

# Developing Culturally Responsive Palliative Care Services



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## **Acknowledgements**

Firstly, I would like to acknowledge the Winston Churchill Memorial Trust Board for its grant of a scholarship to allow me to travel overseas and learn about the delivery of palliative care to ethnic communities. This opportunity to meet with people from a wide range of settings, and to observe and learn about new initiatives and programmes, has provided me with an invaluable learning experience and a vision for the development and delivery of culturally responsive palliative care here in New Zealand.

I am grateful also to Mercy Hospice Auckland for supporting me to undertake this scholarship. Its encouragement and support in allowing me the time to travel is much appreciated; without that support, this project would not have been possible.

I would like to acknowledge the people I was privileged to meet on my travels. I met many caring and committed people who generously shared their time and knowledge with me. I am indebted to these many individuals.

Lastly, I would also like to express special thanks to Barbara Love and Majabeen Ali, of the Culturally Sensitive Services Project at The Prince & Princess of Wales Hospice in Glasgow. Barbara, Maj and their colleagues at the hospice extended a warm welcome to me, shared the challenging and rewarding journey of their project, and provided me with both information and inspiration for the development of culturally responsive palliative care services.

This travel has provided many opportunities for increasing my knowledge and understanding but it has also been a personally enriching and worthwhile experience, for which I am most grateful.

## Executive Summary

The opportunity to visit, meet with and learn from practitioners in the field of palliative care, in Australia, England, Scotland and Canada, has provided me with valuable information that can be utilised here in New Zealand, as we develop and deliver culturally responsive palliative and end of life (EOL) care services to our ethnically diverse communities.

The following is a summary of the report's key points:

- Auckland is becoming increasingly ethnically and linguistically diverse. It is estimated that 40% of the current population was born overseas and that, by 2021, half of Auckland's population will be of non-European origin.
- Cultural beliefs and values shape our approach to death and dying, and need to be acknowledged and included in the delivery of EOL care services.
- Hospices and palliative care providers are committed to the delivery of EOL care that is accessible, affordable and culturally appropriate for the communities they serve.
- The development of a culturally responsive palliative care strategy to improve the delivery of culturally responsive EOL care will provide a framework for the development and delivery of services.
- A culturally responsive palliative care strategy must be based on the principles of partnership and collaboration, with culturally and linguistically diverse (CALD) consumer, carer and community members involved in the development of that strategy.

## **Introduction**

The delivery of culturally responsive EOL care is a challenge for healthcare providers both here in New Zealand and overseas. Because culture shapes our approach to death and dying, the delivery of EOL care must be congruent with the cultural beliefs, attitudes and practices of the individual, their family and their community. While the World Health Organization (WHO) definition of palliative care includes the provision of culturally appropriate care, the delivery of palliative and EOL care is dominated by Western ideals of what is a 'good death'. As hospices meet the challenge of delivering care that is accessible and culturally responsive, they are looking at ways to engage better with their CALD communities, to ensure that EOL care is appropriate and accessible to all in our communities.

Our cultural beliefs provide us with a framework for understanding death, and give meaning to our experiences of suffering and loss. Our traditional practices around death are often linked to our beliefs about the meaning of death and what lies beyond, and have both emotional and spiritual significance.

Cultural beliefs impact on many aspects of EOL care, including the disclosure of information, decision-making, the use of life-prolonging treatments, and the experience of grief and bereavement (Koenig & Gates-Williams, 1995; Kagawa-Singer & Blackhall, 2001; Crawley, Marshall, Lo & Koenig, 2002; Feser & Bernard, 2003; Schim, Doorenbos & Borse, 2006; Todd & Mulry Baldwin, 2006; Clark & Phillips, 2010; Bullock, 2011; Heidenreich, Koo & White, 2013).

The importance of incorporating cultural values into EOL care is now recognised, along with the need for programmes to ensure that cultural values are integrated into interactions between patients and health professionals (Braun, Mokuau, Hunt, Kaanoi & Gotay, 2002).

Recent studies in Australia with indigenous and ethnic minority communities provide valuable insights into the EOL care needs of these groups and have highlighted the need for culturally appropriate models of care (Maddocks, 2003; Sneesby, Satchell, Good & Van Der Riet, 2011; Heindenreich, Koo & White, 2013). Recent research into the perceptions and experiences of EOL care for Māori in New Zealand also draws attention to the need for culturally appropriate models of care (Moeke-Maxwell, Nikora & Te Awekotuku, 2014).

The WHO definition of palliative care includes, “the provision of culturally appropriate care” (WHO, 2000). However, in many countries, the delivery of palliative and EOL care is dominated by a Western approach to death and dying and this is reflected in ideas about what constitutes a ‘good’ death.

Although many of the elements of a ‘good death’, including resolution, family harmony and acceptance, are shared across different cultures, the way that this is achieved does vary across cultural groups and settings (Huang, Liu, Zeng & Pu, 2015). An ideal death, with an emphasis on a peaceful, accepted death, at home in familiar surroundings, may reflect white, middle-class assumptions and not necessarily constitute what is regarded as a ‘good death’ for other cultures. One such example is the belief, for many Chinese, that ghosts may inhabit the place where someone has died, thus precluding home from being an ideal place to die (Koenig & Gates-Williams, 1995; Hathaway, 2009; Heindenreich, Koo & White, 2013).

In many Western countries, the hospice movement has played an important role in the understanding and acceptance of palliative and EOL care. The hospice movement has, however, reflected the values of its predominantly white, middle-class support base and been perceived by many in the community as a ‘European’ institution. This perception has led to a poor uptake of services by our ‘non-European’ communities, often resulting in poorer outcomes for these patients and their families (Bray & Goodyear-Smith, 2013).

## **Background**

Auckland's demographic profile has changed dramatically over the past decade, and it is now estimated that 40% of Auckland's residents were born overseas. The region has the largest Asian population in the country, with two-thirds of the New Zealand Asian population living in the Auckland region (Walker, 2014). Within the Asian population, the most-represented ethnicities are Chinese and Indian, each accounting for over a third of Asian responses. The ethnic composition of the population is projected to change over time, with growth expected in the proportion of Asian peoples in the population and a reduction in the proportion of European peoples.

Migration presents challenges because migrants not only bring cultural and linguistic differences but also have different experiences and expectations of the healthcare system (Ng, Popova, Yau & Sulman, 2007). Communication difficulties, both in verbal consultations and with written information, also form a significant barrier; for example, communications from hospitals, appointments and prescription instructions all present challenges for non-English-speaking people (NESP).

The Auckland District Health Board (ADHB) estimates that 13% of the people that present for healthcare services require the assistance of interpreters due to their having minimal, or no, spoken English. This creates significant challenges for healthcare providers as they manage the additional time and skills required to use interpreters for their consultations.



