukawa, Dr Sophia Georgiou, Eugenia Georgopoulos, Diana Gibson, Alev Guven, Ron Hall, Anatalia Hermosrsima, Sudha Joshi, Balbir Kaur, Sophin Kheav, Lia Kljajic, Jola Kozak, Dr Peter Kreminski, Rebekah Kriticos, Louise Kummerow, Maria Langwell, Walter Lebedew, Joe Leung, Ornella Lewin, Kerry Lewis, Anna Maria Magnera, Maria Maia, Klara Maksimovic, Farida Meier, Father Gabriel Micallef, Lana Mohammad, Mirsada Mohamed, Shahid Naqvi, Lien Nguyen Navas, Dr Thi My Ngo, Ai Hue Nguyen, Cam Nguyen, Lan Nguyen, Savri Ouk, Very Rev Father Patsouris, Tuong Pham, Dung Thi Ngoc Phan, Jelena Poljak-Fligic, Dr Peter Poon, Saliha, Frances Separovic, Christina Shelton, Namiko Shirai, Zena Sidawi, Simone Sumide, Gosia Skalban, Pirun Sok, Yasmina Sumracki, Sathavy Suos, Stelle Tallorito, Ronald Tan OAM, Father Reinaldo Vassoler, Donna Verderame, Lan Young, Ngoat Vu, Dr J Vuckovic, Vasko Vukoje, Rene Weal, and Nina Xarhakos-Godbold.

Editorial advice and proof reading

Dr Mary Brooksbank, Tony Carella, Jelena Poljak-Fligic, and Professor Allan Kellehear.

Other assistance

David Binney, Fulvia Corelli, Carmel Darcey, Kate Fotidiatis, Sue Hilton, Giang Le-Huy, Tim Monson, David Page, Marie Paul, Hellen Taylor, Jan Wilton, and Vivienne Yeoman.

It has been a privilege to work with them all.

Andrew Taylor and Margaret Box
November 1999

Preface

A desire to educate the community about palliative care falters at the doorstep of Non English Speaking Background (NESB) groups. An inability of some Australians to read English is just the first stumbling block. Cultural attitudes and traditions create a tricky path, requiring a delicate tread. Being informed that the words Death, Dying and Cancer are taboo for many cultures creates immediate difficulties in discussing palliative care!

In working with people from other cultures, we inevitably bring with us our own attitudes and beliefs, learnt mostly in childhood. Each participant in a conversation also represents various factors to the other, in areas such as age, status, and gender and, at times disability. Questions that we may regard as 'standard' may offend or embarrass others. We must be sensitive in our use of words, striving to avoid condescension and rather to be regarded as having empathy.

To encourage an open relationship, it is important not to leap to stereotyped conclusions, but rather, that we seek to learn about the beliefs and needs of the person who has come to us for help. Confessing that we know little of another's culture and seeking to learn more about it is a large step towards bridging the gap between cultures.

Each cultural group is by no means homogeneous; some community leaders are well integrated in to Australian society and seek an open 'one size fits all' dialogue, but most are cautious, unwilling to upset the strongly traditional members of their community. Producing pamphlets that will be acceptable to an elderly person with only basic literacy skills in their mother tongue, but not insulting to a recent tertiary graduate of that country, requires careful consultation and consideration.

We should understand that the provision of written material or an interpreter does not entirely solve the problem. The social strata in many ethnic communities are very strongly adhered to and thus if we provide an interpreter from a different stratum to that of the patient and their family then we may insult them. Consideration of gender is important when conveying information – in some societies and with some conditions, information conveyed by a man to a woman or vice versa would be considered highly improper.

It is also important to find out who we should be addressing when conveying information about a patient's condition. In some cases, it would be the patient themselves, others the spouse or the eldest son. If we are not sure, then we must ask what is appropriate. There is no harm in acknowledging our limited knowledge of a particular culture and its customs but there may be significant harm if we ignore our limitations and insult or otherwise breach important customs.

In all groups consulted for this booklet, there was advice that individual circumstances or wishes could vary no matter what the 'usual' may be for that language or religious group. It was difficult to make decisions about what terms were used - NESB, multicultural, ethnic or migrant. Each term has gained or lost its position of political correctness at different periods and each term is more or less evocative. Each of the terms has been used and was conveyed to the authors by those consulted.

How then can we ensure that palliative care is understood by and available to, ALL Australians?

Palliative Care is....

Caring for a loved one who has a terminal illness.

Palliative care is the support of people who are suffering from an illness from which no cure can be anticipated. The aim of palliative care is to maximise the quality of the person's life. This is achieved by coordinating and delivering a range of services in response to the individual needs of the person being cared for and the caregiver.

It is recognised that a range of problems, including physical, emotional, social and spiritual may need attention.

Where?

Palliative care is delivered, where possible, where the person wants to be. It can be provided:

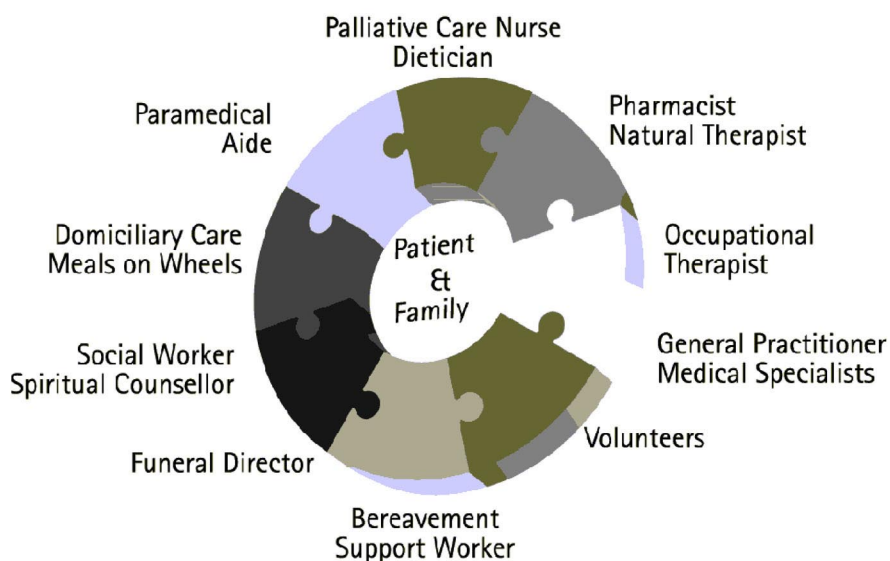
- in the person's own home
- a hospice
- a hospital
- a nursing home

Family, relatives and friends are the main carers. Professional help can come from the palliative care team.

If I am in pain, can it be eased?

In almost all cases, pain relief can be achieved using: a range of painkillers and other drugs, massage, meditation, aromatherapy, acupuncture, and radiotherapy, where appropriate. Recent advances in pain killing drugs include slow release morphine tablets and skin patches.

Palliative Care is a *team* effort



What is a Hospice?

A place devoted to care of the terminally ill, staffed by specifically trained doctors, nurses, social workers, physiotherapists, and volunteers; offering total care for patient and family, including physical, emotional and spiritual support.

Volunteer support

- Caring for someone with a terminal illness can be emotionally and physically exhausting; Volunteers provide relief to carers by providing practical assistance and emotional support
- To find out more about how you can help, contact your local palliative care service

What if you do not speak English well?

The palliative care team is sensitive to your culture and language. Please do not hesitate to ask for an interpreter. You can use a qualified interpreter or a family member.

Who to ask for help or information

- Your treating doctor
- Your nearest palliative care service
- Your priest or religious adviser
- Your cultural associations

The project

In May 1998 the Palliative Care Council of South Australia needed to consider reprinting brochures about palliative care in Italian, Greek, Polish and Vietnamese. Meanwhile Palliative Care Victoria was similarly seeking to revise and expand a range of brochures in 15 languages. Both organisations decided that it would also be beneficial to produce a multi-cultural guideline for health professionals and others working in or associated with palliative care. The Western Palliative Care Service had produced a similar book on the above four languages in 1995. ⁽¹⁾

To reduce costs, a collaborative approach was established and the number of language groups increased to 20. In addition, the work performed in SA and Victoria was offered to the national body, Palliative Care Australia (PCA). PCA enthusiastically endorsed the project and chose this as a focus for National Palliative Care Week 1999. A submission to the Commonwealth Department of Health to fund the extension of the project to other states was successful, resulting in national coverage. This has enabled an outreach capability to sections of the Australian community who have been identified as having less awareness of palliative care than their English-speaking counterparts.

The need

A professional survey of 3000 South Australians in 1998 had shown that community awareness of palliative care was 52% overall, but only 37% for respondents born outside Australia and the United Kingdom. Australian Bureau of Statistics data from the 1996 Census revealed that over **3 million Australians spoke a language other than English at home**. 17% of these had little or no proficiency in English, giving us a target audience of over half a million who would benefit from brochures on palliative care, in their own language and sensitive to relevant cultural issues.

Community consultation was conducted in Adelaide and Melbourne, based on concepts developed by the Western Palliative Care Service Project. ⁽¹⁾ These concepts included: taboo words, communication of diagnosis and prognosis, role of family and friends, cultural aspects, role of health professionals and volunteers, and attitudes to pain relief.

Brochures for the five major cultural groups: Italian, Greek, Vietnamese, Chinese and Polish, comprising 62% of the total print run, were produced for distribution during National Palliative Care Week, July 11 - 17 1999. Brochures in the remaining 15 languages followed in November 1999.

The extension of the project to include some multicultural guidelines was considered to be particularly important. We have welcomed many cultures to this country and their customs, rituals and values have added a richness to our community. We must do our best to ensure that a sensitive approach and respectful consideration are given to any person with a life-threatening illness and their family and friends. Because there are many customs and rituals, with which we may be unfamiliar, these guidelines have been developed to assist those working with these people, and their families.

It should be noted that the information and advice has been given by a number of individuals and organisations from the many cultures. This information is not extensive and there is an understanding by the writers that there will be many other viewpoints. The guidelines are presented purely as guidelines. Health professionals and others working with people with a life-threatening illness and their families should always be prepared to ask their advice on how they wish to be treated.

Traditionally . . .

In most cultural groups, the family has traditionally been the main source of security, assisted by the church. Rituals provided a structured pattern of behaviour and gave comfort. These rituals were perhaps most important at the time of death, when people must cope with strong feelings of loss and of having to confront their own mortality. Migration from the country of birth cuts off many support systems, increasing the sense of helplessness in time of need.

Displacement from the mother country has tended to cause groups of migrants to settle in close proximity, in order to retain their traditional community support. In the post World War Two era, this model seemed to work, but second and third generation migrants have become Aussies. They are not necessarily prepared to stay living in a family enclave. There are jobs interstate and other reasons and excuses for leaving the family. In the last decade, multicultural community leaders have been astonished to find that elderly members of their community are living alone, some of them having little or no proficiency in English.

Our migrants now occupy a unique position. They are to some extent a microcosm of their former country and also sometimes represent a time warp. Many believe that time has stood still in their country of origin and find it difficult to accept that change has occurred. Those who do make a return visit are amazed to find that their former country now has television, MacDonaldis and that some customs have changed.

Australians today

People in the Australian community have lost much of their former strong adherence to religion. The piety and conformity have been replaced with fading belief in heaven and hell, plus a strong individuality of spirit. Death is a private and constrained time for the bereaved. This contrasts strongly with many cultures, for whom death is a public community event, often accompanied by weeping and wailing – public expressions of grief not common in Anglo-Saxon communities.

Our ability to deal with people from another society is limited by our own knowledge and experience. If we were able to step back and view a broader picture of the world's cultures, we may find that it is our western culture that is highly deviant. Colin Murray Parkes in his book *Death and bereavement across cultures* ⁽³⁾ suggests that our culture, which tends to discourage overt emotion at funerals, differs not only from most other societies, but also from our own society, as it was 100 year ago.

The western trend to medicalisation of death has removed death from many Australians' experience. Although surveys indicate that 60% would like to die at home, perhaps only one third of us do so. Childhood death is also very rare and children's involvement in the dying process of relatives is less common here, thus many Australians have not witnessed a death. Funeral arrangements are also handed to other people. On the other hand, the traditional migrant family has members die at home, surrounded by family. The community assists with funeral arrangements, often following strongly ritualistic procedures.

The general community attitudes in Australia are thus barriers to the provision of culturally sensitive palliative care. Awareness of some of the key issues for migrants are essential. This project seeks to explore and present some guidelines to assist health practitioners deal sensitively with people of Non English Speaking Background.

Religion

Religion is the mainstay of many cultural groups. Some religions require strict adherence to rituals, which many Australians regard as odd, although they are generally tolerant of other people's beliefs. At a Hindu funeral, any one who knew the deceased is obliged to attend. In contrast, a middle class Anglican funeral is often seen as a private affair, primarily for the family.

There are a number of religions that cross language and cultural boundaries. It is important when working with a person facing a life-threatening illness and their family to understand where religion fits within the spectrum. There are many for whom religion in the context of their life in Australia does not have as significant a role as it may have in their homeland. However, when faced with a life-threatening illness and the possible or subsequent death of a family member or friend, religious practices, rituals and beliefs may resume an important place.

We must not make assumptions about people on the basis of their language. In addition, we must not assume that all people within a particular religion practice the same rituals, have the same beliefs or the same language. As with many other things that make us individual, there are many choices and many paths followed.

There are a number of books on religion and its practices and rituals. ^{(3) (4) (6) (7)} These cover aspects of death and dying to a far greater extent than is possible in this book. It is important for health professionals and others to acquire some knowledge about these issues to ensure a sensitive approach is taken when working with people facing terminal illness, their family and friends.

The following two religions are but two examples which cross geographic, cultural, and language boundaries:

Christian Orthodox

The Orthodox religion is practiced today much as it was practiced hundreds of years ago, and is highly ritualistic and symbolic. ⁽⁵⁾ After death, the priest says the first prayer and a candle is lit. This is repeated for 40 days, because it is believed that the soul roams on earth for 40 days, as did Christ. The lighting of the candle is symbolic in asking God for forgiveness on behalf of the deceased.

The coffin is taken home on the way to the funeral service, so that the deceased can visit their home for the last time. Wailing usually takes place at the home.

At the church, every person lights a candle as they enter, in memory of the deceased. The coffin is usually open and an icon placed on the body or the coffin. At the end of the service, everyone pays respect to the deceased and the icon, by passing the coffin.

At the cemetery, the last funeral prayer is said and the body is buried facing east, because when Christ was born the guiding star was in the East. The family has supplied a small bottle of wine mixed with oil and some wheat or bread, to the priest at the church. When the last prayer is finished, the priest pours the wine and oil mixture over the lowered coffin, making the sign of the cross three times, symbolising the Holy Trinity and sustenance for the departing soul. The priest sprinkles earth into the grave, followed by family and friends. A wake is held and the priest goes to the house of the deceased in order to bless it for the living.

