



Government of **Western Australia**
Department of **Health**

Multicultural Health Diversity Café 6: **‘Introducing Advance Care Planning to people from CaLD backgrounds’**

Executive Summary and Key Points
28 June 2017

Cultural Diversity Unit
Chronic Disease Prevention Directorate
Public Health Division

Executive Summary

‘Introducing Advance Care Planning to people from Culturally and Linguistically Diverse (CaLD) backgrounds’ was the theme of the Multicultural Health Diversity Café 6, which was held on 28 June 2017 at the Australian Professional Skills Hospitality Academy, 21 Moore Street, East Perth. The Diversity Café brought together 37 staff from the WA health system, other government agencies, not-for-profit organisations and a number of consumers.

The Diversity Café followed the Cultural Diversity Unit’s (CDU) vision of replicating a friendly café where delegates meet to learn from each other, be challenged, share, discuss, listen, ask and showcase current work with consumers and carers from CaLD backgrounds.

The CDU organised the Diversity Café in collaboration with the Department of Health’s WA Cancer and Palliative Network.

In this café, the keynote presenters shared their experiences of and perspectives on Advance Care Planning (ACP), specifically on how to raise awareness of and conduct ACP with people from CaLD backgrounds and respond in a culturally sensitive way. The keynote presenters were:

- Kim Greeve, Cancer and Palliative Care Project Officer
- Dr Felicity Hawkins, Palliative Care Fellow
- Theresa Kwok, Chung Wah Association’s Chief Executive Officer.

The Diversity Café is another learning opportunity for service providers on their ongoing journey to cultural competency around providing equitable access to safe and high quality health programs and services for people from CaLD backgrounds.

Presentation 1

Kim Greeve provided an overview of Advance Care Planning, highlighting his work on developing resources appropriate for Western Australia’s CaLD communities. He noted the Guardianship and Administration Act 1990 provides the legal basis for ACP.

He described ACP as a process of planning for future health and personal care where a person’s values, beliefs and preferences are made known to someone close to them or someone they trust such as family or friends, a doctor, a health professional, a spiritual adviser or a substitute decision maker, if one has been identified. ACP provides guidance in decision-making at a future time when that person cannot make or communicate their decisions. Ideally, these preferences are written down or documented in an Advance Health Directive (AHD), an Enduring Power of Guardianship (EPG) or an Advance Care Plan.

Kim cited that about 85% of people will die after chronic illness and not from a sudden event. This means that most people will benefit from considering the type of care they would want during this time of illness, particularly near the end of their lives. In addition, he said that ACP can:

- improve end of life care
- heighten patient and family satisfaction
- reduce stress, anxiety and depression in surviving relatives and care staff.

Health professionals need to be mindful of how the concerns, hopes and fears of people from culturally and linguistically diverse backgrounds may differ from their own. It is important to ensure equitable access to ACP for people from CaLD backgrounds, enabling culturally, linguistically, appropriate and safe ACP conversations.

The ACP for CaLD Communities Working Group, which supports Kim in his work, is currently developing culturally and linguistically appropriate ACP resources to enable the inclusion of CaLD communities in ACP conversations. This work includes an ACP factsheet which is being translated into various languages, visual and pictorial brochures and a pilot video about ACP in Cantonese.

Kim's presentation was followed by a buzzing session which came up with the following key points.

Buzz Session 1:

What would be the impact of introducing ACP for you as a service provider and for your clients/patients from CaLD backgrounds?