## Palliative Care

In recent decades, the concept of palliative care has gained both recognition and acceptance in Western countries. The 2001 *New Zealand Palliative Care Strategy*, which provides a framework and direction for the delivery of palliative care services, defines palliative care as:

*“the total care of people who are dying from active, progressive diseases or other conditions when curative or disease modifying treatment has come to an end . . . Palliative care:*

- *Affirms life and regards dying as a normal process*
- *Aims neither to hasten or postpone death*
- *Aims to provide relief from distressing symptoms*
- *Integrates physical (tinana), social (whānau), emotional (hinengaro), and spiritual (wairua) aspects of care to help the dying person and their family/whānau attain an acceptable quality of life*
- *Offers help to the family/whānau/carers during the person’s illness and their bereavement.”* (Ministry of Health, 2001, p.3)

The concept of culturally appropriate care is a constant theme throughout the document, including the principle that:

*“All people who are dying and their family/whānau could benefit from palliative care have timely access to quality palliative care services that are culturally appropriate and are provided in a co-ordinated way.”* (Ministry of Health, 2001, p. vii)

The concept of culturally appropriate care is also integral to the *Hospice New Zealand Standards for Palliative Care*, released in 2012. These national standards and the accompanying quality review programme are intended to provide a comprehensive, continuous improvement framework for hospices, but are applicable to all health services working with people who need a palliative approach and EOL care. The following, in particular, relate to the cultural care of patients and their families:

- **Standard 2 – Ensuring equitable access**

*Access to palliative care is available for all people based on need and is independent of current health status, diagnosis, age, cultural background or geography.*

- **Standard 4 – Providing whole person assessment**

*All needs of the patient and their family and whānau are acknowledged in the assessment and care planning processes.*

- **Standard 5 – Meeting the cultural needs of diverse family and whānau**

*The unique cultural needs of the patient and their family and whānau are acknowledged and respected in the assessment and care planning processes.*

(Hospice New Zealand, 2012)

## Key Questions

Attitudes towards death and dying are shaped by cultural perspectives and beliefs, and, for many cultural groups, discussion about these matters is considered taboo and ‘unlucky’. How then do hospices/palliative care providers engage with their local ethnic communities around death and dying in order to deliver care that is culturally responsive?

My key question, therefore, as I embarked on my journey, was:

*How do hospices/palliative care providers engage with their CALD (culturally and linguistically diverse) communities around EOL care?*

I had several other concerns related to the delivery of culturally responsive palliative care, including:

- How do hospices, as predominantly, white, middle-class organisations, engage with their ethnic communities? What methods do they use? What resources do they need? How do they measure whether their engagement is effective?
- How do services and organisations that use cultural liaison workers, recruit, train and support these workers? What roles do these workers have?
- What strategies/initiatives do organisations have for employing culturally diverse staff?
- How do organisations recruit volunteers from ethnic communities so that patients are supported by people who understand what they are going through? How do they train and support these volunteers?
- What culturally appropriate information resources have been developed around palliative care? How were they developed? Are they effective? How are they used?

## **Methodology**

In 2011, Mercy Hospice Auckland initiated the Cultural Care Project. The project was launched in response to the challenges being faced as a result of the increasingly culturally and linguistically diverse community served by the hospice. The aim of the project was to focus the organisation on the challenge of delivering culturally appropriate EOL care.

As project leader, I spent much time exploring how other hospices and palliative care providers, both in New Zealand and overseas, were meeting the challenge of delivering culturally responsive EOL care. I spent time searching the internet to find out what was being done in other parts of the world.

When I learned about the Culturally Sensitive Services Project at The Prince & Princess of Wales Hospice, in Glasgow, I was excited to read about the work being done on the other side of the world, but with the same objectives. I made contact with the project lead, Barbara Love, and she responded generously by sending me reports and information on their project.

I continued to correspond with Barbara and to search for similar initiatives aimed at improving the cultural responsiveness of services. Meanwhile, the need here in New Zealand for more culturally responsive services was growing and so was my sense of frustration at the lack of any clear strategy or direction for the development of services.

An application to the Winston Churchill Memorial Trust for assistance with funding was approved and I began to locate work being carried out in this field overseas, making contact with key people and creating my itinerary.

## **Visits**

I travelled to Melbourne, London, Glasgow and Toronto, visiting a range of different palliative care services and hospices in those centres. Details of those services visited are in the Travel Diary. The following section describes, in more detail, two of the services visited.

### **Compassionate Neighbours St Joseph's Hospice, London**

Compassionate Neighbours is an initiative that was launched by St Joseph's Hospice in June 2014. It has been developed in partnership with local people and Social Action for Health (SAFH), and is designed to increase capacity within communities local to the hospice which support people living with terminal, serious and long-term illnesses, the frail and elderly, and also the carers of people with such conditions.

The primary role of the project is to train and support volunteers who will spend up to two hours each week offering practical, social and emotional support to people with terminal, life-limiting illnesses and those that are elderly and frail, along with their families and carers.

One of St Joseph's strategic priorities is to build capacity amongst its local communities and to be well informed, to support each other and to enable people to care for themselves and to remain independent for as long as possible.

The initiative is underpinned by public health principles, and seeks to improve the understanding and confidence of local people about issues related to dying, death and loss. It aims to develop skills on the part of individuals and communities to participate in discussions on these important issues and to become more confident about using related services such as those available at St Joseph's Hospice and throughout the community. Overall, it aims to

increase choices for individuals who are living in the last years of their lives and for the individuals caring for them.

The hospice has significant expertise in managing death, dying and loss. Its staff and volunteers are confident in having difficult, but crucial, conversations about the end of life and in supporting people who are anxious, distressed or vulnerable at such a time. Staff members know about the range of services and support that is available for people who are living with terminal or life-threatening conditions. The hospice is keen to extend this expertise to people who may not need clinical services but could benefit from related social support and practical help and advice. The aim for Compassionate Neighbours is to support people deemed to be in the last years of lives and their carers by:

- Offering companionship, emotional support and a listening ear
- Providing practical support, such as making cups of tea
- Helping them to stay connected to their friends and their communities or providing a new community for them to be part of
- Directing them to groups and services to help them cope with the challenges that they face.

In addition, Compassionate Neighbours will become champions in their own communities, encouraging discussion about death, dying and loss, driving improvement in related services and promoting engagement with EOL services such as the hospice.

Compassionate Neighbours are invited to understand fully the offers available for everyone at St Joseph's, will be encouraged to reduce misconceptions about the hospice, and will be able to inspire individuals and local groups to visit the hospice and learn about its services. The hope is that the neighbours will be agents of social change, developing relationships with other sectors in society, such as businesses, religious organisations, schools, councils and

clubs, so that, over time, a movement is established and those living in the community in their last years are embraced and fully supported by those living and working around them.

## **Culturally Sensitive Services Project**

### **The Prince & Princess of Wales Hospice, Glasgow**

One of the highlights of my trip was the visit to The Prince & Princess of Wales Hospice (PPWH), where I spent time with the Culturally Sensitive Services (CSS) Project Lead, Barbara Love, and her colleague, Majabeen Ali, the PPWH Cultural Liaison Officer.