Masses are conducted as memorials, at 3 days, 9 days, 40 days, 6 months, 12 months and 3

years. After each mass, food is eaten in honour of the deceased's soul. In the Orthodox religion, cremation is not permitted because it is believed that we are made from earth and that we shall return to the earth.

Islam

The Muslim Guide ⁽⁶⁾ explains that Islam means peace and submission to the will of God (Allah). For one fifth of the world's population Islam is both a religion and a complete way of life. The Quran (Koran) is the sacred book of the Muslims.

Five pillars form the framework of a Muslim's life:

1. Faith (shahada) The verbal pledge that there is only one God and that Mohammed is the messenger of God.
2. Prayer (salat) The performance of five daily prayers.
3. Fasting (Saum) From dawn to sunset during the month of Ramadan.
4. Purifying Tax (Zakat) An annual payment of a certain percentage of a Muslim's property, which is distributed among the poor.
5. Pilgrimage (Hajj) The performance of a pilgrimage to Makkah (Mecca) is required once in a lifetime, if means are available.

Muslims are required to pray five times a day, following ablution. Facilities for ablution and a quiet clean place to pray are necessary to facilitate these activities.

Alcoholic drinks are prohibited. The only food restrictions are that pig in all forms and carnivorous animals are forbidden and that other meat must be Halal (lawful) ie: slaughtered with a sharp knife, in the name of Allah.

Dress should be modest and women are usually covered from head to toe, with only the face, hands and feet showing.

The family is a very strong unit for Muslims. The elderly are revered as valuable members of the family, who reinforce family values and provide a wealth of Islamic knowledge. The aged are cared for at home if possible, but will accept respite care and nursing homes if necessary.

Islam encourages burial as soon as possible, preferably on the day of death. Cremation is forbidden. The body should be handled as little as possible, ideally only by members of the same sex, who are Muslims.

The way forward

Treat each person as an individual.

To assist someone from another culture, we must set aside our own beliefs and seek to understand the needs of the other person. Some concept of basic tenets of other cultures and religions will assist us, but we must resist the urge to categorise. Provision of material in different languages or provision of an interpreter may assist, but these do not address issues of individuality nor the importance in some cultures of a person's place in the societal stratum.

We must seek to learn about the beliefs of the person before us. We should try to gain an understanding of the depth of those beliefs and we should learn whether their religion is more important than other aspects their culture, related to their country of birth. These factors may impact on how we treat or support the person and their family.

When many people age, develop dementia or become ill, they revert to their native tongue. This is a 'comfort zone' and although you may be aware that the person is quite fluent in English at this time it may be important to understand that there is a preference for communication in their native tongue.

The different religions have varying degrees of adherence and influence amongst communities. Sometimes there are different practices depending upon the country of origin of the individual. Many of the customs, rituals, beliefs or constraints may not apply or be important if the person is younger or is from a second or third generation in Australia. As always, it is important to ask the person and their family.

The 'spokesperson' in each family may differ, no matter what is the custom. It may be that usually it is the older son, but family circumstances now dictate it is the youngest daughter. Always check and do not assume. It is important to reiterate that the view of the patient may differ from that of the 'spokesperson' and hence there may be some difficulties or 'politics' surrounding meeting the needs of the person who is ill and not breaching customary or familial boundaries.

The main rule is there is no rule. Treat each person as an individual. We must **ask** how we may help and we must **listen** to the response. Our mere presence as a person who cares, will be a significant starting point.

Practice guidelines ⁽¹⁾

- Consider a family meeting. The key decision-maker may not be the same person as the primary caregiver. Be aware of family dynamics, and power relationships.
- Although people with a moderate comprehension of English may appear to understand discussions, use a professional interpreter to communicate complex medical information.
- Offer the family the opportunity to have a Priest or religious adviser in attendance, to assist with prayer and other rituals.
- Do not hesitate to ask about other relevant cultural aspects. It is respectful to show an interest in other cultures.
- Ensure the family and the patient understands the benefits that Palliative Care can offer. Reinforce to the family that the patient can be more in control if better informed.
- Identify and respect protective behaviour.
- Allow time and be aware of customs that show respect. This will help to establish a strong rapport with the patient, family and their friends. (It is highly respectful to drink a beverage with the family.)
- Use written material to help disseminate information to all family members and others.
- If some basic information is given, this can be followed by an invitation to ask questions. The questions may indicate to us some information about the speaker, as well as clarify their expectations of us.
- Be aware of possible high expectations that doctors and nurses may be expected to completely relieve all symptoms.
- Do not assume that patients will have an extended family that is able to support the dying person. Seek out culturally specific community services. Where these are not available, discuss patient and family needs with local service providers.
- If a referral to community services is initially declined, seek further opportunities for referral.
- Although emotional support may be declined, recognise anxious behaviour and assess if this is an appeal for help.
- Anger that may be directed at you should not be taken personally.
- Be prepared to seek additional support for yourself if required.
- Attempt to accommodate, within reason, the large numbers of visitors for a hospitalised patient.
- Attempt to establish beliefs and fears surrounding pain-relieving medication.
- Show sensitivity and understanding towards patients who may resist using pain medication.
- Use published material to educate the patient and family regarding the benefits of morphine and to dispel myths.
- Introduce information gradually using non-medical terminology and assess if it is being understood.
- Recruit assistance from other community services if necessary.
- It is a highly respectful gesture to offer condolences at the funeral service or cemetery.

Statistics

Our target audience for brochures in 20 languages, were determined by 1996 Census figures from the Australian Bureau of Statistics. We chose Australians who speak a language other than English at home and who have little or no proficiency in English. The final column gives the percentage with "little or no proficiency in English". IE although 45,243 Maltese migrants speak Maltese at home, only the 4,121 (9%) of them who have little or no proficiency in English, are tabulated here.

| Language | NSW | VIC | QLD | SA | WA | TAS | NT | ACT | Aust | Aust % |
|-----------------------|---------|---------|--------|--------|--------|-------|--------|-------|---------|--------|
| Chinese | 55,138 | 29,836 | 8,266 | 3,209 | 5,939 | 275 | 553 | 977 | 104,467 | 30% |
| Vietnamese | 24,759 | 23,942 | 4,699 | 4,507 | 4,117 | 37 | 187 | 708 | 62,956 | 43% |
| Italian | 16,183 | 28,336 | 3,572 | 7,253 | 5,950 | 166 | 78 | 473 | 62,011 | 17% |
| Greek | 15,554 | 24,257 | 1,402 | 4,898 | 816 | 150 | 500 | 295 | 47,872 | 18% |
| Arabic | 22,084 | 7,238 | 465 | 422 | 722 | 56 | 20 | 144 | 31,151 | 18% |
| Spanish | 8,597 | 4,340 | 1,617 | 618 | 854 | 106 | 40 | 408 | 16,850 | 18% |
| Macedonian | 6,276 | 6,845 | 150 | 138 | 1,097 | 5 | 0 | 79 | 14,592 | 20% |
| Turkish | 4,504 | 7,105 | 266 | 135 | 214 | 6 | 3 | 39 | 12,272 | 27% |
| Korean | 9,447 | 871 | 962 | 172 | 390 | 44 | 5 | 141 | 12,032 | 40% |
| Croatian | 4,070 | 4,336 | 609 | 613 | 884 | 48 | 7 | 367 | 10,934 | 16% |
| Hindi | 4,455 | 3,851 | 648 | 251 | 258 | 20 | 38 | 181 | 9,700 | 9% |
| Polish | 2,665 | 3,358 | 666 | 1,525 | 952 | 168 | 8 | 181 | 9,523 | 15% |
| Serbian | 3,654 | 2,812 | 517 | 720 | 537 | 22 | 11 | 190 | 8,463 | 23% |
| Khmer | 3,389 | 3,165 | 329 | 1,016 | 338 | 0 | 23 | 62 | 8,322 | 43% |
| Russian | 3,331 | 3,701 | 469 | 529 | 114 | 25 | 6 | 48 | 8,221 | 26% |
| Japanese | 3,220 | 1,253 | 1,806 | 219 | 581 | 48 | 54 | 104 | 7,285 | 28% |
| Portuguese | 3,294 | 864 | 184 | 129 | 830 | 0 | 115 | 47 | 5,465 | 22% |
| Persian | 2,048 | 1,173 | 241 | 304 | 443 | 18 | 4 | 63 | 4,294 | 23% |
| Maltese | 1,581 | 2,275 | 136 | 95 | 23 | 3 | 0 | 8 | 4,121 | 9% |
| Bosnian | 975 | 1,171 | 422 | 280 | 354 | 14 | 3 | 35 | 3,256 | 33% |
| Total - 20 languages | 195,224 | 160,729 | 27,426 | 27,033 | 25,413 | 1,211 | 1,655 | 4,550 | 443,787 | 23% |
| Total - All languages | 226,670 | 182,700 | 38,787 | 32,211 | 33,889 | 1,990 | 11,873 | 5,888 | 534,719 | 17% |

Map Comments

We include maps of each Australian capital city illustrating the locations of people who speak Italian, Greek, Chinese, Vietnamese and Polish as their first language at home.

Adelaide

A glance at the map quickly illustrates why the North West Adelaide Health Service is strongly involved in the provision of care to members of many cultural groups. The largest group of NESB people in Adelaide is the Italians, who live primarily in the north-eastern and north-western suburbs. The Greek community is predominantly in the western suburbs, while the Vietnamese are almost entirely in the north-west and the north. Polish speakers are mainly in the north-west, the north and a few in the south-west. Chinese are fairly widely spread.

Brisbane

The southern and south-eastern suburbs are where most NESB residents live. The Chinese are strongly represented. The Italian speakers live in the northern and central suburbs, while the Greeks are predominantly in the central southern suburbs. There is a strong concentration of Vietnamese in the south-west.

Canberra

The ACT hosts a diverse group of NESB people, but relatively small numbers. They live mainly in the north-western suburbs. There are also a significant group of Italians across the border in nearby Queanbeyan (postcode 2620).

Darwin

The number of NESB speaking people in Darwin, other than indigenous people, is fairly small. The two largest groups are Chinese and Greek speakers, who live primarily in the northern and eastern suburbs.

Hobart

Tasmania is home to relatively few NESB people. Chinese speakers are the largest group. Not illustrated on this map is the fact that unlike other Australian capital cities, the second largest NESB group in Hobart is the Hmong people, who barely rate a mention on the national scene.

Melbourne

A large number and variety of NESB people now call Melbourne home. Many of the Chinese are descended from forebears who arrived during the gold rush era of the late 1800s. The Chinese are widely spread, particularly in the south-eastern suburbs. The Italians live primarily in the northern suburbs. Melbourne is also known as the largest Greek city outside of Greece and the Greeks are widely spread throughout the suburbs. Vietnamese are concentrated in the western and south-eastern suburbs.

Perth

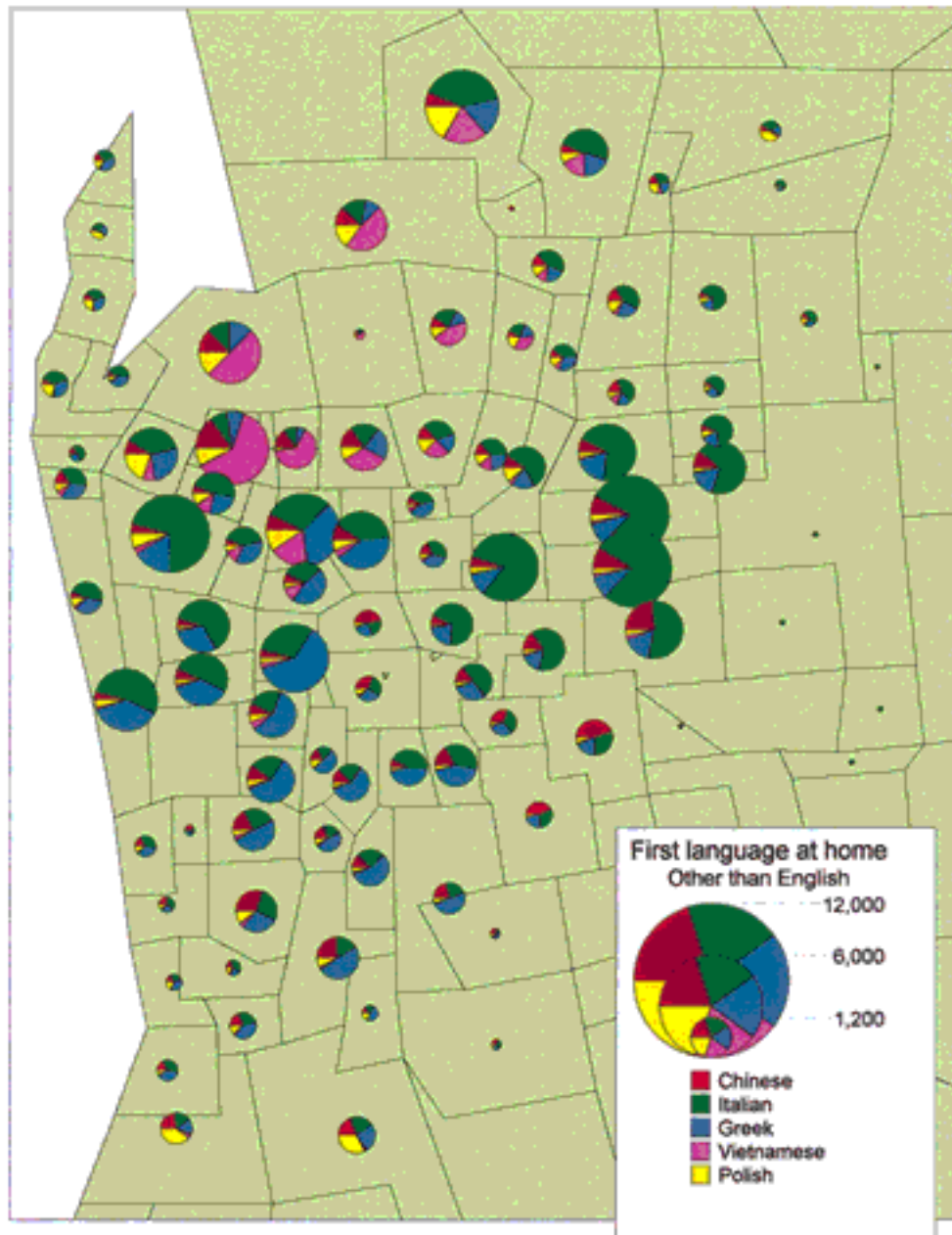
Italians live in the northern and south-western suburbs. Also strongly represented are Chinese, who are widely spread. The Vietnamese are concentrated in the northern suburbs.