- Policy on ACP will help initiate the conversation about options for health professionals and family.
- Creates an opportunity to provide education to make informed choices.
- Greater credibility as a service provider.
- Improved knowledge of clients, Health Service Providers (HSPs) and ACP champions and families.
- Past experience may inhibit conversation (for example, survivor feeling guilty and, therefore, timing of discussion).
- It may disempower multicultural communities if worker does not know or respect cultural traditions. It could lead to more harm.
- As there is no Medicare item for this, this may not happen in GP land.
- ACP may reduce issues related to family dynamics, language barriers, unbiased decisions made through the engagement of interpreters.
- There are concerns that interpreters may not be trained in ACP interpreting. Not sure that what is being said is conveyed in the correct way.
- Introducing the topic would/could provide the first opportunity to start the conversation.
- Need to know which conversation is appropriate to have with patients from CaLD backgrounds.
- As a service provider in acute care, ACP would ensure limited resources in health are used appropriately instead of providing 'futile' treatment.
- Training for health professionals will mean a culturally and faith appropriate approach to ACP conversations.
- Be mindful of the client's status: culturally, level of comprehension, need for interpreter, readiness to discuss ACP.

- Introducing ACP provides an opportunity to plan in advance rather than make a decision at a time of crisis.
- Have to acknowledge the difficulty of dealing with clients over the phone.
- There is a fine line between personal and professional, for example, views, experiences, boundaries, rules.
- ACP is not a straight forward, tick-a-box process. There is a need to be flexible and sensitive to context and timing.
- Would need increased education, collaboration and buy-in from health service providers, consumers and carers.

Be mindful of the client's status: culture, level of comprehension, need for interpreter and readiness to discuss ACP.

Presentation 2

Dr Felicity Hawkins opened her presentation entitled ‘Culturally safe advance care planning’ by asking two questions: If you were so unwell that you could not talk about your treatment with your doctor, is there someone you would want to speak for you? Have you discussed this with that person?

The best times to initiate conversations about ACP, according to her, are at the time of diagnosis, when someone’s undergoing significant change in their health status, is losing independence or experiencing an important life event. She shared two tools that she finds useful when examining deteriorating health. She uses the Supportive and Palliative Care Indicators Tool to check unplanned hospital admissions, poor performance status, significant weight loss over the past 3-6 months, and/or a low body mass index or persistent symptoms despite optimal treatment of underlying conditions. And when breaking bad news to her patients, she follows SPIKES which stands for Setting, Perception, Invitation, Knowledge, Emotion, Strategy.

Dr Hawkins highlighted the importance of person centred care, open communication, shared decision making and supporting all members of the multidisciplinary team.

She cited two case studies that raised the value of case conferences with the patient and their family (which when relevant, included cultural and spiritual leaders). In these case studies, the patients’ and the families’ understanding of dementia and its natural progression as well as the families’ hopes, fears and expectations were discussed and explored further. She stressed that initiating and maintaining conversations are the key.

Her tips for clinicians and other service providers include the following:

- Best to start conversations about ACP early.
- Make it meaningful by knowing what information is required.
- Foster a relationship with GPs around ongoing plans.
- Keep up ACP conversations during regular patient reviews.
- Ensure a significant person in family is helping with decision making.

Dr Hawkins’ presentation was followed by a buzzing session which came up with the following points.

Buzzing Session 2

How would you initiate ACP conversations with your clients/patients from CaLD backgrounds?

- Introduce the concept of ACP during initial conversation with family. Take it slowly, however, and invite family members to attend.
- Do your homework! Try to find out in advance some relevant information about patient’s cultural background.
- Always check if there is a need for a cultural or language interpreter and/or advocate.

- If first approach is not successful, do not give up! Adjust how you make next contact as appropriate.
- Use appropriate language and terminology. For example, instead of saying 'You are dying' you could say 'You are approaching end-of-life.'
- Raise with client/patient need to talk about their care, ask what support is needed and encourage attendance of family or interpreter, if needed.
- Identify the 'culture' and 'person' by speaking to client first, ascertaining what is important to them, speaking with carers and being 'person-centred' in your approach.
- Build a relationship with the clients/patients.
- Practice cultural humility by understanding your own biases and engaging with the client/patient and their family.
- Allow time for planning. ACP is never a quick conversation. Be diplomatic and sensitive about the topic.
- Check out Dyingtotalk.org.au for assistance and guidance in initiating conversations.