The PPWH, situated on the bank of the River Clyde, serves the Southside population of Glasgow (approximately 350,000 people). The hospice, established 30 years ago, has evolved to meet the needs of the local population. This area of Glasgow is home to a large number of people of South Asian origin, whose needs are recognised as being different from those of the indigenous population and for whom barriers exist to accessing services.

In the year 2006/07, there were 875 referrals made to this hospice's services; however, only 16 (1.8%) were from the minority ethnic community. This is in contrast with the proportion of the local population of this group, which is 5.8%. The majority of these are of South Asian origin and predominantly Muslim, and, in some areas, represent up to 40% of the local population.

In 2008, the 'Culturally Sensitive Palliative Care Services Across South West Glasgow' project was established. The aim of the hospice CSS project was to raise awareness and widen access to culturally sensitive palliative care services for ethnic minority communities in South Glasgow, focusing initially on the local South Asian population.

For the first year, 2008/09, the key aim for the project was to identify and examine barriers to accessing hospice services. The second aim was to raise awareness of hospice services within

minority ethnic communities. A steering group was established and specific objectives identified; these included:

- To engage with the individual minority ethnic communities, accessing them via their faith groups (Muslims, Sikhs and Hindus)
- To raise awareness of hospice services through outreach events based in places of worship and at community gatherings
- To gather information on barriers to service use through discussions with key members of these communities
- To design culturally appropriate hospice information – leaflets and posters, which were printed in four core languages (Urdu, Hindi, Punjabi and English). These leaflets and posters were made available in strategic areas in the community, e.g. places of worship, medical facilities, day centres, libraries, etc.

The project began with a scoping exercise. Very early in this exercise, it became obvious that, for these communities, the most effective engagement would be through their places of worship. The project team then began by compiling lists of worship places in the area – mosques, Gurdwaras (for the Sikh community) and Mandirs (Hindu temples). They identified the key people within each place of worship and within each community.

They made contact with the council at the Central Mosque, not far from where the current mosque is situated. Barbara and Majabeen met with the mosque council, presented the project and made a request to use the mosque to hold a Health Fayre for the community with information about healthcare services, including hospice services.

The Health Fayre has been run for the past two years and considered a success by both the hospice and the mosque council; the council is keen that the wider community engage with Muslims and gain a better understanding of their religious beliefs and practices.



## **Key Findings**

My tour included visits to a diverse range of palliative care and hospice services, across four different countries. Although each visit and encounter provided me with a new learning, insight or understanding, there were several recurring themes that appeared.

The most significant of these, were:

### **Community Engagement and Awareness**

In the hospices I visited, both in England and Scotland, there was a strong focus on community engagement. The ‘Widening Access Strategy’, aimed at more-inclusive palliative care services, has been an important driver for this direction.

This new emphasis, underpinned by public health principles, is aimed at increasing the community’s awareness and understanding of palliative care, and demystifying issues relating to death and dying.

At St Joseph’s Hospice, in East London, the Compassionate Neighbours programme, an initiative run in partnership with SAFH, is an example of this community engagement. The Compassionate Neighbours programme trains volunteers to visit patients in their homes, offering companionship and support.

At St Christopher’s in south-west London, there is an emphasis on ‘bringing the community into the hospice’. The hospice has done this by developing programmes that give access to local community groups, such as schools, and also by making its rooms available for community groups to use for meetings, choir practices, etc. The PPWH in Glasgow also offers rooms to local community groups as a way of bringing the community inside the walls of the hospice.

The community engagement process begins with a comprehensive scoping exercise to identify the ethnic communities that reside in the service area. An important part of this exercise is to identify the key people within the communities, the elders and community leaders, each of whom is in a position to influence and guide the community.

Any engagement activities need to be seen as separate from fund-raising or sponsorship aims. In order to gain the trust of the community, services need to be open about their motives for engagement with no other agenda in the form of fund-raising.

Raising awareness of the palliative care approach in CALD communities is important. A palliative approach is often a difficult concept as, for many, especially in Chinese communities, there is a perception that palliative care equates to ‘giving up’ and that is not acceptable to patients and their families.

There needs to be culturally tailored education around how the palliative approach, with its focus on ‘quality of life’, holistic care and balance, can support patients and their families in EOL care. Palliative care is a concept that can be offered as congruent with an Eastern approach to well-being.

## **Collaboration and Partnerships**

The importance of working collaboratively and developing partnerships with other organisations was evident in many of the palliative care services and hospices I visited. This collaboration was seen as a vital way, especially for many smaller services, of delivering culturally responsive care to the patients, and their families. Many healthcare providers, especially hospices, have very little cultural diversity within their workforces and are often challenged to meet the needs of their ethnic communities.

Many services, for example the Mercy Palliative Care service in Melbourne, had developed strong relationships with organisations within their areas that could provide social assistance and emotional support to their refugee and migrant patients, and their families. The social worker at Mercy Health had built a good network of resources and knowledge of services that were available to work alongside the Mercy service to provide culturally appropriate counselling, advocacy and practical support.

## **Information Resources**

The availability of culturally appropriate and sensitive information resources is a key component in the delivery of culturally responsive care. Communication is an important part of palliative care, as patients and their families enter into an often-unfamiliar area.

Information resources can include a broad range of mediums – including written, audio and DVD presentations.

## **Cultural Support Workers**

The value of having culturally appropriate workers to engage with local ethnic communities was evident in many settings I visited. In the CSS project in Glasgow, the Cultural Liaison Officer (Majabeen Ali) has been a key component in the effectiveness and success of the project. She has both cultural knowledge and understanding of the South Asian community in Glasgow, and such knowledge has been invaluable to the project.

In the Temmy Latner Centre in Toronto, a Chinese support worker is engaged to work alongside Chinese patients and families to provide cultural support. There is enormous value

to both the service user and the service provider in using cultural support workers. The connection made through a shared language and culture is an important foundation in building trust. This is particularly so with many migrant and refugee communities where trust may have been a significant issue in their dealings with health authorities.

## **Organisational Commitment**

It is essential that there is an organisation-wide commitment to the delivery of culturally responsive care. This commitment needs to be evident at the governance level of the organisation. It is demonstrated in policies and in the strategic direction of the organisation, through the delivery of care, with attention to such things as rooms for prayer, the provision of ‘halal’ food options on the menu, and in the signage and information available.

This organisation-wide commitment was demonstrated at the PPWH in Glasgow. It was evident throughout the organisation: from CEO Rhona Baillie’s commitment to reduce ‘red tape’ so that initiatives can develop, to the conversion of a bathroom on a lower floor to create an ablutions room for Muslim patients and families to use before prayer rituals.