Sydney

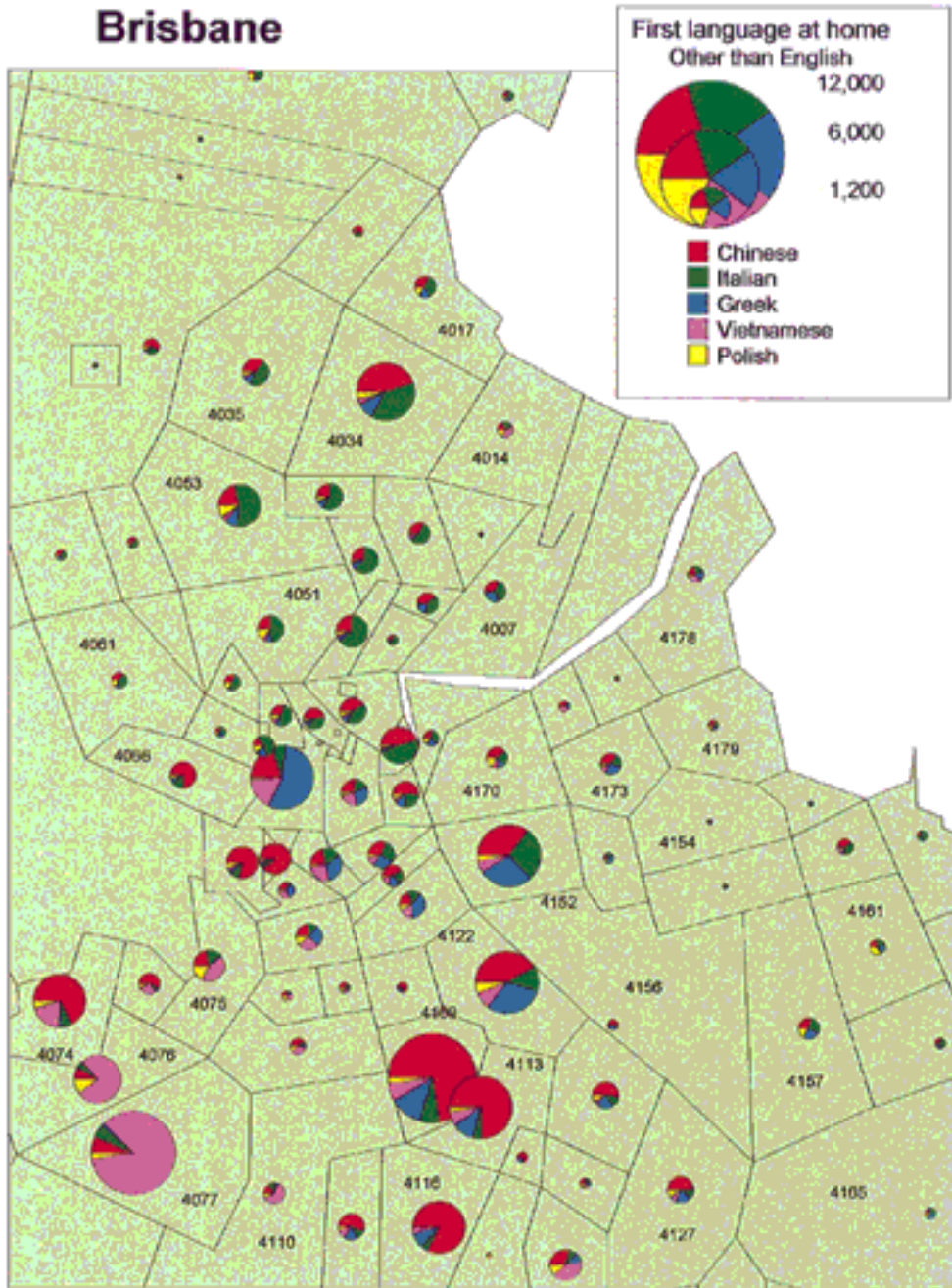
The Chinese community in Sydney is the largest single group of NESB people in Australia. This group is widely spread throughout the metropolitan area, perhaps reflecting their long heritage here, commencing in the 1800s, plus their business acuity. The Chinese have long been astute merchants and storekeepers.

The Vietnamese are living primarily in the western and southwestern suburbs. The Italians are fairly widely spread, mainly in the western suburbs, while the Greek community lives primarily in the southern and south-western region.