Practice cultural humility by understanding your own biases and engaging with the client/patient and their family.

Presentation 3

Theresa Kwok presented about the ‘Challenges of Bringing ACP to the Chinese community’. She started her presentation by showing the video of her talking about ACP in Cantonese. She mentioned that the Department of Health produced this video as a pilot initiative to show that a resource like this could convey the message to members of a community who may not be literate in their own language.

She shared that Chung Wah Association has been servicing CaLD Asian communities since 1909 and that they understand the needs and culture of Chinese and Asian peoples, which are rapidly growing populations in Western Australia. Citing ABS statistics, WA seniors from CaLD backgrounds make up almost one-fifth (18.3 %) of the State’s total population (ABS, 2011). The most spoken language is Mandarin while Cantonese is the fourth most spoken language other than English in Western Australia (ABS, 2016).

She spoke about the challenges brought on in communicating ACP to the Chinese community and the need to consider the following Chinese values when doing so: filial piety which is based on Confucian philosophy (includes longevity and respect for parents); closely knit families and relationships which involve making sacrifices for parents, children and the younger generations; a shared sense of community cohesion and concepts of death and dying.

She expounded on death and dying and Chinese values. For example, the Chinese never talk about death and dying as it is thought to bring bad luck to old parents and family members. Old people do not attend funerals and pregnant women are told not to face the coffin directly. A long process of death could mean not accepting the end of one’s life and the after life cycle.

Theresa then referred back to her video and said that she avoided directly saying the word ‘death.’ Instead, she used generally acceptable and traditionally well-known phrases to describe one’s life processes.

Theresa’s presentation was followed by a buzzing session which came up with the following points.

Buzz Session 3

What would you need to initiate and support continuing conversations about ACP? You may reflect on the online resource and the video that has been developed by the ACP Working Group.

- Create good rapport with clients.
- Come up with policies that address time constraints and allow more time with clients to discuss sensitive topics such as ACP.
- Continued education of service providers and networking to ensure consistent approaches.
- Make use of existing resources – do not reinvent the wheel!

- Videos are good resources, however, suggest using them only after initial assessment or meeting.
- Need to consider the needs of those who do not have access to computers.
- Get permission or support of community through church leaders, community groups and radio programs - they could provide input, suggestions and venues run information sessions.
- Support the dissemination of resources and hold associated information sessions.
- Identify key spokespeople or champions to make similar videos for other CaLD communities such as Serbian/Croatian/Macedonian/Bosnian and other language groups.
- Develop language cue cards specific to ACP and Advance Health Directive and promote use among WA health system nurses.
- Ask, do not assume.
- It would be helpful to have education/resources about different cultures and taboos and rituals.
- Allocate time to connect with community.
- Ensure continuity of care.
- There is a need for education and training for those initiating the conversation and delivery of information about ACP.
- Develop audio-visual resources in key languages that explain ACP and in ways that do not create fear or anxiety.
- Work with family and/or trusted advisor.
- Provide information about cultural and faith beliefs for consideration by health professionals.
- Keep talking about what the client needs and wants. Keep the focus on the client.

Train/educate health professionals how to initiate ACP discussions at different stages of declining health.

Diversity Café participants

The Diversity Café was attended by 34 participants from the Department of Health, Health Service Providers, government agencies, interpreting agencies, not-for-profit organisations and consumers.

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Theresa Kwok	Chung Wah Association Community & Aged Care	Theresa.Kwok@chungwahcac.org.au
Valerie Colgan	WA Cancer Palliative Care Network	Valerie.Colgan@health.wa.gov.au
Zoe Mitchell	Fiona Stanley Hospital	zoe.mitchell@health.wa.gov.au

Presenters' Brief Background:

Kim Greeve

Kim Greeve is a Project Officer with the WA Cancer and Palliative Care Network at the Department of Health. Kim is a Registered Nurse and has a BA Honours in Health Care Management from the University of Westminster (UK). Kim has recently graduated with a Postgraduate Certificate in Palliative Care and is currently studying towards a Master in Palliative Care at Flinders University.