## **Education**

Education and support for the workforce is important to ensure the delivery of culturally responsive care. As the workforce itself becomes increasingly ethnically diverse, challenges arise due to differences in attitudes and approaches to death. Many overseas-trained staff may not feel comfortable with open discussions around death and require support to be able to communicate in a way that feels appropriate.

## Recommendations

The following are key recommendations for the development of culturally responsive palliative care services in Aotearoa New Zealand.

- **Engage with identified CALD communities in each area to understand their needs and cultural practices around EOL care and learn how to better meet those needs.**  
Access available information on community demographic data to identify CALD communities in each region. Identify which CALD communities within the region are priorities for further engagement. Undertake a comprehensive scoping exercise to identify leaders and elders within the different ethnic and faith communities.
- **Improve awareness of, and access to, a palliative care approach in CALD communities.** There needs to be culturally tailored education on how a palliative approach, with the focus on ‘quality of life’, holistic care and balance, is consistent with an Eastern model of well-being and of benefit to patients in EOL care and their families.
- **Develop a framework for the delivery of culturally responsive palliative care that includes specific audit tools.** This framework would include ‘Best Practice Principles’ that can be used across the sector so services can self-audit and identify areas requiring improvement.
- **Develop information resources that are appropriate and accessible for use across primary and secondary palliative care settings.** The development of resources needs to be undertaken in collaboration with CALD communities so that the information made available reflects the relevant cultural perspectives and any cultural sensitivities in

relation to information on palliative care. It is important to ensure that information is provided in accessible written, audio and visual formats.

- **Provide education, mentoring and support to care providers, to enable delivery of culturally sensitive and appropriate care in all settings.** Education must include both the paid and unpaid workforce, as many services rely on volunteers to support patients and their families. A strategy would be implemented to increase recruitment of staff and volunteers from CALD communities, including bilingual staff.
- **Develop greater collaboration and partnership between palliative care providers and CALD support services in the community.** Hospices and palliative care providers can utilise the services of multicultural organisations and other groups with specialised expertise in cross-cultural communication, cultural responsiveness training, language services, etc. These organisations can be involved in the development of support services that meet the needs of patients and families in culturally sensitive and appropriate ways.

## **Presentation of Findings**

The findings from my Winston Churchill Fellowship study are contained in this report, which will be forwarded to the services I visited as part of my study.

A copy of the report will be sent to the Hospice New Zealand Chief Executive, Mary Schumacher, to the Mercy Hospice Auckland Chief Executive, Peter Buckland, and will be available to the Hospices of Auckland group.

The report has formed the basis of a presentation to Mercy Hospice Auckland staff in March 2016. The findings will also be offered as a presentation to the 22<sup>nd</sup> Hospice NZ Palliative Care Conference in October 2016.

The information gained from this study is being used to inform a Hospice New Zealand (HNZ) Innovation Project, aimed at ‘Improving the delivery of culturally responsive palliative care across the Auckland region’, which is being developed in 2016.

The project is being established with funding made available to HNZ in the New Zealand Government’s 2015 Budget; it is intended that the funding be used for new initiatives or innovations in the delivery of palliative care services. The HNZ project proposal is based on the recommendations contained in this report, and draws heavily on the learnings gained while visiting services and projects overseas as part of the Winston Churchill Fellowship.

# Appendix I

## Travel Diary

After nearly 12 months of planning, I left New Zealand on the afternoon of 16 September 2015 for Melbourne, the first stop on my tour. I had arranged to visit four different agencies within the city and so, armed with detailed tram, bus and train routes, I set out.

### Centre for Culture and Ethnicity & Health

#### Richmond, Melbourne

My first visit was to the Centre of Culture, Ethnicity & Health, to meet with the General Manager, Michal Morris. I had been emailing Michal for the past few months about the visit so it was great to finally meet her.

The CEH (Centre for Culture, Ethnicity & Health) is located in Richmond, an area of Melbourne that has a large refugee and migrant community because it has the largest public housing project in the region.





The CEH grew out of, and is located in, the same building as North Richmond Community Health Limited. The health centre provides medical, dentistry, counselling, cultural and allied health services to the communities of the City of Yarra. Since its inception in 1974, North Richmond Community Health Limited has constantly tailored its services to meet the changing needs of a very culturally diverse location.

In 1994, North Richmond received funding from the Victorian Department of Human Services to share its learnings across the state, and the CEH was formed. The CEH was established to build capacity and responsiveness in the healthcare sector. The medical centre and CEH share the same board, and, although each has its own strategic plan, the plans are aligned and share common goals. Their vision is for health care that builds communities. The CEH is autonomous and so able to be flexible and responsive in a way that is often not possible with other funding options. Its focus is on cultural diversity, socially disadvantaged people, refugees and migrants, and intravenous (IV) drug users.

With an initial focus on health, CEH provides cultural competence training to healthcare professionals and has a significant library of resources on multiculturalism and health.

Further state-wide programmes have followed and, in 2007, a new programme, Health Sector Development, was formed to work exclusively with health and community service providers.

### **Southern Metropolitan Palliative Care Consortium**

My next visit was a short train ride away to Ripponlea, to meet with Tanja Bahro. Tanja is the Consortium Manager for the SMR (South Melbourne Region) Palliative Care Consortium, based at Calvary Health Care Bethlehem, in Caulfield South. The SMR Consortium provides a local network for palliative care services, which includes the Cabrini Palliative Care unit, Monash Health Consultancy (16 beds), 80 residential aged care facilities (RACF) with 700 to

800 patients, Casey Hospital Unit (five beds), Alfred Health Consultancy and the Peninsula Health Consultation.

This consortium also has a disability support worker who advocates for people in group homes, educates workers in group homes and develops resources.

## **Mercy Palliative Care**

### **Sunshine, Melbourne**

The next day, I set out for Sunshine, in the north-western suburbs of the city, to visit the Mercy Palliative Care service located there. I took the train and arrived an hour early, so I enjoyed a walk around the streets and through the Sunshine shopping centre. The area appears to have a large Vietnamese population and to be an area of relative economic disadvantage.

Mercy Health is a Catholic organisation, founded by the Sisters of Mercy, which provides care to people in metropolitan Melbourne, regional Victoria, southern New South Wales and the Australian Capital Territory. It offers a range of services, including acute and subacute hospital care, aged care, a mental health programme, specialist women's health care, early parenting education and support, palliative care, and home and community care, as well as health worker training and development.

Mercy Palliative Care offers a level of specialist care that focuses on quality of life. Its team works together with families and carers, providing the following services:

- Pain management
- Symptom control
- Personal support such as counselling and music therapy
- Practical support such as equipment, respite and managing financial issues

- Spiritual support
- Bereavement support.

When I arrived, I met with Social Worker Bedmen, who had been with the service for six months. Bedmen, herself from Zimbabwe, described the community served by Mercy Palliative Care as being CALD, with entrenched disadvantage; the population includes established Greek and Italian communities and newer African migrants. There is also a large Burmese community within the area.