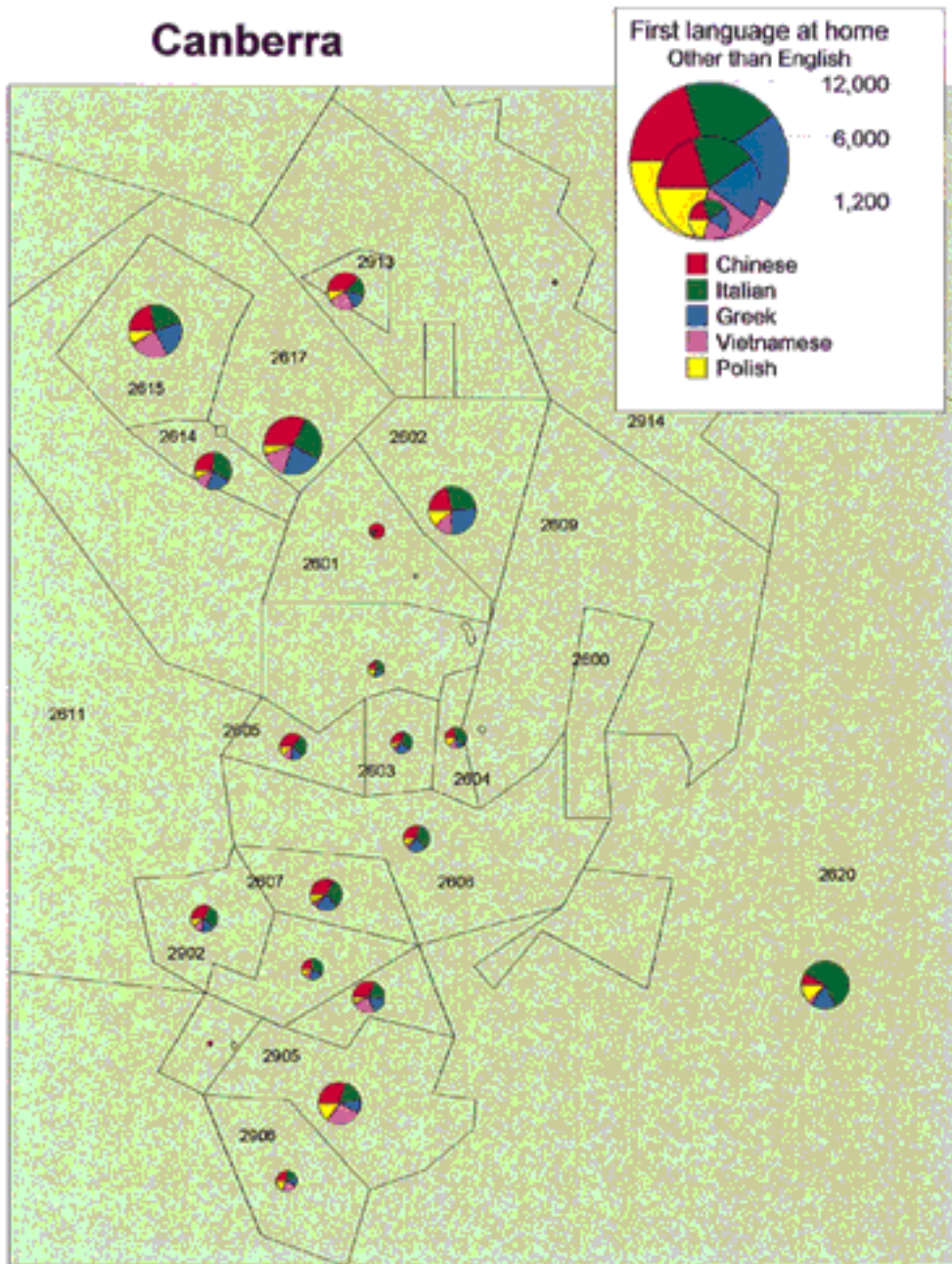
Adelaide



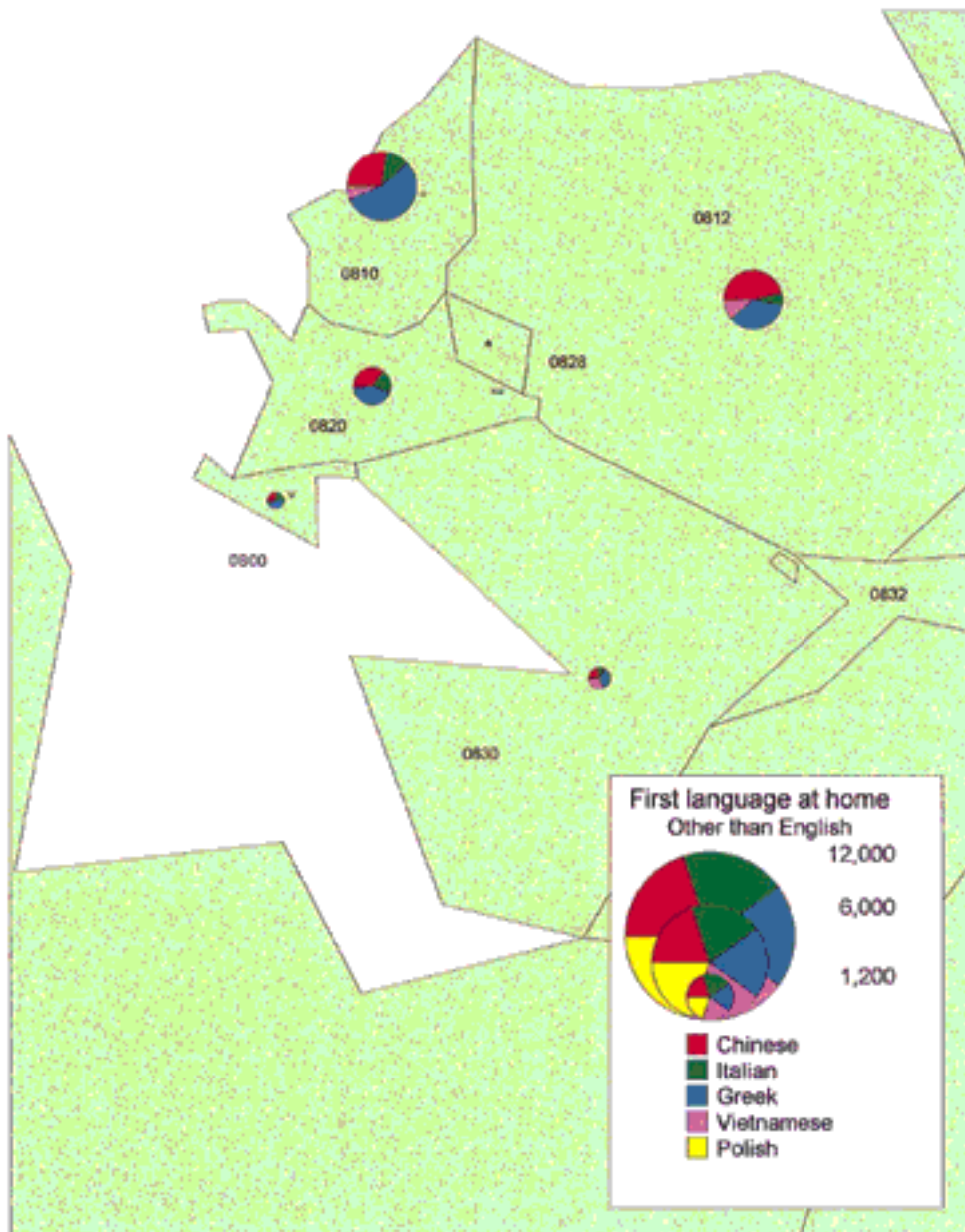
Brisbane



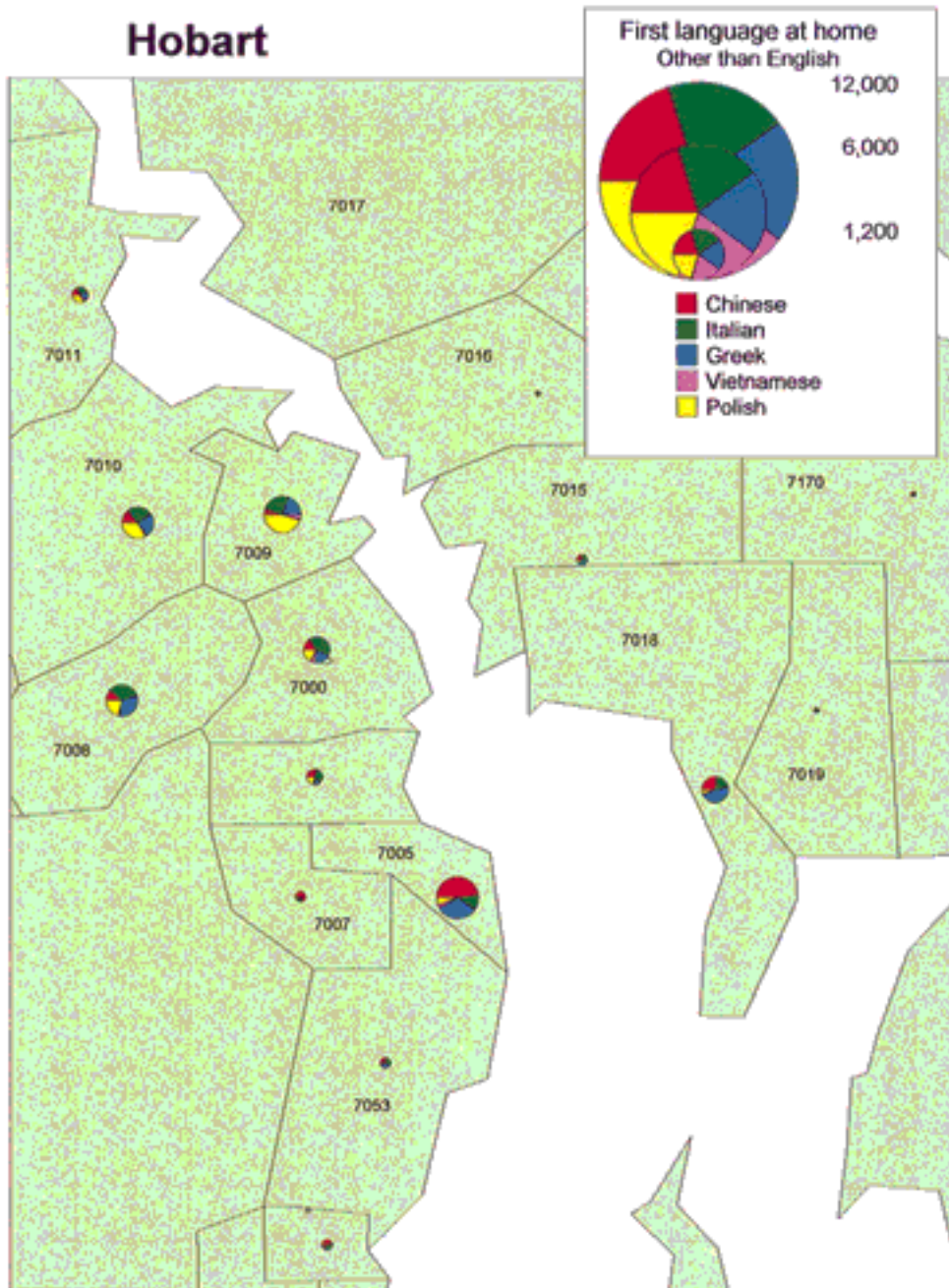
Canberra



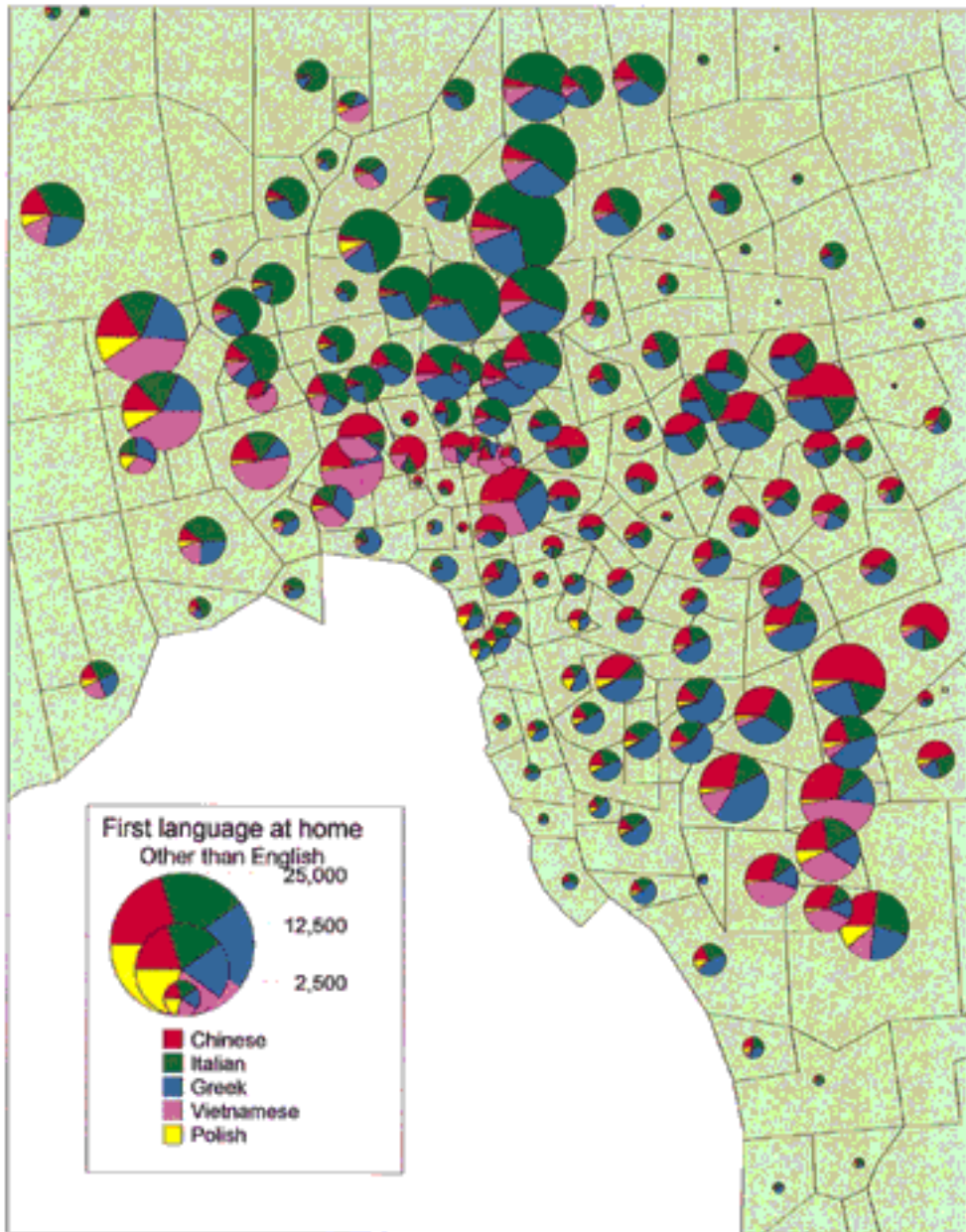
Darwin



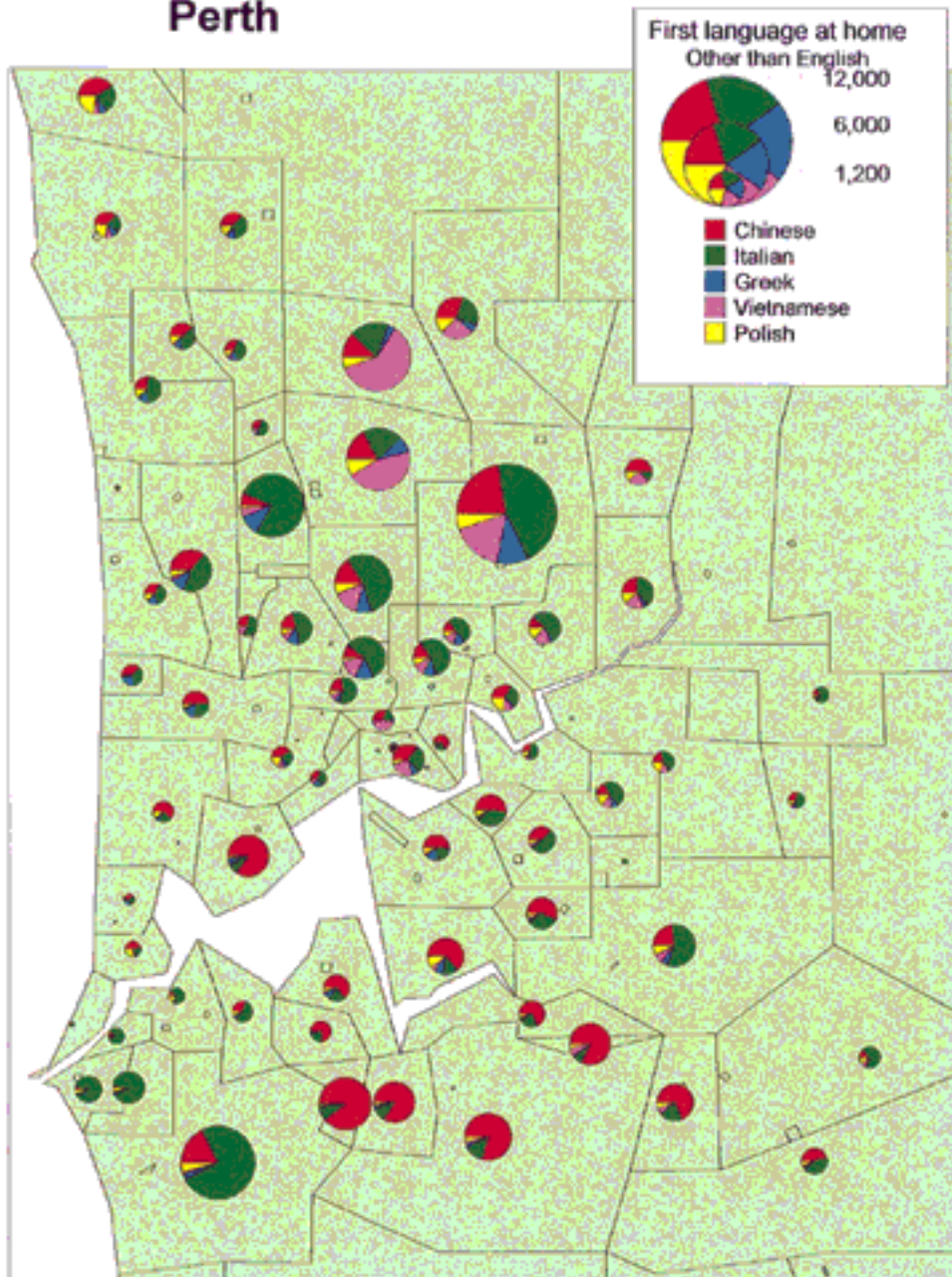
Hobart



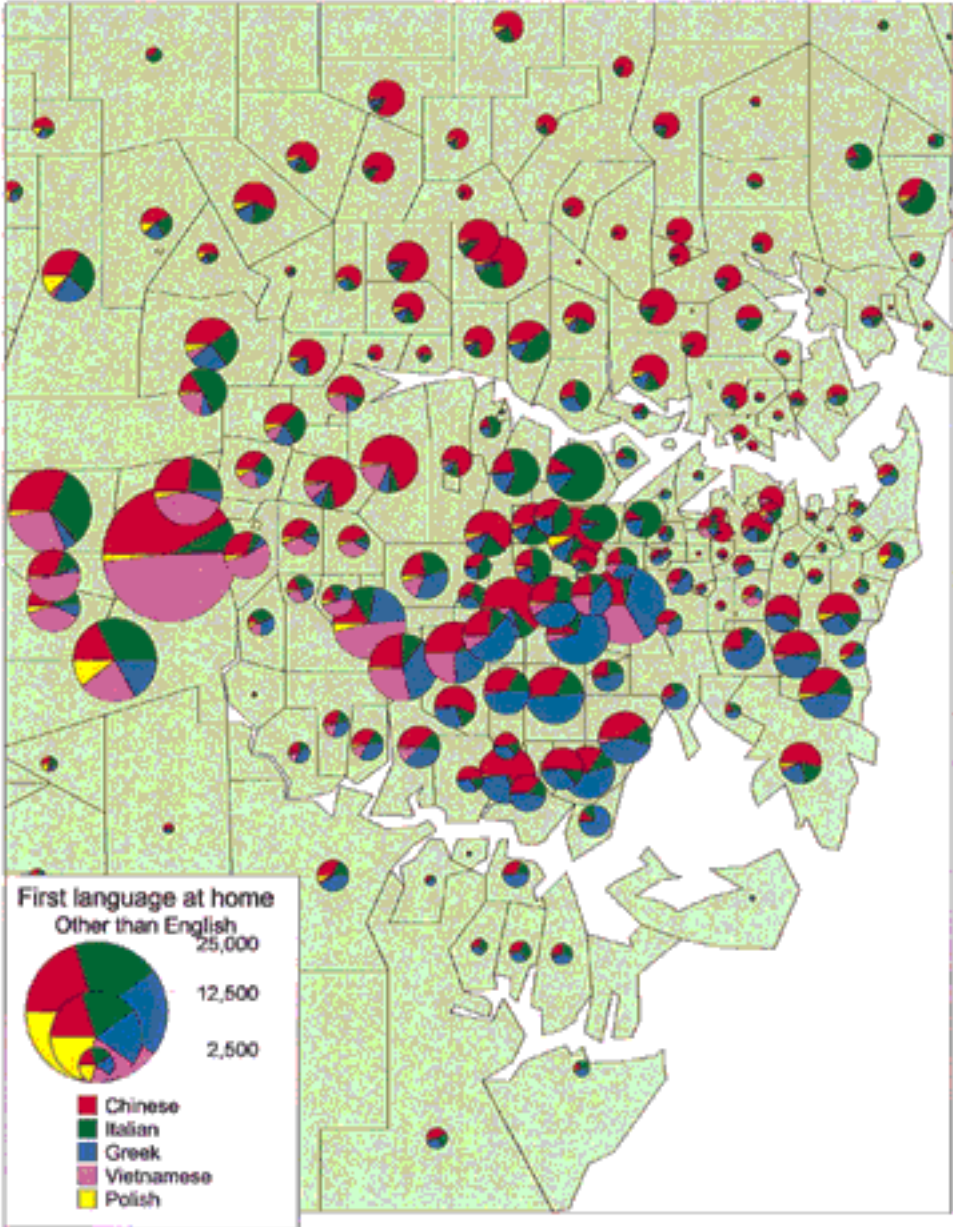
Melbourne



Perth



Sydney



Language Groups

Arabic

General

The Arabic-speaking people in Australia came from various countries in the Middle East and North East Africa including Algeria, Egypt, Iraq, Lebanon, Morocco and Syria, mostly over the last 40 years. They migrated due to displacement by war and political upheaval, or a desire for economic and professional advancement. ⁽⁶⁾

Many are Muslims, for whom the religious perspective over-rides the cultural background, especially when issues of death and dying arise.

Another group is the Coptic Orthodox. Most householders are qualified doctors, engineers, lawyers, and teachers who migrated originally from Egypt and surrounding countries. Their society also gives assistance to other citizens from the Middle East and looks after the new generation from all aspects of life, to the welfare of Australia.

A significant group of Arabic speaking people in Australia is from Lebanon. These people are from four religious groups: Muslim, Maronite, Orthodox and Druze. They have similar culture in their way of living but have different ways of burying their dead.

Religion

They are primarily Muslims with strong religious beliefs and customs. Muslims from other countries and speaking other languages had already built mosques, the first of these in Adelaide in 1889. Although from diverse cultural backgrounds, Muslims pray in Arabic, professing one faith, Islam. The Quran is the sacred book of the Muslims, contains a guide on the standards and ethics of leading a wholesome life.

Place of treatment

The aged are valuable members of the family and are looked after at home if possible. If not, respite care and nursing homes may be utilised. Hospitals are also acceptable to many. However people without English are terrified of remaining within mainstream institutions.

Communication of diagnosis/prognosis

The news is first given to the family - the closest member to the patient. The next of kin will advise the immediate family, but perhaps advice will not be given to friends.

Patients are often not told about a life threatening illness or disease, as it is felt that to do so may exacerbate their condition. They may also be ostracised by the community because people consider them to be infectious and/or cursed.

Role of family/relatives/friends

Every family is different; if the patient wishes to know, the patient's wishes are paramount. Even if the patient is not told, the family will try to make decisions in the patient's best interest. In some cases the family leaves all decisions about treatment to the treating doctors, in others, the person seen as the wiser in the family may make the decisions.

Family and friends are very important and are a great source of support for the patient providing constant help and attendance. Allowance needs to be made for this in hospitals. Family support could mean bringing a relative from overseas.

Role of health professionals/volunteers

For a volunteer to be welcome in the family home, it would be preferable that they were of the same gender and religion as the person who is ill.

Visitors to Muslim households should be aware that alcoholic drinks are prohibited. Pig in all forms and carnivorous animals are forbidden. Other meat must be slaughtered with a sharp knife, in the name of Allah. Health professionals must be aware of the need for ablution and prayer 5 times per day.

