Golden Years

Palliative Care and CALD Communities

GOLDEN YEARS is a newsletter on ethnic aged care issues produced by the Ethnic Communities’ Council of Victoria, jointly supported by the Victorian and Australian Governments.

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On 20 November ECCV hosted its biennial multicultural conference at the Melbourne Convention Centre. We are pleased that representatives from a variety of ethnic and multicultural organisations and other stakeholders met to discuss Victoria’s multicultural identity. We ought not to take multiculturalism for granted, and an event such as this provides the community with an important opportunity to highlight its continuing importance. While we live in a culturally diverse country, with migrants and refugees forming such a large component of our communities, we must keep working to not only recognise existing good practice, but to also work for a sustainable future for multiculturalism. Particularly, Victoria has a strong and well-positioned multicultural community. Over almost four decades the Ethnic Communities’ Council of Victoria (ECCV) has been advocating for multiculturalism and we will continue to do so.

The conference, I believe, has been an expression of Victoria’s identification with multiculturalism. It presented participants with different perspectives on multiculturalism and highlighted some of the key issues the ethnic and multicultural community sector is presently facing.

The topic of the breakout session on ageing at the ECCV conference was: How can cultural identity be respected in a generic aged care system? Panellists included the Community Services Manager from Fronditha Care, a senior researcher from Monash University and the manager of Aged & Disability Services at Moreland City Council. One panellist mentioned that there is no national aged care standard or accountability measures for cultural identity and that CALD issues should not be an add-on, but should be integral to all policies, practices and programs. Ethnic seniors need to be engaged in the decision making process regarding their choices rather than expecting them to fit the box. It was also emphasised that cultural identity encompasses more than culturally appropriate food and that the service system should recognise the value of individualised care.

This edition of Golden Years focuses on Palliative Care and CALD communities. ECCV is actively engaged in Palliative Care Victoria’s initiative to develop a Palliative Care Cultural Responsiveness Strategy in order to raise awareness of the issue among ethnic communities.

Throughout the calendar year, our aged care policy sub-committee under the leadership of Marion Lau has worked together with the ethnic and multicultural community sector to ensure that the voice of ethnic seniors is heard.

I thank those who have supported us over this year and I wish you all an enjoyable and safe summer!

Joe Caputo, OAM
Chairperson
ECCV
Golden Years Editorial: Palliative Care and CALD communities

The summer edition of Golden Years provides information on CALD specific issues in palliative care and how palliative care is being promoted in the ethnic and multicultural community sector.

Ethnic seniors are often reluctant to make use of these services because the concept of palliative care is not well understood by Victorians from CALD backgrounds. This links to our fairly recent policy paper on health literacy titled *An Investment not an Expense: Enhancing health literacy in culturally and linguistically communities*. As CALD seniors have lower levels of health literacy, they are less likely to use health services they need.

The introductory article by Palliative Care Victoria looks into cultural considerations for end-of-life care and the lack of understanding within the health sector when working with ethnic communities. A further article by Palliative Care Victoria emphasises the necessity to make palliative care more culturally responsive. Additionally, an article by the Victorian Healthcare Association analyses how the palliative care services in Australia could be enhanced. Another article by Kalyna Care illustrates culturally appropriate palliative care in an ethno-specific residential care facility.

In the *General* section, the topic of homelessness among older people, including those from ethnic communities, is featured. I hope that this 111th edition of Golden Years will be informative for you as a reader.

With all the best wishes for the holiday season,

**Nikolaus Rittinghausen**
Policy Officer Aged Care Editor
With Victoria’s culturally and linguistically diverse (CALD) population growing and ageing at a faster rate than the rest of its population, health care staff are facing increasing challenges around communicating with and meeting the needs of older patients and their families.

These ethical and communication challenges are often highlighted when medical or health staff need to discuss advance care planning. Through advance care planning, we can communicate our values, beliefs, wishes and preferences, to guide the type of care we want to receive. It involves having conversations with family members and health care professionals about future health and personal care.

The following report considers moral disagreements over cultural beliefs in end-of-life care, and show how services can work to meet the needs of people with different cultural and religious beliefs.

Cultural considerations for end-of-life care
Dr Megan-Jane Johnstone from the School of Health at Deakin University believes that cultural considerations relevant to end-of-life care “remain poorly understood, poorly guided, and poorly resourced in health care domains”.

In an article published in the Journal of Medical Philosophy, she describes the challenges faced by those whose minority cultural world views do not fit with the conventional principles of western bioethics, and their struggle to have their care needs met in a meaningful, safe and healing way.