Bedmen described how, on the initial visit, the nurse carries out a language assessment to ascertain whether interpreters are required, or whether the patient has basic English language skills and an interpreter is required only for complex or difficult communication. Bedmen emphasised that the 'language skill assessment' is ongoing.

She also stressed the careful use of language – avoiding words like death and dying and, instead, focusing on quality of life. She talked about the use of other mediums such as art, music and play that can transcend language barriers. To help identify and recognise emotional responses, especially around grief and loss, she also uses the Care Bear cards (picture cards).

Bedmen described the therapeutic role of telling a story. She talked about the grief within the grief: the grief for patients of losing family, home, identity and language, and then the sadness of a diagnosis of terminal illness. She feels it is important to acknowledge the difficulties of migration.

Training for staff is provided through Palliative Care Victoria, the Australian Centre for Grief and Bereavement, and the Migrant Resource Centre. When needed, cultural support workers

can be accessed from the Migrant Resource Centre. Many of these workers have worked previously in the health sector.

Bedmen said that she often avoids introducing herself as a social worker because of the negative connotations the title has for many people; instead she uses the title: 'Support Worker'. She said before visiting, she does research around the patient, and their ethnicity and background: not to stereotype but to have awareness of potential issues.

Bedmen explained that, although counselling is a Western concept, she will help the person to see a connection from the past, with the therapeutic experience of talking to someone, perhaps an aunt or another family member. Now, because that family member is not available, 'talking' is done differently. She also described the importance of acknowledging the role of church/community leaders and involving them in decision-making when appropriate.

## **Melbourne City Mission Palliative Care Team**

### **North Fitzroy, Melbourne**

From Sunshine, I travelled across the city to the Melbourne City Mission Palliative Care team, located in North Fitzroy, not far from the central city. I met with Fiona, a health psychologist by profession, who is the clinical team leader.

Fiona described the community they serve as being mainly older migrants, Greeks, Italian, Vietnamese, etc., with fewer new migrants in the area. They have approximately 240 patients at any one time on the service.

Fiona explained how the service adheres to best-practice standards regarding the use of interpreters, and that there is an unlimited budget for interpreters. She said they are encouraging patients to use the telephone interpreting service to make contact with them. She

said they use Level 2 interpreters as they have the necessary skills. They use Level 1 interpreters for making appointments and simple communication. Ongoing staff training is provided on ‘working with interpreters’ and there are regular sessions on updating resources.

Fiona described the importance of patient-centred, culturally sensitive care. She said that, despite there being talk about an emphasis on health promotion in palliative care, she felt that very little of that goes on as most services are too preoccupied with the day-to-day tasks. However, the Mission’s bereavement service had done some recent work in that area. Fiona talked about how the service uses cultural support and advice from a range of different agencies.

Fiona said the service has about 45 volunteers, including those from its ethnic communities. The volunteers undergo an intensive training programme and receive ongoing support and regular training updates. A recent volunteer recruitment drive had included running volunteer stories in the local paper.

Fiona talked about the service having an investment in quality improvement. One area she identified as needing improvement was ACP (Advanced Care Planning). She felt staff members were having conversations but not documenting them. We agreed that ACP is a Western model of care planning and, therefore, is problematic for many cultures.

Regarding cultural practices around death and dying, she described how, with Muslim patients, they work hard to ensure that death certificates and papers are ready so there is nothing to impede the burial which must be completed within 24 hours following death.

## **St Joseph's Hospice**

### **Hackney, London**

I left Melbourne and flew to London. After a couple of days' rest, I set out to visit St Joseph's Hospice in Hackney, East London. St Joseph's Hospice is one of the largest of its kind and serves multiple boroughs in north-east London, which includes a community of two million people. The hospice serves the communities in some of the most diverse boroughs in England.

The doors of the hospice were opened in 1905, with the Sisters of Charity having come from Dublin to work with the poor of East London. Today, the hospice is still under the care of the Sisters of Charity; however, there is now a formal management structure in place that manages the day-to-day operations of the care environment. The hospice is a registered charity and not part of England's National Health Service (NHS), although nearly half of the funding that operates the hospice is given by the NHS.

There are 42 beds in the hospice, making it one of the largest in the country; each year, there are around 750 admissions to the wards and many more people are cared for and supported at home in the community.

There are 250 full-time-equivalent members of staff working at the hospice and out in the community across the boroughs that are served by St Joseph's. In addition to this, there are nearly 500 volunteers supporting the hospice and working alongside staff.

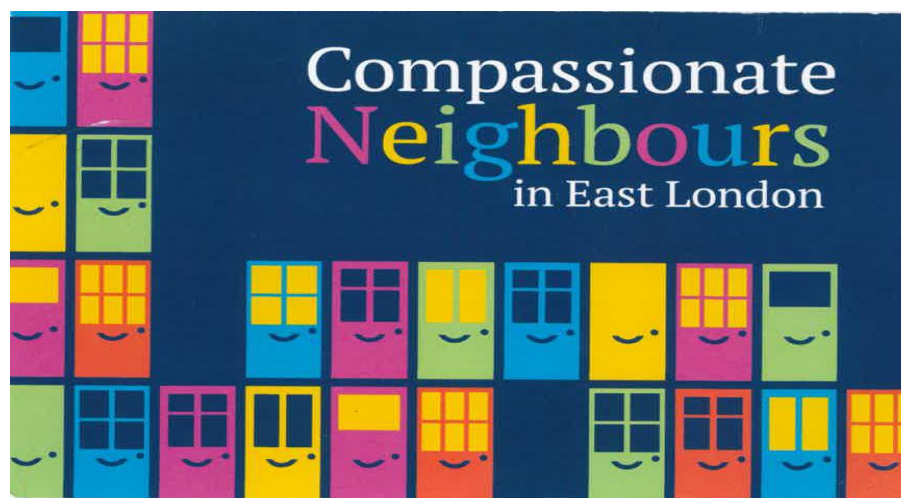
I met with Sally Muylders, co-ordinator for the Compassionate Neighbours project, and three of the Compassionate Neighbours volunteers. Sally has a background in community development and has worked in a variety of community settings.

Sally talked about the organisation's commitment to engagement. The current CEO has a background in public health and the new building was very much designed with space

available for public use. For example, two local choirs meet there for weekly practices and there are other community groups that meet in the centre; this is in keeping with the philosophy of making the hospice accessible and demystifying the place. The centre has a multicultural, multi-faith focus: from the prayer room for Muslims, to the family room where large families can spend time with the bodies of their loved ones.

The Compassionate Neighbours project is a joint initiative with the SAFH. A pilot for the project was run in 2014 and the project started early in 2015. The aim of the project is to connect socially isolated people, who are often unwell but not necessarily on hospice books, with caring visitors. The visitors are recruited by SAFH, which runs recruitment drives among the community groups with which it works.

Each volunteer then undergoes an eight-week training programme, followed by a police check, and is partnered with a patient to visit. The training programme is run by SAFH and is aimed at enabling people to be self-aware and to acquire listening skills, etc; they use a great deal of role play and group work. This is very interactive learning with no PowerPoint presentations!