Attitudes to pain relief

There are no taboos with regard to pain relief. Check whether medications contain alcohol or ingredients made from pigs (applicable for practicing Muslims).

The community attitude towards euthanasia

Euthanasia is forbidden.

Taboo words

The words death, dying and cancer should be used with sensitivity and a feeling for others. Cancer is often referred to as "that" disease. This is usually followed by the sentence "God keep it away". Avoid discussing death, dying and how long a person is likely to live.

Handling of the body

A Muslim body should ideally be handled as little as possible and by persons of the same sex, preferably Muslims. The body should be turned to face Mecca. The body must be handed over to the Muslim community as soon as possible to permit burial and washing rituals to be performed.

For Coptic Orthodox, at the time of death it will be wise to notify the community priest or Imam and they can do what is necessary.

Burial

Cremation is forbidden for Muslims and Coptic Orthodox. For Muslims, the burial should be done immediately after the first prayer, after the death. For Coptic Orthodox, burial will be arranged with a funeral director.

Bosnian

General

Bosnians and Herzegovinians migrated to Australia primarily after World War II. The family is the focus of life and religion plays an important part in people's lives. Many Bosnians are Muslims, for whom Islam is both their religion and a way of life. In Muslim society the aged are regarded as valuable members of the family, providing a wealth of Islamic knowledge. They reinforce family values and assist in raising children. Bosnians generally do not have an understanding of palliative care.

Religion

Although Bosnians are predominantly Muslim, some are Orthodox and some are practising Catholics and Jews. Mourning is a prescribed way of dealing with death and wailing is practised.

Place of treatment

Our consultants varied on this question, ranging from "home strongly preferred, to "depends on the individual" to "hospital preferred". It is not always possible to stay at home and respite care or nursing homes may be used.

Communication of diagnosis/prognosis

The news is traditionally given to the family, but this varies with the patient. The family normally passes on the news to relatives and friends.

Role of family/relatives/friends

Treatment options are normally discussed at a family level and then a decision is made. Family support is strong, with many visitors to alleviate boredom and distress.

Role of health professionals/volunteers

Professionals are held in high regard and depended upon to advise and inform. It is important for professionals to show compassion and understanding.

Volunteers may not be welcome in the family home, as Bosnians are not used to this concept. The family and friends usually provide all the support needed. If a volunteer is sent to a family home, he/she has to be strongly recommended as an expert.

Attitudes to pain relief

There are no taboos, however giving morphine is usually regarded as a sign of being "near the end" and this can increase anxiety. Check whether medications contain alcohol or ingredients made from pigs (applicable for practicing Muslims).

The community attitude towards euthanasia

Not well received, due to religious convictions, but still an individual decision. Some may support it.

Taboo words

Our correspondents varied. One felt that the words death and cancer were taboo, but another considered that Bosnians accept that in Australia, doctors are likely to use the words death, dying and cancer.

Cancer is sometimes seen as punishment and that it could be inherited. Also that it may be contagious. Do not point at the location of a cancer, because this "invites trouble". It is acceptable to describe a location in words.

Handling of the body

This will vary depending on the religious background. For Muslims, the body should be handled as little as possible, ideally only by members of the same sex, who are also Muslims.

Burial

A cemetery burial is usual, following the tradition of the appropriate religion.

Islam encourages burial as soon as possible, preferably on the day of death. Cremation is forbidden.

In the Orthodox religion, cremation is not permitted because it is believed that we are made from earth and that we shall return to the earth. Elaborate mausoleums may be used.

Chinese

General

Chinese migrated to Australia in the late 1800s, lured particularly by the gold rushes in Bathurst, Ballarat and Bendigo. Many Chinese landed in Adelaide and made their way by paddle steamer up the River Murray to Echuca, before setting out on foot for the gold fields. Others landed in Robe and walked from there. As the gold petered out, many stayed on, taking up a variety of occupations including fishing, labouring, construction, farming, laundering, cooking, and gardening. As they saved money, some later became merchants, grocers and restaurateurs.

The next main group migrated from China at around the time communist rule was established in 1949. Some of the more recent Chinese speaking migrants have come from Malaysia, Indonesia, South Africa, and Hong Kong. Many Chinese students became stranded in Australia at the time of the Tienanmen Square incident. After each wave, there has been sponsorship of parents to Australia.

There is a hierarchy within the Chinese family. If the person is elderly it may be the older son who is seen as the decision-maker in the family. It is generally whoever is 'supporting' the family who makes the decisions. If there is more than one son then ask the family who you should 'deal' with. Families would not want to expose any family ructions even if the patient is not being well looked after. You would have to abide by what the 'head' or leader of the family says.

Religion

Chinese are traditionally pragmatic and eclectic. Their main religions are: Daoism (Taoism), Buddhism, Muslim and Christian. It would be best to check with the family. Death is not feared. Buddhists may wish to set up a simple shrine and to call a Monk to bless the dying person.

Place of treatment

Chinese families are adapting more to what is happening in Australia and so it may depend on how long the family has been in Australia as to their attitude to the place of treatment.

The family may still prefer to go to a hospital. Again, this may reflect on the fact that in their 'home' country it is difficult to obtain a death certificate if the person dies at home. A death at home is likely to necessitate an autopsy. There is strong opposition to autopsies because the body would be violated and perhaps not seen to be whole.

Most would seem to prefer to die in hospital. Taoists may prefer to lie on the floor to die.

Communication of diagnosis/prognosis

The doctor should give the diagnosis to the patient first. The patient would then advise others, not the doctor, unless the patient requests this. The doctor would give information about the patient between health professionals or services.

Role of family/relatives/friends

Decision making about treatment will depend on the position of the patient in the family. If the patient is the 'head' of the family then he/she would make decisions about what treatment to have. If the patient is placed somewhere else in the family, then it could be the 'head' of the family who makes decisions about what, if any, treatment to have. You should ask the family about who to consult.

If the patient refuses treatment, the family might actually support the doctor and override the patient. Again, it will depend on the family situation.

Support depends on the family situation. Some of the resistance to support might be a hangover from what occurs/can occur in their 'home' country. The family would provide the support in this instance because there are limited, if any, such services in e.g. Hong Kong or China.

Role of health professionals/volunteers

Whether or not health professionals and volunteers would be welcome in the family home, will depend on the age of the household. If the family/patient is older they may not be comfortable with someone in their home. Some of the younger generation have adapted or grown up here and are not so worried about this aspect. You would need to check with the family about how they feel.

The patient or family would communicate the diagnosis/prognosis to others. The doctor would need to ask permission of the patient to tell the family. Some may not want to tell children (depending on their age) what is the matter.

Volunteers would need to be cautious, especially with things like bathing. General assistance with household chores and so on would be acceptable. Again, you should ask the family.

Attitudes to pain relief

No medications are regarded as taboo. It would be expected there would be medication if someone is ill. Feedback indicated that if the doctor did not prescribe some medication the patient and family would not be happy.

There is not seen to be any connection between pain relief and euthanasia.

Other issues we should be aware of

Do not talk about money. If the patient or family really feels the need of this type of assistance they

would ask, otherwise this is the family's business.

Taboo words

There are not particularly any words which the patient would see as taboo. The family, however, may not want to hear words such as death, dying or cancer. Many of these words are considered 'bad luck' or very threatening. There is an elaborate list of synonyms for "cancer" in particular. 'Long life' is the aim. Shortening of life may be considered as punishment. "Death is represented by the number 4 and this number is commonly avoided, even in skyscraper construction and naming. When the diagnosis is being given there is nothing particularly to hide.

The most sensitive thing is going to be any discussion about the 'term of the illness', how long the patient has to live, or how bad the disease is.

Handling of the body after death

No autopsy - the Chinese believe that the body should remain intact after death. If Buddhist, the body may be bathed and dressed in special clothes. If Taoist the body may be placed with the head facing south and cleansed with a white cloth.

Burial

Do not suggest funeral details eg burial or cremation — this is the family's business. Burial is preferred older people from Hong Kong, but cremation is generally well accepted by the younger generation (it is less costly and burial space is at a premium)

The funeral should occur as soon as possible. There are a number of things which are important at this stage. There are certain taboos:

- If you are of a certain age you do not see the body.
- At a certain time of the year you may not see the body.

It is very important to check with the family about these details. They will be well known and indicated at the time by those conducting the funeral preparations and ceremony.

If you attend the funeral you must not wear bright colours. Do not wear red.

As with weddings, the Chinese give money at funerals as a mark of respect. Whilst it is customary to give money, it is not taboo to bring flowers. Giving money is more common and generally preferred.

If the person is a Buddhist they may choose a certain time of the day and a certain place for the funeral.

preferred, many elderly now live alone, and actively seek nursing homes.

Role of health professionals/volunteers

Health professionals should ask the sick person, "Who is your parish priest?"

Volunteers are welcome in the family home if the patient can speak English (or the volunteer can speak Greek). The training of carers and support workers is vitally important. Volunteers must be sensitive and careful what they say, and be guided by the family. It would be impolite for volunteers to visit on the name day of a saint. They should be aware that many elderly Greeks do not eat meat.

Attitudes to pain relief

There are mixed attitudes within the Greek community towards the taking of pain-relieving medication such as morphine. Some Greeks express inordinate fears concerning the use of morphine, which in most cases is associated with death. As with English speaking people this is a reflection of the need for education to dispel common myths.

The community attitude towards euthanasia

Croatian

General

Religion plays an important part in people's lives. Most Croats are Roman Catholic. The family is the focus of life and provides the first support mechanism.

Religion

The predominant religion is Catholic and hence the Rosary is important. There are also some Orthodox and a small number of Slavic Muslims and Protestants.

Place of treatment

Home preferred.

Communication of diagnosis/prognosis

The news is first given to the family, who will pass this on to relatives and friends.

Role of family/relatives/friends

The family is involved in decision-making about treatment. Family and friends provide strong support.

Role of health professionals/volunteers

Professionals can be highly regarded, but volunteers may not be welcome. The concept of volunteering in Australia is not something that Croats are accustomed to. The family and friends usually provide all the support needed. Given the status of medical professionals, it is important for them to show compassion and understanding.

Attitudes to pain relief

No medicines are regarded as being taboo, but giving morphine is usually a sign being "near the end", which can increase anxiety.

The community attitude towards euthanasia

Not well received, in line with Catholic beliefs.

Taboo words

Opinions varied. One consultant felt that death and cancer were taboo. Another felt that in Australia, Croats accept that doctors are likely to use the words death and cancer. Cancer is sometimes seen as punishment and possibly inherited. Also that it may be contagious.

Handling of the body

Funeral director.

Burial

Cemetery burial –for the majority who are Catholic. The usual rituals of Roman Catholicism prevail.

Greek

General

People from a Greek background are extremely sensitive towards issues relating to death, dying and cancer. Many Greek families, relatives and friends may wish to prevent the communication of the diagnosis and prognosis from medical professionals to the dying person. Their reasons may include a need to 'protect' the dying person, and to prevent further suffering. Some may believe that if the prognosis is communicated to the dying person they will give up hope and lose the will to live. The word 'Cancer' is in most cases automatically associated with death. Many people prefer to use euphemisms such as 'that terrible sickness' or 'the situation'.

Religion

The role of the church is very important within the Greek culture. The Greek Orthodox Church dictates the behaviour of people in bereavement; certain procedures need to be followed. There is, in general, a high emotional reaction to death and dying. The body is considered to be highly sacred. Practices include clothing the body in a white sheet under other attire. A vigil may be held in the funeral parlour. Traditionally the body is placed facing in an eastward direction, representative of Christ's resurrection. The body is buried; cremation is not permitted. On the 9th day after the funeral service a memorial service is held. Wheat seed cake with white icing is consumed at this time, symbolising the resurrection. On the 40th day another memorial service is conducted representing Christ's resurrection and Ascension to Heaven. A further service is held 3, 6, 9 and 12 months after the death. At all services candles are lit symbolising the celebration of life and eternal faith. The wearing of black is still very traditional.

Place of treatment

Home is preferred to hospital, if possible. Greek quality of life is linked to the home.

Communication of diagnosis/prognosis

Traditionally the news would have been given to the family, but this has changed with time and now the patient is usually given the information. In some cases the family will ask the doctor not to give the patient bad news, lest the patient lose the will to live. The family gives the news to relatives and friends.

Our community consultants recounted two stories:

One gave the story of a patient who was told he had cancer and 8 months to live. This patient had wanted to go back to Greece all of his life to visit a brother not seen since age 3. He now did this and when he was near death, he was happy that he had achieved his goals in life.

Another felt that a doctor must give hope to everyone. A patient was incorrectly given a diagnosis and told he had 3 months to live. The diagnosis was later corrected and although the patient lived another 10 years, he was desperately unhappy and had lost the will to live.

The priest will never say 'you're going to die'. Thus priest will prefer not to give 'last rites', but rather to give communion, which should also not be given too soon. If a patient telephones his priest and requests a visit, the priest may say to the patient that he will see patient 'in 3 days', rather than immediately on request.

Role of family/relatives/friends

Family, friends and relatives play a very important role in the care of a dying person within the Greek culture. The wife of a dying husband needs to be directly involved in the care of the patient as this fulfils her sense of duty and obligation. The presence of carers is essential in helping to reassure that the dying person is being loved and nurtured. It is culturally acceptable to display strong emotional reactions.

The family wishes to have a strong role in decision making and care for the elderly. However, most families are no longer the stereotype large extended family living together. Although home care is preferred, many elderly now live alone, and actively seek nursing homes.

Role of health professionals/volunteers

Health professionals should ask the sick person, "Who is your parish priest?"

Volunteers are welcome in the family home if the patient can speak English (or the volunteer can speak Greek). The training of carers and support workers is vitally important. Volunteers must be sensitive and careful what they say, and be guided by the family. It would be impolite for volunteers to visit on the name day of a saint. They should be aware that many elderly Greeks do not eat meat.

Attitudes to pain relief

There are mixed attitudes within the Greek community towards the taking of pain-relieving medication such as morphine. Some Greeks express inordinate fears concerning the use of morphine, which in most cases is associated with death. As with English speaking people this is a reflection of the need for education to dispel common myths.

The community attitude towards euthanasia

The strong Orthodox belief of the Greek community leads them to reject euthanasia. Suicide is not permitted in the eyes of Orthodox religion, because God put you on earth and only God can take you away. Therefore, in the event of a suicide, an Orthodox funeral does not take place.

Taboo words

In the Greek community we found the greatest disparity of opinion regarding taboo words. Some Greeks regard illness as a taboo topic. One consultant has been battling for years to have Greek people talk openly about Thallassaemia, that it was hereditary and that all family members should be tested. Consequently he was keen for brochures in Greek to use the traditionally taboo words death, dying and cancer. By contrast, a Greek Orthodox priest felt that the taboo words should not be used directly, but there are appropriate sensitive words that can be used. The word 'cancer' is in most cases automatically associated with death. Many people prefer to use euphemisms such as 'that terrible sickness'.