This is despite a strong emphasis in recent years on making policy commitments to patient-centred care and respecting patient choices.

While some health professionals are unaware of the impact of culturally inappropriate approach, others justify their behaviour as professional or ethical duty.

“But truthful disclosure to a patient in a culturally inappropriate way can create negative health beliefs and expectations, which then lead to a worsening of symptoms or even the shortening of life,” says Johnstone.

In her article, she gives the example of a Greek patient whose family refused palliative care, as they saw it as giving up on their father. He was turned away from acute care and refused rehabilitation, as he was deemed a palliative care patient. The man disclosed to his family that he felt “worthless” and that hospital staff saw him as “a piece of meat”. The only option for him and his family was to care for him at home.

“For people like this, whose cultural world-views are different from western bioethics, the values of advance care planning and euthanasia intensify rather than soothe their death-related anxieties,” says Johnstone.

“If medical and health staff don’t know what specific cultural differences might apply to a patient, they should start by asking the patient about their beliefs and talking to their family.”

Contact Palliative Care Victoria on (03) 9662 9644 for further information.

Palliative Care Victoria
Specialist health care and practical support

Dr Megan-Jane Johnstone
Over the next 40 years, the number of people aged 85 years and over is expected to increase four-fold. Of this cohort, it is estimated that up to 85% will die as a result of a chronic illness, creating a growing demand for appropriate palliative care.

This demand is growing at 4.6% each year, yet there are many barriers in the health system that prevent people from receiving quality palliative care. Far too often it is sub-populations such as those from a CALD background who miss out.

Palliative care in Australia should be available to all who require it – irrespective of the person’s location, income, age or cultural background. International research indicates that up to 90% of people with a life-threatening illness would prefer to die at home or in a home-like environment, yet only 26.5% of Victorians die at home.

Episodic care with different providers and settings results in a lack of continuity of care and the absence of a multidisciplinary approach necessary to meet the physical, emotional and social needs of a patient. Inequities and inconsistencies in access to care can lead to avoidable hospitalisations or lead to the inability of people to access appropriate pain and symptom relief. For CALD individuals, these problems are further exacerbated by language and cultural barriers and create further difficulties in accessing palliative care in a timely and effective way.

The problem is we currently have a health system that is shaped by the way our Commonwealth government funds our health services. Commonwealth funding arrangements skew the delivery of palliative care towards bed-based options in a hospital as opposed to services provided in place. From 1 July 2013, palliative services delivered in hospitals will be funded on a per-activity basis and there are concerns that this will place restrictions on hospitals’ ability to truly cater for patient needs. In comparison, home and community based programs deliver specialised, patient-centred medical care and care coordination, which are enabled by block funded grants.

Particularly in Victoria, palliative care reflects a substantial discrepancy in funding. While the provision of palliative care is becoming increasingly necessary in residential aged care (RAC) facilities, it is still funded within ‘general care’ budgets and not adequately resourced. In fact, the funding for delivering palliative care in a RAC facility is a quarter of the total amount of funding received for delivering palliative care in a hospital.
With almost one-quarter of people admitted into permanent RAC facilities dying within eight months of admission, and one-half dying within 14 months, the predominant need is for care, not accommodation. The current funding inequity means that older people entering a RAC facility for palliative care will be charged a daily accommodation fee, as opposed to being admitted into a hospital or palliative care unit where accommodation costs nothing.

However, even if the government adjusts the funding in all palliative care settings, it will only be one answer to the challenges in access and availability of choice.

Health services should no longer operate merely to service those that walk in the door, seeking immediate medical care. By adopting a population health approach to palliative care provision, health services can play a key role in addressing local community needs and actively targeting groups across the spectrum, including those vulnerable or at risk.

Appropriate funding mechanisms must be matched by cultural change and enhanced community education about the role of palliative care and the benefits it can produce. The stigma of palliative care being equivalent to terminal care is a result of the limited understanding amongst communities and health professionals and has deterred options of early referral – which leads to better care management and coordination.

The provision of palliative care must be appropriate to a person’s needs at the right time and in the place of their choice. This is possible in Australia – it will just involve government, service providers and community organisations working together to respond to the flexible and dynamic needs of individuals, particularly those from CALD background.