Sally interviews prospective patients and partners them with volunteer visitors. One of the major considerations is geographical location as Sally believes this replicates the model of a 'neighbour'; also, transport is a major issue as there is no travel reimbursement for volunteers. Sally said the police check, which follows the training course, had presented difficulties for many volunteers who were wary of authorities and, for some, there were fears about immigration, etc.

Sally works full time so is easily accessible by volunteers if they have any issues.

I spoke with three of the project volunteers; they talked about how they enjoyed the training and felt it had improved their confidence, describing it as empowering. Sally runs a weekly 'coffee morning' for volunteers each Thursday at the centre. It is an opportunity to spend time with other Neighbours and those interested in being involved with the project.

We discussed the availability of ethnic-specific resources; they currently have none. Sally explained that the cost of having materials translated is very high so, unfortunately, is prohibitive. It appeared from the discussion that people are encouraged to learn English rather than the service providing linguistically appropriate resources. However, two of the Compassionate Neighbour training courses have been delivered in Bengalese to include volunteers with limited English. Sally said that they have more Bengalese volunteers than patients at present so she is keen to include more Bengalese patients in the service.

## **St Christopher's Hospice**

### **Sydenham, London**

The following day, I headed out to St Christopher's Hospice in Sydenham, in south-east London. Sydenham is a very pretty area, with tree-lined streets.





St Christopher's hospice was established in 1967 by Dame Cicely Saunders to change radically the experience of dying people and those close to them. Based in south-east London, St Christopher's serves a diverse population of 1.5 million people in the London boroughs of Bromley, Croydon, Lambeth, Lewisham and Southwark. In addition, the hospice's influence has national and international reach through education and research programmes.

I arrived early so sat in the Anniversary room, a lovely, light-filled area, and enjoyed a cup of tea while I read some of their pamphlets. I met with Ruth Sheridan the Support Care Co-ordinator. Ruth had been at St Christopher's for only a few months, having come from St Joseph's in Hackney.

Ruth talked about the focus of the hospice on community engagement and promoting awareness around death and dying. She described some of their projects, including: the community choir that meets and practises weekly at the hospice; and 'The Brit School' project (The BRIT School for Performing Arts and Technology), located nearby in Croydon, where students come into the hospice and talk to patients. Another recent project, with Macmillan (a UK-based cancer support service), saw a group come into the hospice, take photos of patients, caption the photos and then mount them into an art display.

Ruth felt that the usage of the hospice does reflect the community served, in terms of ethnicity, but that the ethnicity of staff does not reflect the community served. We talked about this being a challenge everywhere and acknowledged the importance of trying to address this. Ruth described the phenomenon of ‘snow capping’ where the top layers of the hospice – the board, CEO and senior clinical staff – are all white, and that the domiciliary and cleaning staff are not.

Ruth showed me the Diversity Tool Kit, which can be used by organisations as an audit tool to see how they are doing in terms of managing diversity. She explained that many migrant communities are well established and developed with newer migrants coming from Russia and Eastern European countries, such as Romania, Hungary, Croatia, etc.

Ruth described the emphasis being on inclusion, rather than on targeting of specific ethnic groups. She felt that, in Britain, they had moved on from that, to developing an organisation that is inclusive. The hospice doesn’t provide any ethnic-specific resources at present. An interpreting service is available but it does cost the organisation. Ruth said they discourage family members from interpreting as is considered to be best practice in most places.

Migrants are encouraged to sit the citizenship exam and to learn English if they intend to reside permanently in Britain (I have more of a sense of ‘assimilation’ here).

Ruth is keen for the organisation to develop a Compassionate Neighbour programme that is similar to the one at St Joseph’s. She said they will find another organisation to partner with but this will not be SAFH as it is in different area.

I had lunch with Ruth and then joined the Wives Club for the presentations of their bursary students. These five people – a social worker from Cameroon, a doctor from Kerala, India, a doctor from Burundi and two nurses from the Seychelles – had all been at St Christopher’s to learn about palliative care. They each presented about their home setting: the challenges and

the opportunities. It was a very interesting presentation and highlighted the huge challenges faced in many countries as they develop and deliver palliative care services.

## **The Prince & Princess of Wales Hospice**

### **Glasgow, Scotland**

My next visit was to The Prince & Princess of Wales Hospice in Glasgow. I met with Barbara Love and her Culturally Sensitive Services (CSS) project co-worker, Majabeen (Maj) Ali, who is the hospice Cultural Liaison Officer. While Barbara, a clinical nurse specialist at PPWH is Glasgow born and educated, her colleague, Maj, also born and raised in Glasgow, is of Pakistani descent, and a fluent speaker of Urdu, Hindi and Tamil. Maj, who had completed a Social Services certificate, began with the hospice as a volunteer, after her own personal family experience with hospice care. Maj moved into the role of Cultural Liaison Officer to join Barbara on the project.

It was obvious to me that Barbara and Maj's partnership played a significant role in the success of the project. Each woman brings her own cultural heritage and background to the project, thus creating a broad understanding and skill base from which they work. Barbara and Maj took me on a tour of the hospice, introducing me to staff as we went; everyone was very warm and welcoming.

I then met with Jane from the Education team, and heard about her project working with people with learning disabilities. We then met with Mr Shaukat, an Indian man, who has been instrumental in liaising with the local Muslim community and the mosques.

I met with the hospice CEO, Rona Baillie, who described 'reducing red tape' to make the hospice more innovative. She talked about identifying the needs of the community and is

keen to look at working with other disadvantaged groups, such as the city's homeless people and prisoners.

I recorded an interview with Barbara in which she describes the reasons for the project and how they started – it is very informative. Barbara was planning to move on to looking at developing relationships with Glasgow's refugee and asylum-seeker communities, as part of the hospice's commitment to the 'Widening Access Strategy'. She would like to do this by inviting groups to meet in the hospice so they become familiar with the place; this helps in fostering awareness and acceptance of hospice services. We took a photo at the front entrance of the hospice, before I said my farewells to Barbara and Maj and then left for the day.



My second day at PPWH was as action packed as was the first! I met with Maj and recorded an interview with her about her role as Cultural Liaison Officer. Maj described her journey, her work on the project and her role as Cultural Liaison Officer for the hospice. We talked about the work that she and Barbara are planning to do with those from refugee and asylum-seeker communities.

I then met with the Clinical Services Manager, Jackie, who manages the IPU (In-patient Unit) and Community Nursing teams. We talked about recruiting staff members who reflect the community served. Jackie described how they have a diversity policy, which ensures that ethnicity and other data are removed from applications, so that people are recruited on a skills basis only. We talked about how ethnic background and cultural experience should be recognised as skills and attributes. I shared our experience of recruiting both a Māori and a Pacific Island social worker, and how their ethnic backgrounds are a huge advantage in connecting with communities.