A compromise position was to not use the words death, dying and cancer, but to describe palliative care as "Caring for a loved one with a terminal illness". Using this on the cover, plus discussing pain management and the difficult to translate word "hospice" ('an asylum for those with an incurable illness') were seen as a significant strengthening of the wording compared with previous brochures from 1995. The translator must paraphrase if necessary, to convey the meaning, not merely translate text.

Handling of the body

Call the priest if he is not already present and the funeral director.

Burial

At the cemetery, the last funeral prayer is said and the body is buried facing east, because when Christ was born the guiding star was in the East. At the church, the family will have supplied a small bottle of wine mixed with oil and some wheat or bread, to the priest. When the last prayer is finished, the priest pours the wine and oil mixture over the lowered coffin, making the sign of the cross three times, symbolising the Holy Trinity and sustenance for the departing soul. The priest sprinkles earth into the grave, followed by family and friends.

Hindi

General

An Indian person is one who is a citizen or native of India. Most migration occurred in the 1800's. Those Indians who were born in India often speak in Hindi and maybe two or more state (regional) languages and the international language, English. At primary level all three languages are compulsory. The state language will be from any state of India; it may be Hindi, Punjabi, Sindhi, Gujrati, Marathi, Tamil, Rajisthani, Bengali, Bihari or Kashmiri languages.

More than 80% of Indians are members of Indian-Australian Associations, clubs and state language associations in Australia. These are listed in telephone, ethnic, multicultural community and Internet directories in Australia and world wide.

Many Indians in Australia are experienced and well qualified professionals in medical, engineering, agricultural and computer science fields. A few Indians arrived in Australia along with their domestic and business animals (camels, elephants and horses) and family business skills in producing wheat, cane sugar, fruit and vegetables.

Religion

Hindi speakers may believe in many religions. The main types of religions in India are:

- Hindu** who pray in temples of Hindus - bhudhs, jaines, and arria samaji. Their religious books are the ramayana and mahabhartah.
- Muslims** who pray in musjids in India, Pakistan and other Asian countries around the world. The kuran is the book of the Muslims.
- Christians** who pray in churches of India and around the world, with the aid of the bible.
- Sikhs** who pray in gurdwarahs. Their religious book is the gurgranth sahib.
- Buddhist** Although Buddhism was born in India, less than 1% of Indians are Buddhists

Religion is important among all Indian communities. It is religion which keeps them together during crises and at times of social and cultural significance. They communicate with each other through various methods: 50% by word of mouth, 20% by telephone and 30% via correspondences such as letters and newsletters. Religion provides faith, trust and support for all Indian communities. It guides each person during the happy and the hard times of the family.

Place of treatment

Home, hospital and hospice are all accepted, with the order of preference being home, hospice, hospital.

Communication of diagnosis/prognosis

The news should be given to the head of the family. A local Indian Association member will then be asked to advise others in the community.

Role of family/relatives/friends

Decisions regarding treatment location and options will depend on the wishes of the patient and their family. The extended family often provides support.

Role of health professionals/volunteers

This is seen as minimising discomfort for the patient. They are welcome in the family home.

Attitudes to pain relief

Vegetarians may not want substances obtained from the killing of an animal.

The community attitude towards euthanasia

Positive.

Taboo words

Death and cancer may be taboo for some.

Burial

Hindus prefer to be cremated, Christians & Muslims prefer to be buried.

Other issues

- We should be sensitive to Indian cultural activities.
- Sympathy and the treating of a person with dignity, transcends the language barriers.

Useful contacts

- The Indian consulate
- Australia India Association
- The Hindu Society

Italian

General

Many Italians, particularly from the farming community, migrated to Australia in the late 1940s, and in the '50s and '60s. The loss of community supporting structure in Italy was gradually replaced by the development of similar supports in Australia, modelled on those of the former home-land at the time of departure. As one of the largest Non English Speaking Background (NESB) groups the Italian community in Australia has had a significant impact on the Australian culture and has played a leading role in the multicultural arena. The lack of culturally appropriate services has spurred the development of Italian services such as bereavement self-help groups and Italian Meal Services.

Religion

The Catholic Church plays a very important role within the Italian culture, although religion is a stronger influence with the elderly than the young. There are a number of rituals which are necessary e.g. administration of the Last Rites and the Rosary. The Rosary is a prescribed mix of vocal prayer (Our Fathers and Hail Marys) and of silent prayer, reflecting on important events in the life of Christ and Our Lady.

Place of treatment

Home if possible, but hospital and hospice are acceptable, if supported by religion.

Communication of diagnosis/prognosis

Traditionally the family must be involved from the start, to deal with any terminal illness. Some families, relative and friends may wish to prevent the communication of the diagnosis and prognosis from medical professionals to the dying person. Their reasons may include a need to 'protect' the dying person, and to prevent further suffering. Some may believe that if the prognosis is communicated to the dying person they will give up hope and lose the will to live.

Doctors in the Italian community are conscious of the need for sensitivity and will decide on an individual basis whether to give a diagnosis of cancer to the patient or family first, based on their understanding of the wishes of the patient and family. The tendency now is to advise the patient and also to warn the patient of possible bad news to be given by a specialist. The degree of detail wanted by the patient varies.

The families of a few patients insist on being informed of bad news first, but the patient is usually told as well. Because of the tradition that the patient does not know their diagnosis or prognosis, a charade is often played out, in which visitors will talk about the patient soon being up and about, while they and the patient often realise that this is unlikely.

Role of family/relatives/friends

Almost invariably, the family needs to be involved at all stages of decision making concerning the care of the dying person. They often have extremely high expectations, that doctors and nurses will completely relieve all symptoms. The level of care provided by a range of close people is usually very high. There are many expectations and obligations based on sibling status and gender role, coupled with a general belief that it is necessary 'to do one's duty'. This may also lead to a reluctance to ask for help.

Emotions may be displayed openly, e.g. anger, despair, depression. This is an acceptable means of behaviour and is sometimes expected. Anger may sometimes be directed towards health care workers. Emotional support is generally not sought, as this is considered to be an 'in house' matter. When a loved one is hospitalised, family and friends are obliged to visit in large numbers to show their respect to the dying person. Food is important in the Italian culture. A dying person may be encouraged to eat unnecessarily by the family, as they believe that it is good for the sick person.

Role of health professionals/volunteers

Health professionals and volunteers are welcome in the family home. Their role is crucial. Ideally volunteers should have a knowledge of the culture, combined with palliative care training.

Attitudes to pain relief

There are mixed attitudes within the Italian community towards the taking of pain-relieving medication such as morphine. Morphine should only be used when other medications are ineffective. Some Italians may accept morphine whilst others may express many fears associated with its use. As with English speaking people this reflects the need for education to dispel common myths. Some Italians may also exhibit stoicism towards pain, in the belief that one is expected to endure discomfort because this shows one is really sick.

The community attitude towards euthanasia

The strong Roman Catholic belief of the Italian community leads them to reject euthanasia. An Italian doctor reported little interest in euthanasia by his patients: "Only a couple have asked for it."

Taboo words

An earlier Multicultural Project ⁽¹⁾ in 1995, found that for many Italians the words death, dying and cancer were taboo. The word 'cancer' is, in most cases automatically associated with death. Many people prefer to use euphemisms such as 'that terrible sickness'. We sought to confirm this, and found quite a disparity of opinion in 1999. Cancer was still 'very scary' and spoken of as 'a horrible illness'. However some support groups of the Italian community, many of whom have lost a partner recently, or are currently a carer for someone with a terminal illness felt that "the words dying, cancer and hospice are reality." Only one person felt that these words were taboo.

In general, Italian community health workers felt that we should be more direct, using these words to shift public perception, and that many Italians are over protective. "They forget that things change, and have changed in Italy." A consensus view was that brochures should perhaps not have the word dying on the cover, but that the terms 'incurable disease' or 'terminal illness' would be very appropriate.

We were advised that the word hospice had problems with translation - 'Auspizio' is a place for elderly and frail, but not necessarily those with a terminal illness. Also, the word carer has multiple translations, but there is now a 'carer's payment', which should have paved the way for an understanding of the word carer. If they have trouble understanding the written word, people of the older generation go more by word of mouth.

Burial

Southern Italians, in particular, receive condolences at the family home, a gathering known as a '*lutto*'. Viewings are held at the funeral home. At the church, a Rosary is recited over the body. A full service

is held the next day, followed by a burial at the cemetery. Mourners, who traditionally wear dark colours, have an opportunity to throw a flower on the casket as a final goodbye. Elaborate headstones and caskets are often regarded as fitting tributes.

In our community consultation, some members of the Italian community, many of whom have lost a partner recently, or are currently a carer for someone with a terminal illness preferred there to be much less condolence shown at the church and cemetery.

Japanese

General

Some Japanese who arrived after World War II as war brides found Australians quite hostile towards them initially. Most Japanese now living in Australia, have arrived in the last twenty years and many of them are here for only a 4 to 5 year period, working for a Japanese company. These newer arrivals consider the post World War II group to be 'Aussies', who left Japan so long ago that they had not fully absorbed the Japanese culture.

Many Japanese are not good at expressing their feelings such as happiness and love. "We hardly ever kiss or hug each other, especially old people, even though we are very close friends or relatives." They are also reluctant to discuss a life-threatening illness with others, preferring to "deal with the problem within family members".

Religion

For most Japanese, religion is not a very important thing in their daily life. However they tend to observe both Shinto and Buddhism. In Japan there is a tendency to prefer a Shinto wedding ceremony, but a Buddhist funeral.

Place of treatment

There is a strong expectation in Japan that patients will be given care by the hospital system. Some people feel more secure in hospital (and hospice) than home. At this point many people know what a hospice is, but tend think of it only as the place where people die.

Communication of diagnosis/prognosis

The news is usually given to the family rather than the patient. It is believed that not telling the truth to patients is the best thing, as people think that patients are not strong enough to cope with the facts. The family would probably not pass on the news to other relatives and friends. However one consultant believes that the patient has the right to know about his/her own body.

Role of family/relatives/friends

The family would be involved in decision making. When the patient's condition is deteriorating, some friends might hesitate to visit them, thinking that the patient would prefer not to be seen in a deteriorated state.

Role of health professionals/volunteers

Health professionals would be welcome in the family home, but some people might not be happy to have a stranger (volunteer) in their home. Traditionally, it is said that the wife should look after her family. For a woman to seek help from volunteers might embarrass her. If a volunteer was accepted in to a Japanese home, the main point to remember would be to expect to remove one's shoes, just inside the door.

If the patient is competent, sensitive supportive and compassionate discussion between the patient and professional people is essential. In many cases family members are willing to be involved in such a discussion.

In Japan there are few types of health professional such as social workers. Doctors tend to focus on symptom control, with all other tasks falling to nurses.

Attitudes to pain relief

There are no taboos regarding medication, but many people, both medical professionals and patients, still think morphine would cause addiction.

The community attitude towards euthanasia

Our consultants were unable to offer an opinion on this matter.

Taboo words

The word dying might be too strong for some Japanese. The word cancer is not taboo but for many people this word still means death, and would be regarded as "too direct".

Handling of the body

This needs sensitivity. People believe that the dead body is pure and sacred. When a patient dies in hospital, nurses are the first to touch the body, but families would not mind about that. Traditionally, the body is brought home for one night for a wake and then taken to funeral parlour for the funeral service.

Burial

Cremation would be expected, as in Japan they are not allowed to bury the body, due to the shortage of land.

Other issues

Respect each individual's need, considering differences such as social status, age, gender and belief systems.

Khmer (Cambodian)

General

90% of Cambodians are of the Khmer ethnic group. There are small numbers of Vietnamese and Chinese. Religion plays a major role in the Cambodian community. Most are Buddhist and they could be offended by attempts to bring another religion to them. A small number are Christian. It is advised to ask what religion the patient believes in.

"There is not a general understanding of palliative care and more promotion in Khmer would be welcomed." Those assisting Khmer people would benefit from an understanding of:

- The culture and individual needs
- Families backgrounds and experiences in the past

Religion

Primarily Buddhist, which one consultant has described as being similar to Christian.

Place of treatment:

Many people feel more comfortable to be treated in their home. They feel that this is "a better place" and will enable more care from the family. If treating in a hospice, language assistance may be needed.

Communication of diagnosis/prognosis

Opinions differed here, with one consultant advising that the news should first given to the family and another suggesting patient and family. The first felt it preferable that the news be given to the closest members of the family by a doctor or specialist and for the family to decide whether or not it is best to tell the patient. If the next of kin is a friend, then the friend should be told.

The family would then mainly give the news to relatives only.

Role of family/relatives/friends

Decision-making about treatment is likely to involve the patient first, but also the family. "It depends on the degree of the illness. If the treatment is not too frightening then we usually discuss the option with the patient".

Family and relatives will typically provide support.

Role of health professionals/volunteers

Health professionals are expected to clarify with the family the diagnosis and prognosis. A social worker from the hospital would be expected to provide emotional support.

For health professionals and volunteers to be welcome in the family home, some basic understanding about what is culturally appropriate may be necessary. This also depends on the workers ability to communicate with the family and the guarantee of confidentiality. It is important for a volunteer providing care to determine with the family what their role as a volunteer entails.

Attitudes to pain relief

The taking of medication should not be an issue as long as the medication and the benefits it could bring to them are explained.

The community attitude towards euthanasia

Not really positive.

Taboo words

Our consultants varied on this issue. One felt that we can use any words. Another perceived problems with the words cancer, death and dying: "You have to work around the words by explaining to patients or family of the illness and chances, before saying cancer or dying." One must be sensitive about saying, "the time has come".

Handling of the body

A priest may be present before the last minutes of the death. Handling of the body after death is usually left up to the family, who will decide whether they want the body to be buried or cremated. In either case there will be a ceremony as the last sign of respect to the deceased and to release the spirit to heaven. This also enables the family a chance to say farewell.

Burial

Burial is more often preferred than cremation. At the funeral service, it is common for a monk to chant and incense to be burned.

Other issues we should be aware of

Many migrants are coming from a country where they have never been exposed to health checks and therefore some tests such as a Pap Smear may be seen as uncomfortable or an invasion of privacy.

Korean

General

The migration history is short, the first Korean migrants having come to Australia 25 years ago, with more in the last ten years, including students.

Most are unemployed and have language problems. Hence they need community help, but provision of this is hampered due to the church split in the community. People feel lonely, so they invite people from the church to pray in Korean.

Religion

Most are religious but are split into two groups.

- Fundamentalist, Presbyterian – This is the largest group. It includes people who are business brokers for migrants and students. They adhere to the old testament, do not eat pork, and do not mix with the other group. They are strongly against traditional anniversaries and ancestor worship.
- Uniting Church – this is a slightly smaller group. They still have a belief in Confucianism which is very strong in Korea. They celebrate Harvest Day, New Year's Day and an annual Ancestor Memory Celebration.