Eloisa Evangelista
Eloisa.evangelista@vha.org.au or on (03) 9094 7777 for further information.
On 21 May 2012, the Victorian Palliative Care Cultural Diversity Leadership Group held a forum attended by over 80 people from ethnospecific and multicultural organisations, palliative care services and consortia, and other key stakeholders. We appreciate the input and contributions from all those who attended the forum – outcomes from the forum are guiding the development of a palliative care cultural responsiveness strategy.

We were also very pleased with the media coverage we had after the forum – over 40 media items were published in six different languages. The take-up in the Chinese and Vietnamese media was particularly strong.

While Victoria’s older culturally diverse population is ageing more rapidly than the average population, figures show a lower take-up of palliative care services among people from culturally and linguistically diverse backgrounds. As such, the priorities of the Palliative Care Cultural Responsiveness Strategy are to raise awareness of palliative care among CALD communities and promote the provision of culturally responsive palliative care services. This will hopefully then lead to increased use of palliative care services by people with a life-threatening illness and their families from CALD communities.

Chaired by Palliative Care Victoria, the current membership of the Leadership Group includes representatives from key government, multicultural, health and palliative care stakeholders.

“The concept of palliative care is often not well understood among people from culturally and linguistically diverse backgrounds, which is partly due to limited access to information about palliative care in community languages,” says Palliative Care Victoria CEO Odette Waanders. Palliative Care Victoria’s online library now offers resources in 24 different languages, including brochures and short online videos that explain palliative care. These are available at www.pcvlibrary.asn.au – visit the multilingual section. Bulk copies of printed brochures in different languages are available from Palliative Care Australia (www.palliativecare.org.au).

“But it’s not just about language – culturally appropriate palliative care necessitates cultural awareness, particularly with regards to understanding the diverse cultural perspectives of illness, dying, death and grief.”

Palliative Care Victoria
Specialist health care and practical support

from left to right:
Pino Migliorino, FECCA Chairperson;
Marion Lau, OAM, Deputy Chair ECCV;
Odette Waanders, CEO, Palliative Care Victoria
The Leadership Group has met several times since the forum, with its latest meeting on 8 October 2012 focusing on different approaches for raising awareness of palliative care among CALD communities. Taking into account the group’s guiding principles, resource capacity and available evidence of need and effectiveness, these approaches may include volunteer community ambassadors, bilingual peer education, participating in community events and expos, and linking with appropriate staff in palliative care services. We will also be looking into better ways of sharing information in plain English, using interpreters or language lines, connecting with ethno-specific media, and linking to relevant multimedia campaigns.

To progress with this important work, the Leadership Group is looking into opportunities for philanthropic funding to enable on-the-ground engagement with different community groups and providing some resource capacity for them to promote awareness of palliative care within their communities in ways that each community would find appropriate.

For further information about the Palliative Care Cultural Responsiveness Strategy, please contact Nikolaus Rittinghausen, ECCV Aged Care Policy Officer on (03) 9349 4122, or Meg Polacsek or Odette Waanders at Palliative Care Victoria on (03) 9662 9644.
Palliative Care the Kalyna Care Way

If there is ever a winter time of life then it is when we reach the palliative care stage. When our body has succumbed to illness from which we cannot recover then we turn to those who love and care for us with the expectation that our passing will be as comfortable, simple and as dignified as possible.

The instruments of support we need are not only the people around us but also our cultural past; our identity, our history, our values and our beliefs. It is by calling upon these foundations that we gain strength to cope with the increased confusion, agitation and pain often associated with the palliative stage. And one of our main concerns, also involving our family and often our friends, is how we will deal with all of this and our final stage of life.

Kalyna Care provides culturally specific palliative care. Our holistic approach involves practical care with special regard for cultural tradition. While concerns about physical management such as CPR, hospitalisation, the attention of GPs, and other requisites are documented on an Advance Care Directive and acted upon by our experienced nursing staff, cultural preferences are given particular attention.

Our responsiveness to the personal begins by understanding our residents the moment they come to live with us. We listen to their story and through respect for what we learn, adapt our caring to their experiences and current needs. Our staff are guided by the resident and their family as to what interventions are culturally appropriate for them. Our service becomes culturally specific in the provision of traditional foods, language and lifestyle choices that reflect the individual’s lifelong experiences.

Personalising care is often spiritual in nature and Kalyna Care provides culture specific faith support for all denominations. Our close connections with our community means that we can call upon priests, nuns and ministers of faith to be involved in the palliative care stage. These, who are often lifetime friends, visit our home to comfort and prepare palliative care residents and their families.