Jackie talked about the enthusiasm of nurses to engage in cultural competence training. We acknowledged the importance of developing awareness around cultural differences and not relying on assumptions.

Maj and I had some lunch and she introduced me to Audra Cook, the Clinical Governance Co-ordinator. Audra has been involved with developing the evaluation measures for the CSS project. Audra explained to me how quantitative measures may not be as useful as are qualitative data in evaluation. I was very keen to learn more about project evaluation and developing meaningful measures so Maj arranged for me to meet with Audra the following morning.

I met with Carol Graham, the Family Support Service Manager. Carol is a social worker and had moved recently into the manager role. We talked about the use of ethnic-specific resources, which they do not have currently. We also talked about the challenge of reaching people with low literacy and how DVDs may be useful to achieve this. We acknowledged the dominance of counsellors in the hospice setting and how this is slowly changing as the role of social work in addressing the social determinants of health is better understood. Carol talked

about service development as being a requisite for the social work role in her team, and how she is keen to develop a supportive care model.

After meeting with Carol, Maj and I returned to her office and looked at her resources, including those on cultural competence, and ethnic and faith traditions. I returned home, exhausted but brimming with new ideas and information.

The following day, I met with Audra Cook, the Clinical Governance Co-ordinator, and recorded an interview. Audra provided me with very useful information on evaluation and measures for the project. She emphasised the need for qualitative data that demonstrate that the patient and the family have had a better care experience due to the project interventions.

Then Maj and I headed out for the day. Our first visit was to the Central Mosque, just a couple of streets away. Maj took me on a tour of the mosque and to the upper floor where the women pray. It was a great experience to go into the mosque and have things explained to me.



From there we went to the Sikh Gurdwara, home for the Sikh community in Glasgow. Opened in 2013, it is Scotland's first purpose-built Sikh Gurdwara and can accommodate 1,500 worshippers. Situated in multicultural Pollokshields, the Gurdwara acts as a cultural, educational and religious hub for Sikhs and the wider community. The Gurdwara serves the whole community by promoting free education services, a free kitchen, faith and cultural services, and political engagement activities.



Maj and I were greeted by a Gurdwara volunteer, who took us on a tour of the temple. She took us to the dining room and invited us to have something to eat. Vegetarian food is available every day for people coming to the temple.

We then went to the Hindu Mandir in La Belle Place in the central city. Here we just wandered around as the Pundit was busy with someone else.



We then visited WSREC (West of Scotland Regional Equality Council). WSREC's vision is: **We see an inclusive society free from discrimination.** Maj had links with this organisation and we were greeted very warmly. We met with Ghzala Khan, a project leader with the Council, who described their work and the different projects with which they are engaged.

From there we went to Amina, The Muslim Women's Resource Centre, whose vision is: **We aim to inspire Muslim women to fulfil their true potential. We empower women to participate fully in all aspects of society, without fear of discrimination or inequality.**

At Amina, we met with one of their organisers and she described the background to the organisation and the range of services it provides including a helpline, a befriending service and campaigns against domestic violence. That was our final visit for the day and the end of my time with Majabeen and The Prince & Princess of Wales Hospice.



## **Wellness Centre, Mt Sinai Hospital Community Program**

### **Scarborough, Toronto**

My next stop was Toronto where I travelled out to Scarborough, about 90 minutes' train ride away from the centre of Toronto, to the Mt Sinai Wellness Centre. At the centre, I met with the Program Director, Maria Choi.

The Wellness Centre provides mental health care for older Chinese people. It accepts referrals from GPs and self-referrals. It operates with no physical boundaries but patients are encouraged to come in to the centre wherever possible. Maria talked about the stigma of mental illness for Chinese people and the shame felt by patients and families. She described how the service had been developed following a study by Mt Sinai Hospital into the mental health of both Chinese and Tamil seniors.

The findings of the study were presented back to the community in the form of a 'drama performance'. This was to ensure that the findings were understood well and accessible for all people regardless of their levels of literacy. The centre has very limited resources and is struggling to meet the need. Waiting times are growing so the service is looking at ways in which it can work more effectively.

Maria talked about the importance of using concepts that are positive and not intimidating. For example, instead of running a workshop on dementia, it is advertised as 'Ways to improve your memory'. She said that, over time with education and increased awareness, concepts around mental health can be introduced. Also, the name of the centre, Wellness, reflects a holistic model of care; this is a concept that is acceptable to Chinese people. The centre itself is very well appointed, light, airy and welcoming for patients and families.

## **Yee Hong Centre for Geriatric Care**

Maria took me across the road to the Yee Hong Centre for Geriatric Care, where she introduced me to the Executive Director of Social Services, Kwong Y. Liu (KY). KY is originally from Hong Kong, with a background in social work. KY gave us a tour of the facility and an overview of the centre's programmes. He talked about their focus on moving away from the medical model and achieving wellness in a more holistic way.

KY described how the centre is currently involved in a study looking at the effect of cognitive stimulation on memory impairment. This was initiated after it was found that the rate of deterioration in dementia patients attending a programme was slower than that of the general public. KY also talked about their new initiative around 'Sexuality and Intimacy', and gave me a book and DVD describing the initiative.

KY drove us over to the Finch facility, the newest of the centres, built 10 years ago. At Finch we met with Mary-Lou Ip, the Clinical Manager. Mary-Lou described the palliative care programme they were launching at their long-term care facility. They have introduced a range of measures – including more training for staff and the use of various nursing assessment tools to improve care.

We met with Hing, a nurse on the unit, and discussed some of the issues for Chinese patients that we encounter including 'truth telling' and the 'continuation of feeding'. Hing explained that, when a patient is identified as moving into the dying phase, a meeting is held with the family, to explain to them the process and what to expect. This is an opportunity to answer questions and make decisions about appropriateness of transfer to an acute setting, etc. We talked about the importance of communication and relieving distress of families, even if that means giving IV fluids so the family can be reassured that the patient is not starving.

## Carefirst

I was then taken to the Carefirst facility, where I was welcomed by Edith, who is the Director of Development and Communication. Edith gave me a tour of Carefirst's new facility, due to open in the following few weeks, and gave an overview of their services. Carefirst is being promoted as a 'one stop shop' for health and social services, providing:

- Medical centre
- Home care providers
- Daycare programme – six days a week, from 9.30am till late afternoon. This is to cater for families who are working and require longer hours.
- Respite facility – where patients can stay for up to four weeks to give families a break, or to convalesce following hospitalisation. They are supported in the programme by the local hospital, which is keen to be able to discharge patients from its care as they generate high costs.
- Rehab programme – with occupational therapy, physiotherapy, computer lab, kitchen facilities to learn healthy cooking and classrooms to provide training for healthcare workers.

The aim of the centre is to support elders to live independently so it provides a range of holistic care to promote wellness. Although the Scarborough area has a large Chinese community, the centre caters for all ethnic groups, as that is a requirement of its founder.