There are also some atheists.

Place of treatment

Patient's choice, but flexible. Hospital is a popular place of treatment and to die, especially if there are young children at home. Hospice has a short history in Korea and most Koreans do not know about palliative care.

Communication of diagnosis/prognosis

The news should be given to the eldest son, first. It is advisable to have a family meeting. If there is more than one child there could be a family split due to the different churches, which can cause communication problems.

The role of the family and friends

The patient will express his or her wishes to their children at a family meeting, but decisions will be made by the eldest son. The family will provide strong support if the patient is at home.

Role of health professionals/volunteers

They may be welcome in the family home, but this depends on the family.

- Expect to remove one's shoes, just inside the door.
- If the patient is aged, they may refuse food and water three times out of politeness. You must offer anything four times.

Attitudes to pain relief

There are no taboos with regard to medicines.

The community attitude towards euthanasia

Personal choice, but mostly no.

Taboo words

There are no taboo words - Koreans have been influenced by America for 50 years and are thus used to the words death, dying and cancer.

Handling of the body

Similar to the west, some would like a Shaman but this is not possible in most Australian cities. If someone dies at home, the body is taken to a hospital for 3 days viewing by friends and relatives. The body is often flown home for burial.

Burial

This is decided by personal choice; some are buried, while others prefer cremation. Some believe in organ donation.

Attitudes to pain relief

The taking of medication has no particular taboo.

The community attitude towards euthanasia

Prohibited by the church.

Taboo words

The words death, dying and cancer, were traditionally regarded as taboo, but this is now "changing for the better". "Terminal illness" is a good alternative, but "terminal" still needs to be explained, because this is an educated word.

Handling of the body

The body must be left to lie overnight, either in the family home or chapel. The family should have the option i.e. there may be a 'village tradition'.

Burial

Burial is essential. Within orthodox religion, cremation is not an option. An orthodox funeral ceremony is conducted. The body must be buried in such a way that the eyes face where the sun rises.

Other issues

The Macedonian situation is very sensitive, and there are some people who are still afraid to identify as Macedonian, for fear of persecution by e.g. Greek, Bulgarian and Serbian health professionals.

People facing illness and death as well as their family members, take matters very tragically most of the time. This needs to be considered, as extra attention may be needed to improve this way of dealing with the problem.

Macedonian

General

Macedonia is broader than just the Republic of Macedonia, which is located in the former Yugoslavia. Cultural Macedonia also includes:

- Aegean Macedonia (located in Northern Greece) and
- Pirin Macedonia (located in North-Western Bulgaria).

Therefore, due to the occupying countries (Greece, Bulgaria), although some people identify themselves as Macedonian, they are generally educated in the language of the occupying country (if they are educated at all). Consequently, just because a person says that they are Macedonian, do not assume that they can read Macedonian.

The Macedonian culture places great importance on tradition, which is passed on from generation to generation. Culture is more focused on family life, not on self.

Religion

It is important to note that the Orthodox Church (amongst many nationalities) is politically divided. The families should know what church they belong to (archdiocese/community) and therefore which priest to contact.

When death is imminent, it is important that the patient receives confirmation and communion from a priest, especially before death. The priest usually reads the person their last rites and there is opportunity for confession. Cremation is not permitted.

Place of treatment

Home would be the first choice, however hospital/hospice are not ruled out. The family should have

the option.

Communication of diagnosis/prognosis

Depends on individual cases. Ask the family and patient what they prefer.

The news is not usually given to relatives and friends, but this is up to the family. If the news is given, it is done by closest family member(s).

Role of family/relatives/friends

Through education, the family, in consultation with the patient should make decisions about treatment. Often, having consulted with the doctor on what is best, advice from the priest/church is sought.

Great effort is put into making the patient as comfortable as they can be and with everything done as well as possible for the patient.

Support

- Generally, there is a very strong support network of family and friends, however most family, relatives and friends tend to be very negative and tragic about illness and death.
- Often spiritual support is sought by families.
- Carers do not want to be seen as not coping.

Role of health professionals/volunteers

Doctors and nurses are welcome in the family home. Volunteers and social workers are unlikely to be welcomed, as this is a fairly new concept for a lot of these families. They may see the role as ambiguous and therefore resist support. One consultant said "I believe there could be an element of shame."

Doctors are expected to communicate the diagnosis and prognosis, while nurses are expected to provide ongoing nursing care, to help ease the pain of those who are ill.

Maltese

General

The Maltese are originally descendants of ancient Carthaginians and Phoenicians, with strong elements of Italian and other Mediterranean stock. Their culture is typical southern European, where family support and family unity comes first. The Catholic religion plays an important and very influential part in the daily life of most Maltese. There are no major cultural splits (religious or otherwise) even though there is a small minority of non-Catholics.

Old age is regarded as something holy. Until recently, very few would opt to go to a nursing home or hospice. Family members used to sacrifice themselves and make the last years of the aged, happy and peaceful ones. Nowadays, it's becoming almost impossible to keep them home, but with a bit of understanding, ways and means could always be sorted out for the better. "What keeps most of our aged from going to a nursing home is the different type of food and missing their own home."

Religion

98% are Catholic. Most of the early settlers do ask for a priest, and if unable to do so, they would nevertheless be very pleased to see him.

Place of treatment

First preference is home, then hospital, then hospice. One consultant commented "They prefer home, but hospital and hospice may be seen as the best answer".

Communication of diagnosis/prognosis

News should first be given by the doctor himself or by some competent person to the immediate family. They will pass the news on to relatives and friends, unless it is a "taboo" terminal illness such as "AIDS" etc.

Role of family/relatives/friends

The immediate family usually has an influential role in decision making, whereas the input of relatives and friends is minimal. The family would take an active role in administering treatment whenever possible and give full support. To a lesser extent so would relatives and maybe close friends. "You find those who would abandon them once they are away - but others won't miss a day from visiting them."

Role of health professionals/volunteers

The communication of a serious diagnosis/prognosis is preferably done by a doctor or by a priest, especially if the illness is terminal. Family members trust them a lot and often times they are very practical and down to earth.

In Adelaide, the introduction of the Maltese Home Care Support Service has resulted in the acceptance of health professionals and volunteers in the family home, over the past 3 years. They are now most welcome and often times are looked upon as family members. Typical western behaviour by volunteers is acceptable. Try to be on time and keep family members informed of the sick person's state.

Acceptance of volunteers in the home may vary in other states and territories.

Attitudes to pain relief

There are no taboos with regard to taking of medications.

The community attitude towards euthanasia

Mostly negative, in line with the teachings of the Catholic Church. "Our people do their utmost until the very end to assist their aged".

Taboo words

It would be preferable if death and dying were referred to indirectly.

Handling of the body

The customs follow the usual procedures preceding a Catholic burial. If the patient wishes to be cared for and to die at home, family members should be trained and acquire the necessary skills to handle this situation.

Burial

The majority prefer burial in the ground or a tomb, with a Catholic service, but cremation is becoming accepted.

Other issues

The aged who find themselves in nursing homes and respite places often times miss their usual home food.

Persian

General

Iranians are of several ethnic groups. Most are Persian, followed by Azerbaijani, with lesser numbers of Gilaki, Mazandarani, Kurd, Arab, Lur, Baloch and Turkmen. The vast majority of people from Iran are Muslim. However, there are other religions and beliefs including, Zoroastrian, Jewish, Christian, and Baha'i.

The main language group is Persian, with some speaking Turkic and Turkic dialects, Kurdish, Luri, Balochi, Arabic and Turkish.

Religion

Muslim is the main religion, prescribing a way of life, which includes modesty of dress and five sessions of prayer each day.

Place of treatment

Hospital is preferred. The book "The Muslim Patient" ⁽⁷⁾ is recommended.

Communication of diagnosis/prognosis

Doctors should give the diagnosis/prognosis to close family members first, since some patients will not be able to cope with the news. The news is given to close family, but not normally to friends.

Role of family/relatives/friends

Normally the patient would decide on the type of treatment, however some families would make decisions about how the patient should be receiving treatment. The family will provide support in such a circumstance, in the majority of times, but certain families may not have time to do so.

Role of health professionals/volunteers

Health professionals are welcome in the family home. They should keep the information confidential.

Attitudes to pain relief

The taking of particular medications is not taboo.

The community attitude towards euthanasia

As euthanasia is against the religion it is not considered culturally appropriate. Nevertheless, some patients may wish to discuss the question with their doctors.

Taboo words

Death, dying and cancer.

Handling of the body

Handling of the body is according to Muslim religion. The body should ideally only be touched by Muslims of the same sex. The body will be moved to face Makkah (Mecca) which is approximately northwest from Australia.

Burial

A Muslim burial is completely different from Christian customs. Muslims do not use a wooden coffin. The body is wrapped in a shroud.

Other issues

The suggestion of providing a suitable contact on the back of the brochures, was rejected. "No. People like to keep a terminal illness to themselves. They do not like anybody else, especially other community members, to know about their problems, especially in small communities".

The community attitude towards euthanasia

The strong Roman Catholic belief of the Polish community leads them to reject euthanasia.

Taboo words

Hospice is acceptable: - "Hospitziu" is referred to in SBS news broadcasts in Polish.

The words death, dying and cancer are a problem for some. Community members consulted were keen that we include the definition of palliative care, plus segments on hospice, pain and volunteers.

Burial

Most are Catholic, hence the importance of the Rosary, Service, Wake (lunch or morning tea). Despite being 'forbidden', cremation is becoming more popular. Some ashes are sent back to Poland, which is seen as acceptable, despite the views of the Catholic Church in Poland.

After the burial, mourners are invited for a 'stipar' where drinks and food are served in memory of the person.

Polish

General

A significant number of Poles migrated to Australia after World War II. Most are Roman Catholics. Respect for the Church, and a strong belief in God is of the utmost importance in the Polish community.

Religion

The Catholic Church is a very important component of Polish culture. Religious rituals include the administration of Holy Communion and the Last Rites. The Church determines funeral customs. Cremation is forbidden.

Place of treatment

Home preferred, but hospital or hospice accepted later as the disease progresses

Communication of diagnosis/prognosis

Opinions varied.

- A traditional viewpoint is that the family is given the news. Cancer is a taboo. "Do not tell the patient, lest they lose the will to live."
- One doctor of Polish background, who is pro-assimilation had a different point of view, preferring to be "frank and honest" with the patient in most cases. However he is aware that some patients do not want to admit to bad news, and conceded that he has occasionally "played the game".

Some patients with cancer think that they are being punished. Some turn to the church.

Role of family/relatives/friends

When caring for a terminally ill person the role of the family is very important. There is often a moral obligation to provide as much care as possible. Numerous Polish people within the South Australian community do not have extended family. Immediately after the Second World War, many Polish people immigrated to Australia with only their spouse, or alone. Generally they are well educated and have an excellent command of the English language.

Younger Polish people who immigrated later are now bringing out their elderly parents who may have limited English.

Role of health professionals/volunteers

The Australian concept of volunteers is not well understood by Poles, following a time in Poland when the government demanded that everyone 'volunteer' to spend their Sunday working for the good of the community.

Volunteers are of little use if they can not speak Polish, due to language and cultural factors, especially shared previous experience. For example, virtually the only volunteers in Adelaide are from the Polish Women's Association, who are assigned to hospitals, nursing homes and senior's clubs. These volunteers listen to Polish radio programs and play cards with patients.

Attitudes to pain relief

Polish people can at times display stoicism towards pain and may 'suffer' in silence. Pain-relieving drugs such as morphine are generally well accepted. There is a desire to learn as much as possible about the side effects of various medications. Due to a tacit faith in health professionals, particularly doctors, pain management and other advice given by health care workers is rarely questioned.

Some patients (even those in their 60s and 70s) turn to homoeopathic remedies and change their lifestyle and eating habits. For example, recipes from a Polish Monk produced in a local newsletter in Adelaide are sought after.

The community attitude towards euthanasia

The strong Roman Catholic belief of the Polish community leads them to reject euthanasia.

Taboo words

Hospice is acceptable: - "Hospitziu" is referred to in SBS news broadcasts in Polish.

The words death, dying and cancer are a problem for some. Community members consulted were keen that we include the definition of palliative care, plus segments on hospice, pain and volunteers.

Burial

Most are Catholic, hence the importance of the Rosary, Service, Wake (lunch or morning tea). Despite being 'forbidden', cremation is becoming more popular. Some ashes are sent back to Poland, which is seen as acceptable, despite the views of the Catholic Church in Poland.

After the burial, mourners are invited for a 'stipar' where drinks and food are served in memory of the person.

Portuguese

General

Portuguese ethnic groups include homogeneous Mediterranean stock from the mainland, people from the Azores and Madeira Islands, plus citizens of black African descent who immigrated to the mainland during decolonization. Most are Roman Catholics.

They arrived in Australia mainly between 1965 and 1975 from Portugal. There are some Portuguese clubs, but these are not strong, because most want to be Aussies. The clubs attract patrons to soccer and an Annual Ball.

Religion

90% Roman Catholic. Some are now Jehovah's Witnesses.

Place of treatment

Home is preferred, but hospital and hospice are acceptable.

Communication of diagnosis/prognosis

The diagnosis/prognosis should preferably be first given to the family, especially when the patient is elderly. The news is passed on to relatives and friends by the family, but hidden from the patient.

Role of family/relatives/friends

Decision-making about treatment is made by the family, who will give strong support and prefer that the patient stays at home.

Role of health professionals/volunteers

Health professionals are welcome in the family home, but the family will be concerned about confidentiality and advising the patient. Volunteers may be welcome, but "it is difficult for outsiders". The correct approach is to speak to the family first, before doing anything.

Attitudes to pain relief

There are no particular taboos regarding the taking of medications.

The community attitude towards euthanasia

Not allowed, as prescribed by the Catholic Church.

Taboo words

There are no taboo words, in keeping with their desire to be integrated as Aussies.

Handling of the body

No special requirements.

Burial

Cremation not allowed. A Catholic service and burial is usually followed by a wake.

Our consultants differed. One felt that there are no taboo words here and that Serbs in Australia accept that doctors are likely to use direct words such as cancer, death and dying. Another felt that the word death was taboo.

Russian

General

Russians are made up of many ethnic groups: mainly Russian, with small numbers of Tatar, Chuvash, Bashkir, Byelorussian, and Moldavian.

Generally Russians have a strong tendency for self-diagnosis, using medical books and natural treatments (herbs etc.). It should be noted that the concept of a hospice and palliative care as such

would not be very widely known in Russia. Care of the terminally ill has been strictly a family responsibility and in some cases there could be some opposition to the perceived 'intrusion' by outsiders.

Religion

Mainly Russian Orthodox

Place of treatment

Mainly at home

Communication of diagnosis/prognosis

The news is given to the family, by a medical professional, and then they decide whether to tell the patient.