They bring with them the experience and understanding of the resident’s personal heritage that enhances the support they can give. Our chapel is there for solitude, contemplation and prayer.

While our basic needs are identical, our individuality determines different requirements for end of life care. Kalyna Care understands what makes you different.

Contact Deborah D’Costa, Care Manager, or Monique Sheldon-Stemm, Grants, Marketing & Media Officer on (03) 9367 8055 for further information.

Monique Sheldon-Stemm, Grants, Marketing & Media Officer

Deborah D’Costa, Care Manager
Thomas Fong, a 79 year old Chinese Malaysian survived his own cancer challenge to help others facing their final journey in palliative care. In 2006, after three years’ treatment at the Alfred he was declared to be in permanent remission from bladder cancer. He wanted to ‘give back’ and surprised staff by choosing palliative care.

“I was always curious about the twilight zone the transitional phase from life to death, and thought I might learn more by volunteering in palliative care. Besides, if I worked with younger patients, they might think they had to look after me, an older man, rather than me helping them,” he said during a break from his work at Calvary Health Care’s Bethlehem Centre in Caulfield.

Thomas was born in Borneo and educated in NSW where he matriculated and obtained a degree as a biochemist before qualifying as a dietician in WA. Returning to Borneo he managed the blood bank and blood laboratory for thalassemia - a major problem in the region. He returned with his family to Australia in 1982.

He undertook general volunteer activities at Bethlehem before finding his calling - therapeutic touch, or gentle massage. His foreign accent and hearing disability sometimes made communication difficult, until a patient said “you have magic hands” after Thomas had held his hands. Thomas saw this as a message that this is what he should concentrate on, and he now massages up to 14 patients (and some staff) on each of his thrice weekly visits.

He remembers and was thankful that the first time he responded to a patient’s request for a foot massage, a nurse gave him a towel to reduce the pain on his knees from the cold hard ward floor. He links his foot massages to humility and to the examples of Christ and the Pope washing the feet of disciples.

“I am deeply and emotionally rewarded by the response of the patients to my touch,” he said. “They show this by their sweet, contented, grateful and graceful smiling faces, even though they are suffering from pain or other discomfort. Those who can thank me with words also, but some who can’t smile through their tears or touch me back. Many say that in that time, the pain has gone.”

He develops bonds of friendship with some of the patients in the palliative wards before they either die or move to a nursing home. These are different to the bonds he establishes with others in the neurological day centre from whom he says he “learns so much; how lucky I am to be able to look after them and how grateful they are to me.”

“I believe that sympathetic and empathetic feelings can be transmitted from the massage practitioner to the patients, and that patients can feel the emotional mood of the practitioner.”

Thomas has volunteered for over 2000 hours at Bethlehem and has no plans to stop. While he was initially unfamiliar with the term volunteer he had undertaken such work in Borneo, starting a Blood Donors’ Association and co-founding a Thalassemia Association. Both activities sought to educate and change cultural views about blood, and he hopes that his current work helps to promote multiculturalism amongst Australia’s culturally diverse communities. “I hope that I have set an example to other Chinese migrants to join volunteer services, not only for multiculturalism but also for humanitarianism.”

In Victoria, some 2000 volunteers provide support to people receiving palliative care. It is a very rewarding way to make a difference at a very important time in people’s lives.

Contact Palliative Care Victoria on (03) 9662 9644 or further information.
Guided by the principle of getting to know the person in the patient, palliative care consultant Dr Barbara Hayes and the Advance Care Planning team at Northern Health have developed advance care planning resources informed by different cultural and religious attitudes.

In researching and developing the program and resources, they consulted widely with religious and community leaders to understand different ways of valuing life, death and medicine.

“If you only focus on treatment decisions, you run the risk of not understanding the person and damaging relations between clinicians and patients,” says Hayes.

Northern Health started by interviewing health interpreters to learn how they discuss death and dying information. In consultation with Northern Health’s community advisory committees, plain language information brochures were produced.

Further consultation was undertaken with representatives of the Islamic and Catholic faiths, to ensure the approach and materials would not be inappropriate or upsetting. Translated into nine languages, Advance care planning in 3 steps – Appoint an agent, Chat and communicate and Put it on paper encourages patients to consider who might best represent them. This may lead to appointing a medical enduring power of attorney.

The patient may need to talk to others—their GP, palliative care or community nurse, priest or spiritual advisor - to help them and their substitute decision-maker to reach a shared understanding of how the substitute decision-maker can represent them well and to family, friends and clinicians.