The building was designed by a Chinese architect and has a distinctive Chinese feel. Much of the furniture was imported from China and this adds to the feel of the place. The centre of the building is a courtyard, which provides a very pleasant outdoor space with trees, a garden, etc. The corridors provide a good circuit where the elders can exercise, especially in winter when they are unable to walk outdoors due to harsh weather.

## Mon Sheong Court and Long-term Care Facility

Maria took me to visit the Mon Sheong Centre and Long-term Care facility in Richmond Hill.

The Mon Sheong Centre is operated by the Mon Sheong Foundation, which is a Canadian-registered charitable organisation, “*dedicated to the promotion of Chinese culture, heritage, language and philosophy through caring for the elderly, encouraging the young and providing programs and services to meet the needs of our communities*”.

The Foundation provides a range of services to the Chinese community in the Scarborough area. According to its literature, these services include:

- Chinese School, offering Cantonese, Putonghua and Mathematics classes
- Youth group – building community and developing leadership skills
- Long-term care facilities
- Senior apartments
- Adult day program
- Community and volunteers service centres
- Private care
- Assisted living units.

New services include:

- Charity care beds – for those with financial need who require immediate long-term care
- Senior apartments – 460 currently under construction.

At Mon Sheong, Maria introduced me to the Senior Manager, Martin Chai. Martin gave us a tour of the facility. The Mon Sheong Foundation has three facilities and was one of the first organisations to set up these types of home in Toronto. It is a beautiful facility, with well-appointed areas, and seems very well thought out and designed. It offers accommodation to people over 55 years of age. There is a significant waiting list of two to three years.

The morning we visited, the dining room was full of residents, sharing a coffee morning and listening to local politicians who were campaigning in the general election, which was to be held in a couple of weeks. There seemed to be a very positive energy in the building with a good mix of meeting rooms, a games room for mah-jong, a theatre/karaoke room and quiet rooms, such as a library and sitting rooms for residents.

When asked about the difference between this centre and one for European Canadians, Martin was unsure what the differences might be. There is obviously an emphasis at Mon Sheong on wellness with plenty of physical activities available – t'ai chi classes, ping-pong, a gym, ballroom dancing – but also on social events and on celebrating all cultural festivals. There are weekly quizzes for residents to keep them mentally agile and, during the week I was visiting, there was a bus trip to a national park to see the maple leaves. There is a medical facility on-site, and a personal support worker (PSW) available who comes in twice a week to check the blood pressure of residents.

We then went to the Mon Sheong Long-term Care facility and met with the manager, Stella. Stella showed us around and talked about the philosophy of the centre. We discussed the centre's delivery of palliative care and how, when it is apparent a resident is entering the final stages of life, a meeting is called with the family to inform them and to make plans in terms of what treatment is to be offered to the resident and to prepare the family generally.

I raised with Stella the issues we have encountered with Chinese families wanting to protect loved ones from distressing information and how that can be managed. We also talked about the issue of continuing feeding. Stella said they focus on education and do their best to explain to the family that the body is shutting down and no longer requires food and that, for the patient, there is no sensation of hunger at this stage. If family is still insistent, they do their best to relieve the family's distress and provide IV fluids or minimal oral intake.

## **Temmy Latner Centre for Palliative Care, Mt Sinai Hospital**

### **Toronto**

My next visit was to the Temmy Latner Palliative Care Centre, which is a department within Mt Sinai Hospital. The centre provides EOL care to those who are dying from life-threatening illnesses and makes support available to their families.

This is one of a few physician groups who provide patients with EOL care in patients' homes. Through its Home-Care Program, a doctor is available to their patients, seven days a week, 24 hours a day.

Through a recent strategic planning process, the centre's staff had articulated a refreshed vision, a purpose and core values for the centre:

### **Core values**

- ***Humanity:*** The dying and grieving deserve passionate palliative care that serves their physical, emotional and spiritual needs.
- ***Collaboration:*** Compassionate palliative care requires the efforts of many, including the patient and family.
- ***Innovation:*** We promote continual learning and teaching to improve others and ourselves in creative and responsible ways.
- ***Communication:*** We are committed to communicating openly, honestly and respectfully with our patients, their families, our colleagues and each other.

I met with Dr Leah Steinberg, leader of the In-Hospital Care Program, at the centre. We had a good discussion about the cultural responsiveness of the service and any initiatives that were used to engage with minority communities. Leah described the use of a Chinese volunteer to work with Chinese families and a woman who is native Indian and is employed as a navigator with the service.

Leah was interested in the resources Mercy Hospice Auckland had developed, but said that, currently, they don't have ethno-specific information resources to give patients. She explained that, because the Canadian migrant communities are more established, the children and grandchildren of migrants have become health professionals and so the healthcare workforce in Canada is very ethnically diverse; this means that migrant patients are cared for by people who look and sound like they do, and so cross-communication is not such an issue.

I happened to read an article in the *Toronto Sun* paper earlier that day, which reported that Canada rated at a very low level on a list of countries as a place to die. Both the UK and New Zealand scored in the top three countries as 'good' places to die. One of the reasons they gave for this was that Canada has no national strategy for palliative care. This could be the reason the palliative care services appear to be rather ad hoc and underdeveloped when compared to those in other places.

I felt a little disappointed following the visit as I had expected that this centre, serving such a multicultural city, would be doing really innovative and creative things around diversity and engagement. It was, however, an informative visit and I was interested to see a country that is perhaps 20 years ahead of New Zealand in terms of the migration journey, and to observe the way in which it has responded to the challenges of delivering EOL care to a multicultural society.

## **Appendix II**

### **Personal Reflections**

In 2015, as I travelled through Australia, England, Scotland and Canada, there was a growing awareness that the world was facing an unprecedented ‘refugee crisis’. As thousands of Syrian people, and others, fled their homes seeking refuge and safety, news reports and political debates were dominated by how countries should respond to this crisis. These debates, often polarising, included fearmongering about Muslims but also provided a platform for the many voices calling for inclusion, and the acceptance and value of diversity.

In the 1990s, New Zealand opened its doors and welcomed many new people to our shores. While diversity brings colour and vibrancy to a nation, it also brings challenges. These challenges are evident in the delivery of healthcare services and, in particular, the delivery of palliative and EOL care services.

Hospices are committed to improving the delivery of care to the communities they serve and ensuring that all New Zealanders have access to EOL care that is culturally appropriate. This commitment is a first step in the journey. It needs to be followed up by the development and implementation of policies that support this, strategies for increasing awareness of the palliative approach and the ways to access services, and a commitment to educate the workforce so it can confidently deliver culturally responsive and appropriate care.

New Zealand is a small country but has proven leadership in our commitment to biculturalism. While we still have a way to go, our understanding and acceptance of biculturalism is a strong foundation for building Aotearoa New Zealand as an inclusive multi-cultural society in which to live, thrive and die well.



## Appendix III

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