Role of family/relatives/friends

The extended family take a very strong role in all aspects of decision making.

Role of health professionals/volunteers

Both are welcome in the family home and there are no special requirements, common sense being the only request.

The communication of diagnosis and prognosis is best to come from professionals.

Attitudes to pain relief

There is a general tendency to restrict 'chemical' medicines.

Community attitude towards euthanasia

Euthanasia is not an option in Russian society.

Taboo words

There are no taboo words.

Handling of the body

Often the body is prepared for burial at home by friends or relatives.

Burial

Cremation is rare. The burial is conducted by an Orthodox priest.

Other issues

There are Russian sectarians, Baptists, Molokans, etc. whose attitudes may be different.

Serbian

General

- The family is the focus of life and provides the first coping mechanism. "Sad is the house without children".
- Religion plays an important part in people's lives.
- A concern for Serbs living in Australia, is how will the second generation handle the care of their dying parents.
- Another problem for Serbs and others now in Australia is coping with the death of a loved one back in the home country. This brings a feeling of abandonment. One way of coping with this is to pay for a mass, that resembles a funeral and to attend a meal afterwards, even though the deceased is not here.

Religion

- Primarily Orthodox.
- Mourning is a prescribed way of dealing with death.
- Loud wailing and expression of grief is practised.

Place of treatment

One consultant felt that treatment at home was strongly preferred and that there is guilt felt if a relative dies in hospital. An Aunt said that after an operation, she was prepared to go "There", meaning a Nursing Home. "There" is outside the family. "If children won't look after me, this must mean that I have failed as a parent and the children are paying me back." There was also fear of being shamed by other families.

A second consultant felt that hospital was the treatment place of choice, followed by the home.

Communication of diagnosis/prognosis

News of diagnosis and prognosis is traditionally given to the family. The family then passes this on to relatives and friends.

Role of family/relatives/friends

Decision-making about treatment is a joint decision by the family and patient. Family and friends provide strong support. Many visitors come, to alleviate boredom and distress.

The role of health professionals/volunteers

Professionals can be highly regarded. Volunteers may not be welcome in the family home. Serbs are not used to this concept. The family and friends usually provide all the support needed. If a volunteer is sent to a family home, he/she has to be strongly recommended as an expert.

It is important for professionals to show compassion and understanding and it is extremely important that their body language reflects the words that they are saying. Serbs are not used to developing a professional relationship that ends when the patient is discharged. Any friendship developed is expected to continue and to be reciprocated.

Attitudes to pain relief

The taking of particular medicines is not taboo, but giving morphine is usually a sign being "near the end". This can increase anxiety.

The community attitude towards euthanasia

The idea of euthanasia is generally not well received, but it is an individual decision, which some may support.

Taboo words

Our consultants differed. One felt that there are no taboo words here and that Serbs in Australia accept that doctors are likely to use direct words such as cancer, death and dying. Another felt that the word death was taboo.

Cancer is sometimes seen as punishment and that it could be inherited. Also that it may be contagious.

Handling of the body

Funeral director

Burial

Serbs prefer burial to cremation.

- Elaborate Mausoleums are common in Serbian culture - seen as an expression of love and loss. Mausoleums can also be a status symbol.
- Serbian people visit the cemetery regularly, including at 7 days and 40 days and one year after death. Certain foods are eaten. Some spirits are drunk and some is spilt on the ground for the soul of the deceased person.
- The deceased's partner and immediate family are not allowed to listen to music or to attend celebrations such as christenings and birthdays for one year. In Australia 6 weeks may be accepted.
- Some Serbs want to be buried in their country of origin and their body may be flown back to Serbia.

- Black clothes may be worn for one year or for life. In Australia 6 weeks may be accepted.
- Men sometimes may not shave for one year.
- A black arm band is a sign of mourning among men. It helps people to recognise the bereaved's pain/loss and to offer support/condolence/sympathy, which is helpful in the healing process.

Other issues

It is recommended not to point at the location of a cancer, because this "invites trouble". It is acceptable to describe a location in words.

Spanish

General

Spanish speaking people have come to Australia over many decades and from many countries, including Argentina, Bolivia, Chile, Colombia, El Salvador, Mexico, Nicaragua, Peru, Spain and Uruguay. Almost all are Roman Catholics, however many are non-practising.

Religion

Roman Catholic

Place of treatment

Home is preferred, but hospital is acceptable if necessary. Nursing homes and Hospices are not preferred.

Communication of diagnosis/prognosis

The news is usually given to the family, who may discuss this with relatives, before deciding when and how the news will be given to the patient. "Usually family members are protecting the patient."

Role of family/relatives/friends in

The family has a strong influence regarding the patient's treatment and where the patient will be looked after. They are very supportive and usually quite involved with care. It is an expected "role of life".

Role of health professionals/volunteers

Professional people are highly respected and welcome in the family home. Their role is seen as clarifying, providing knowledge and expertise. It is important never to make decisions with the patient only, always check with the family first.

One consultant was not sure about volunteers being welcome, due to the family being very protective.

Attitudes to pain relief

There are no taboos regarding medication.

The community attitude towards euthanasia

Not well received, as prescribed by religion.

Taboo words

The words death and cancer should not be mentioned if the family has not used these words.

Handling of the body

Opinion varied. One consultant suggested that if a person dies at home, "the body will be cared for by relatives, who will dress the body". Another suggested that a funeral director be called.

Burial

Due to the Catholic influence, there is usually a Mass followed by a cemetery burial, not cremation.

Turkish

General

Turkish migrants started coming to Australia after an agreement signed in 1967. The first migrating groups were mainly from villages and small towns who were looking for jobs. These migrants were illiterate or without high school education. After 1980 - 85 people with qualifications started coming from Turkey.

The main language group is Turkish, with some speaking Kurdish and Arabic. Turkish people are open minded - if things are explained clearly, they welcome the information.

Religion

98% of people living in Turkey are Muslim. This does not mean that they all are very strict Muslims. Islam is the main religion, prescribing a way of life, which includes modesty of dress and five sessions of prayer each day.

Place of treatment

The preferred place of treatment is at home, if possible. The book "The Muslim Patient" ⁽⁵⁾ is recommended for further information.

Communication of diagnosis/prognosis

Doctors should give the diagnosis/prognosis to close family members first, since some patients will not be able to cope with the news. The news is given to close family, but not normally to friends.

Role of family/relatives/friends

Normally the patient would decide on the type of treatment, following the advice of the doctor. However some families would make decisions about how the patient should be receiving treatment. The family will provide usually provide support, if possible.

Role of health professionals/volunteers

Health professionals are welcome in the family home. They play the biggest role regarding health diagnosis and prognosis. They should keep the information confidential. Volunteers should be aware of possible religious requirements (ablution and prayer 5 times per day). Otherwise they should just use their common sense.

Attitudes to pain relief

The taking of particular medications is not taboo.

The community attitude towards euthanasia

It is against the religion and not culturally appropriate. Nevertheless, they should take into consideration the patient's condition and wishes.

Taboo words

People try not to use the words death, dying and cancer in order to avoid hopelessness and its devastating effect on the patient, particularly if he or she is young. Instead of cancer "illness" is used.

Handling of the body

Handling of the body is according to Muslim religion. The body should ideally only be touched by Muslims of the same sex. The body will be moved to face Makkah (Mecca, which is approximately northwest from Australia).

Burial

Muslims do not use a wooden coffin. The body is wrapped in a shroud.

Other issues we should be aware of

Having a Turkish social/community worker involved would help. If everything is explained clearly there should be no problems.

Vietnamese

General

Vietnamese culture contains a number of different religions, the main ones being Buddhism and Catholicism. Some 'Chinese' Vietnamese worship their ancestors which is characteristic of Confucianism. Vietnamese people, in common with some other South-East Asian communities, may be disinclined to answer questions with a negative reply.

Religion

Religion dictates the various rituals in the dying and bereavement process. Vietnamese Catholics have a strong need to pray to God, to help the dying person reach Heaven. Vietnamese Buddhists consult their Monk in time of death. Traditional practices have been significantly simplified in Australia. Families decide how they will mourn the death of their loved one.

Place of treatment

Home is strongly preferred. If a person does not die at home this is regarded as causing bad luck for the family. If taken to hospital, the patient will always hope for a cure or a miracle, but must be taken home at the last minute, to die.

It is important for relatives and friends to see the patient's face, even if the patient is unconscious (and he theirs if possible) in the last minute of life. Thus, even if the patient is seen on the day before death, notification that he is dying will bring them back quickly.

Communication of diagnosis/prognosis

Within some sections of the Vietnamese community there is a considerable degree of stigma attached to a diagnosis of cancer. This stems from a belief that the person must have acted wrongfully in the present or a past life to have 'attracted' cancer. Consequently many family members do not wish the dying person to know their diagnosis or prognosis. Many also believe that exposure to chemicals in the Vietnam War may have caused their cancer. There is sometimes an initial belief that if the diagnosis and prognosis is communicated to the dying person, they will give up hope and lose the will to live. Families may also prevent communication in an attempt to reduce further suffering of the dying individual.

Once the family has accepted the prognosis, carers may present a more matter of fact and pragmatic approach. Emotional expressions of grief may be repressed. Traditionally the eldest male (the father, or the eldest son if the father is dying) will make or ratify important decisions. In general the individual patient will not question directions from doctors, due to their elevated status. The patient accepts the authority of the family.

To whom the news is first given varies with the individual. "Some patients can't handle the news, and some families can't handle the news". Vietnamese doctors and nurses in Australia prefer to tell the patient up front. "How to tell is more important than what to tell." Another consultant felt that bad news is still mostly given to the family and that bad news is hidden from the patient. The family may pass on the news to other family members, but not to others, even the next door neighbour.

The family play a strong role in decision making about treatment. Family support is strong, including the extended family (in-laws) if necessary, but families are now often fragmented. Some patients without family support die in fear and distress.

Role of health professionals/volunteers

They are welcome in the family home, but are ideally Vietnamese. The family often needs counselling and assistance (eg client caring for a dying father, who also has two children to organise.) Volunteers

are regarded as good if the doctor sends them.

- Vietnamese carers may be reluctant to openly accept emotional support. Consider subtle ways to introduce emotional care, eg. offer to visit 'for a chat'.
- Introduction of practical help from community services may need to be accomplished without causing home carers to 'lose face'.
- Phrase questions carefully to avoid forcing a 'yes' answer when the person may mean 'no'.

Attitudes to pain relief

Endurance and stoicism may be viewed by some Vietnamese people as an indicator of strength of character. Some Vietnamese people may also engage in practices such as vigorously rubbing a coin on selected parts of the body, particularly the chest and back of shoulders. This practice aims to clear the 'poison' air, which is believed to be responsible for their illness. Complementary practices, in the hope of a cure, are strong components of care in the Vietnamese community, eg. ingestion of herbal medicines and acupuncture. Some Buddhists can deal with pain via meditation: - "the patient is calm and accepts where he is going." Western pain-relieving medications are, however, generally well accepted.

Taboo words

Vietnamese do not fear the use of the words death, dying and cancer. Hospice is not understood by most Vietnamese, although there are some volunteer hospices in Vietnam, run by Christians and Buddhists. Nursing homes exist, but residents are regarded as having been deserted by their family.

Handling of the body

The body should ideally be at home for one day, lest the lost spirit bring bad luck to the family. Emotional and spiritual issues are more important than physical issues, regardless of religion. The family should be offered an opportunity to have a Priest in attendance, to administer Communion and the Last Rites, or a Monk to perform required Buddhist rituals.

Burial

Many Vietnamese Buddhists still prefer cremation, with the ashes stored in the local Temple below a photograph of the deceased. Numerous Buddhists believe in reincarnation. It is important for the 'soul' to leave the body 'contented' so that it may have a favourable rebirth.

Other issues

Shame and punishment may be felt regarding deformity, disability and cancer. The belief that the person must have acted wrongfully in the present or past life to have 'attracted' cancer, is from Buddhist Karma. 'Bad fruit comes from a bad seed'. One consultant advised that she counsels that life is a continuous cycle and god loves us all.

The most important people to the dying patient are, in order:

- 1 Doctor
- 2 Family
- 3 Spiritual advisor - Monk, Priest, Nun
- 4 Friend, Neighbour, member of Vietnamese association

Bibliography

- 1 Carella A (1996) *Palliative Care guidelines for Italian Greek Polish, Vietnamese* Woodville, South Australia, Western Palliative Care Service.
- 2 Campbell D, Small D, Moore G (1997) *Improving Palliative Care in a Multicultural Environment*, St Leonards, New South Wales, Hope Healthcare Limited and Northern Sydney Area Health Service.
- 3 Parkes CM, Laungani P, Young B (1997) *Death and Bereavement Across Cultures*, London, Routledge.
- 4 Babacan H, Obst P (1998) *Death, Dying and Religion*, Brisbane, Queensland, Ethnic Communities Council of Queensland.
- 5 Dinef O, (1999) *Orthodox Perspectives on Death, Dying and Bereavement*, Woodville, South Australia, Western Palliative Care Service.
- 6 *Guide to the Needs of Muslims in the Community*, Adelaide, South Australia, Muslim Women's Association of South Australia.
- 7 Haffejee F, (1993) *The Muslim Patient*, Melbourne, Victoria, Islamic Council of Victoria.

PALLIATIVE CARE AUSTRALIA

NATIONAL OFFICE

Palliative Care Australia
PO Box 55
YARRALUMLA ACT 2600

Telephone: (02) 6232 4433
Website: <http://www.pallcare.org.au>

MEMBER ASSOCIATIONS

ACT ACT Hospice and Palliative Care Society Inc
PO Box 88
CIVIC SQUARE ACT 2608

Ph: (02) 6247 4511
Website: www.dynamite.com.au/acthpc

NSW Palliative Care Association of NSW
PO Box 55
ALLAWAH NSW 2218

Ph: (02) 9587 4546

NT Northern Territory Hospice and Palliative Care
Association
PO Box 42255
CASUARINA NT 0811

Ph: (08) 8927 7004

QLD Palliative Care Association of Qld
494 Boundary Street
SPRING HILL QLD 4000

Ph: (07) 3832 3522
Website: www.pallcare.org.au/qld

SA Palliative Care Council of South Australia Inc
202 Greenhill Road
EASTWOOD SA 5063

Ph: (08) 8291 4137
Website: www.pallcare.asn.au

TAS

Tasmanian Association for Hospice and
Palliative Care Inc
PO Box 517
NORTH HOBART TAS 7002

Ph: (03) 6224 3808

VIC Palliative Care Victoria
2nd Floor
182 Victoria Parade
EAST MELBOURNE VIC 3002

Ph: (03) 9662 9644
Website: www.pallcarevic.asn.au

WA WA Hospice Palliative Care Association
City West Lotteries House
2 Delhi Street
PERTH WA 6005

Ph: (08) 9420 7211
Fax: (08) 9420 7211