“Even within cultures where there is an understood view about the appropriate substitute decision-maker, the families may be fragmented so the authority and decision making process may not always be clear,” says Hayes.

As well as conducting education for staff from Northern Health and other health services, the team also provides community education, including using interpreters for cultural-specific community groups. They take advance care planning self-referrals from community groups, as well as referrals for Northern health in-patients and from outpatient clinics.

“Just as with English-speaking patients, there are huge differences both within cultures as well as between cultures, so you shouldn’t stereotype. But with people of CALD backgrounds, you need to be informed about cultural attitudes so that any discussion about advance care planning is done sensitively,” says Hayes.

Northern Health is now working on a much larger advance care planning project funded by the Department of Health, which will take forward the cultural insights gained from the pilot project.

For more information please visit: www.nh.org.au/services/advance-careplanning

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Dr Barbara Hayes
When it comes to obtaining affordable, secure and appropriate housing, older people from CALD backgrounds are struggling with many of the same challenges faced by Australian-born older renters. Older renters can often find it difficult to access the limited stock of affordable housing and may find it hard to get housing that suits their mobility needs as they age. Obtaining housing that is well maintained and a good standard is also a challenge for those struggling to get by on an aged pension who may be paying more than half of their pension in rent.

Unfortunately Housing for the Aged Action Group (HAAG) has seen many examples of older tenants from CALD backgrounds whose landlords and agents have taken advantage of their lack of access to information, and have purposefully not informed them of their tenancy rights. For example, one recent HAAG client was told by their landlord for 20 years that he had no legal obligation to do essential maintenance to the property. Independent advice and advocacy can therefore be crucial to ensuring older people are protected and assisted.

Most importantly, all older people have the right to obtain long term, secure and affordable housing in the public or community housing sectors. In HAAG’s experience getting the right information about housing options is a real problem if a person has difficulty understanding English, especially when it is written in bureaucratic language in housing application forms.

**Home at Last**

Happily, there are housing services that can help older CALD Victorians. One such service is Home at Last. Home at Last is HAAG’s new Older Persons Housing Information and Support Service. Home at Last is one of 11 Homelessness Innovations Action Project funded by the Department of Human Services that aim to assist people at risk of homelessness. You can call Home at Last on 1300 765 178 from anywhere in Victoria between 10am and 4pm, or drop into our Information Centre on the 1st floor of Ross House, 247-251 Flinders Lane, Melbourne. Currently one-third of Home at Last clients are from a CALD background and HAAG provides information in languages other than English. Interpreters are always made available where required.

Home at Last is tailored specifically to the needs of older tenants, and can help people to find secure and affordable housing for the rest of their life. Home at Last can also provide advice on tenancy issues, advocate for a tenant’s rights and provide advice about retirement housing options for people with low incomes and low assets.

HAAG is currently reaching out to CALD older people who may be in housing stress to make sure information and support is available. If you run an activity group or know of a group of older people who would benefit from hearing about Home at Last Services, please contact us on (03) 9654 7389.

**Jeff Fiedler**

For further information contact Home at Last client services on 1300 765 178 or HAAG administration 9654 7389 or visit www.oldertenants.org.au.
Grants program to address social isolation for ethnic seniors

Regularly connecting with people is important to a fulfilling and healthy lifestyle. Unfortunately, it is not easy for many people to see friends and socialise. We know that for older ethnic seniors the risk of social isolation can be higher because of a range of issues, such as the language barrier.

The Victorian Government has announced the second round of this grants program to help culturally and linguistically diverse (CALD) seniors groups to reconnect or connect with isolated seniors in their community.

For some seniors there may not be any existing activities in the local area. Therefore the grant can also be used to start new social networks where there are identified gaps or focus on strategies to empower older people to participate in social activities.

This is a small grants program for projects of up to 12 months in duration. Grants up to $4,000 (metropolitan area) or $5,000 (regional Victoria) are available for social groups with an ethnic or multicultural focus. Grants of up to $10,000 are available to organisations for more larger or more complex projects.

Applications are due in before 5pm on Friday 8 March, 2013.

ECCV is funded as an implementation partner. We give advice and support to applicants and to organisations that receive a grant.

For an application form or help completing an application contact ECCV on 9349 4122 or kling@eccv.org.au. Also visit the Seniors Online website for more information and resources www.seniorsonline.vic.gov.au

For more information please visit http://eccv.org.au/community/news/how-open-participation-for-cald-seniors-grants-program