Kim has been involved with the introduction, awareness raising and training around Advance Health Directive since 2009. Kim is also currently working on the Introduction of Advance Care Planning into Western Australia.

Felicity Hawkins MBBS (Hons) FRACP

Dr Felicity Hawkins completed specialist training in Palliative Medicine in 2016 and is currently completing dual training in Geriatric Medicine. Dr Hawkins is currently the recipient of a highly competitive Research Fellowship from the WA Cancer and Palliative Care Network focusing on improving the detection of delirium in patients admitted to Bethesda Palliative Care Unit. Dr Hawkins is also studying towards a Master in Health Professional Education with the University of Western Australia. Her Master's thesis is around the experiences of junior doctors in negotiating not for resuscitation decision-making with patients and families.

Dr Hawkins was a Council Member of the Australian and New Zealand Society for Palliative Medicine and a Board Member of Palliative Care Australia WA from 2014 to 2016.

Theresa Kwok JP

Mrs Theresa Kwok is the Chief Executive Officer of Chung Wah Community and Aged Care. She migrated from Hong Kong in the late 80s and has qualifications in Social Work.

Theresa has been with Chung Wah for over 25 years and has worked tirelessly to promote access and equity in migrant and aged care services for Asian and ethnic communities. She has been the driving force and architect of Chung Wah's culturally appropriate age care services.

Theresa has been recognised for her exemplary community work. She was awarded the Multicultural Community Service Award in 2003 by the Office of Multicultural Interests for her dedication to the Chinese, Vietnamese and Cambodian communities. She was a finalist in the 2013 WA Champion for Seniors Awards and received a Highly Commended Award for her work in age care in the 2016 Community Organisation Award for Outstanding Contribution to Multiculturalism.

Diversity Café Convenors

The Diversity Café 6 was convened by:

Ruth Lopez, Senior Policy Officer, Cultural Diversity Unit, DOH
Kelli Monaghan, Policy Officer, Cultural Diversity Unit, DOH
Kim Greeve, Project Officer, WA Cancer and Palliative Care Network, DOH.

For more information, contact:

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Diversity Cafe convenors and presenters: Kelli Monaghan, Ruth Lopez, Kim Greeve and Dr Felicity Hawkins



Multicultural Health Diversity Café 6:

'Introducing Advanced Care Planning to people from CaLD backgrounds'

Date and time: 28 June 2017, Tuesday, 9 am - 12 noon
Venue: Australian Professional Skills Hospitality Academy
21 Moore Street, East Perth

Program

Welcome and introduction to Diversity Café 6	9:00 am	Ruth Lopez , Senior Policy Officer, Cultural Diversity Unit (CDU), CDPD, Public Health Division, DOH Overall Diversity Café Facilitator
Housekeeping	9:10 am	Kelli Monaghan , Policy Officer, CDU, CDPD, Public Health Division, DOH
Presentation 1	9:15 am 9:35 am	Kim Greeve , Cancer and Palliative Care Project Officer, DOH Buzz session 1: What would be the impact of introducing ACP for you as a service provider and for your client/patient from CALD backgrounds? Discuss, identify 3 key points and display on ideas wall
Presentation 2	10:00 am 10:20 am	Dr Felicity Hawkins , Palliative Care Fellow, Sir Charles Gairdner Hospital Buzz session 2: How would you initiate ACP conversations with your clients/patients from CaLD backgrounds? Discuss, identify 3 key points and display on ideas wall
Presentation 3	10:45 am 11:05 am	Theresa Kwok , CEO, Chung Wah Association Buzz session 3: What would you need to initiate and support continuing conversations about ACP? You may also reflect on the online resource and the video that has been developed by the ACP Working Group. Discuss, identify 3 key points and display on ideas wall
Summary	11:30 am	Key ideas from the conversations
Close	11:50 am	Thanks and Close

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