# ANNUAL REPORT 2018-2019



# Eastern Metropolitan Region Palliative Care Consortium

# ANNUAL REPORT 2018-2019

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#### ANNUAL REPORT 2018-2019

Members of the Eastern
Metro Palliative
Care Consortium provide
services on the traditional
lands and waterways of the
Wurundjeri people and offer
our respect to their Elders,
past and present.

# MESSAGE FROM THE CHAIR

# Message from the Chair

On behalf of the members of the Eastern Metropolitan Region Palliative Care Consortium (Emrpcc), I am pleased to present the 2018-19 annual report. This year has seen a significant change in the landscape for palliative and end of life care at both the state and eastern region levels.

As 2019 began, the Consortium confirmed its commitment to the 2017 – 2020 Strategic Plan. It agreed the focus for 2018-19 should be upon community engagement with an emphasis on diversity and inclusion. There is a strong commitment of consortium members to the ongoing engagement of all palliative care services in open and transparent communication. Executive members have previously identified a need to engage with private hospitals to promote access to specialist palliative care services and support for end of life care, and this remains one of the identified priorities.

In 2016 Emrpcc members initiated a project to investigate inpatient respite care. Early findings suggested that respite care is frequently initiated when a patient is approaching the terminal phase. Additional support for carers in the home was identified as a factor influencing carer capacity to support death at home where this is the identified preferred option. EPC has received additional funding to pilot initiatives in response to this need.

Currently the Victorian Department of Health and Human Services is undertaking a review of the role of Consortia within the state. At present the exact configuration and function of the various consortia in the future is uncertain. While the Emrpcc has continued to implement the strategic priorities of Victoria's End of Life and Palliative Care Framework in a changing cultural and policy environment, we have experienced our own process of change. In early December 2018 we said farewell to Karen Conte, who served as the Consortium Manager for three years. Karen very ably steered the Consortium through the development and initiation of our current strategic plan, was a member of the PCCN, supported PCV as a Board member and initiated a range of creative projects in the eastern region. Early January saw us welcome Barb Dobson

# MESSAGE FROM THE CHAIR

to the role of Consortium Manager. With her public health and community engagement expertise we have extended our interaction with community organisations who contribute to the care of people approaching the end of their life, educating community and health professionals about palliative care.

Throughout the first six months of 2019, members of the consortium were involved in intense preparation for the enactment of the Voluntary Assisted Dying (VAD) Act (2017) Legislation on June 19. This legislation provides an additional option for the ending of one's life for those people experiencing unbearable suffering associated with a terminal condition. As the June 19 implementation date approached, we saw wide engagement and collaboration to ensure the sector was informed and that policies and processes were in place for people with terminal conditions wishing to access VAD services could do so, and also to receive ongoing support and care from specialist palliative care services within the region. The need for high quality palliative care to be visible and accessible within our community is very important in the light of VAD.

VAD marked a significant social shift and provided a catalyst for reinforcing the importance of excellent communication at the policy, procedural and interpersonal levels.

Our work in community capacity building and engagement will remain the focus of our Emrpcc members as we anticipate the outcomes of the Consortia review.



Professor Claire Johnson

Eastern Health end of life care Clinical Lead

Vivian Bullwinkel Chair of Palliative Care Nursing

# CONSORTIUM MANAGER'S REPORT

# Consortium Managers Report



Members of Emrpcc provided a warm welcome to their new Consortium Manager in January. It has been a privilege to work with a great team of committed and dedicated professionals who model such high levels of respectful collaboration in working together to provide excellent palliative care to all people residing in the Eastern Metropolitan Region.

I would like to thank Emrpcc Executive, Consortium Chair, Professor Claire Johnson, Vice Chair, Jeanette Moody and Lesa Stewart from St. Vincent's for their passionate contribution to the

palliative care sector, to the work of Consortium and their support to the role of the Consortium Manager. I would also like to acknowledge and thank Jeanette Moody, CEO of EPC, for hosting this position within EPC.

The last twelve months has seen the palliative care sector prepare for the implementation of VAD in June, respond to the implications of the 2018 Medical Treatment and Decisions Act, contribute to the Commission into Aged Care, and assist with the broad dissemination of relevant information into the community sector.

Since January, Emrpcc has focused on assessing the scope of its connections to key stakeholders across the Eastern Metropolitan Region (EMR), affirming our priorities, engaging new stakeholders, redesigning our website and undertaking new projects. Our colleagues have also been swept up in a theme of change with some key partners experiencing structural and/or leadership changes. Some key networks have ceased to operate which has required a reassessment of the most effective platforms for communication and information sharing.

## CONSORTIUM MANAGER'S REPORT

Emrpcc has continued to strengthen our links to Aboriginal, diverse cultural and social representatives, local Councils, community houses, community health leaders and Primary Care Partnerships which has resulted in collaboration on key projects. The Eastern Metropolitan Region is proud to acknowledge that it now has an Aboriginal Community Controlled Health Organisation (ACCHO), and we congratulate Healesville Indigenous Community Services Association (HICSA) on this significant achievement for local Community. We look forward to extending our collaborative initiatives as we strengthen our ties with representatives of social and cultural diversity.

Working together with our colleagues across the sectors provides a significant opportunity to build the capacity of the EMR to support its residents in their end of life journey, and their loved ones during their time of caring and bereavement. In looking to fulfill our vision for excellent palliative care in the EMR, we have an excellent opportunity to work collectively to establish the intersections that facilitate an integration of public health, community strengths, and health and wellbeing clinical expertise.

Barb Dobson

Consortium Manager

# **OUR PRIORITIES**

### Our Vision:

The vision that inspires the partners and associates of Emrpcc is:

"that Eastern metropolitan residents with a life limiting condition, their families and carers have access to a high quality palliative care system that fosters innovation, and provides coordinated care and support that is responsive to their needs".

#### Who are we

The Eastern Metropolitan Regional Palliative Care Consortium is an alliance of all DHHS funded specialist palliative care services in the region. It is inclusive of a range of associate members with a specific interest in working together to ensure the provision of quality palliative care. We work together to undertake regional planning that acknowledges issues of concern for local community, coordinate palliative care service provision in the eastern region, and advise the Department of Health and Human Services about regional priorities for future service development and funding.

## **Emrpcc Partners**



Eastern Health

Eastern Palliative Care

St Vincent's Hospital Melbourne

North Eastern Metropolitan Integrated Cancer

Service

Eastern Melbourne Primary Health Network

Bolton Clarke

Fernlea

### **OUR PRIORITIES**

# Strategic Priority 1 – Delivering person-centred services

- All communities and groups have access to end of life care and planning
- Improved
  engagement with
  community
  leaders to
  enable them to
  connect their
  communities to
  end of life care
- Communities understand the services available for end of life care and bereavement support

# Strategic Priority 2 – Engaging communities, embracing diversity

- People
   experience
   services that are
   coordinated and
   designed locally
- The primary, hospital, palliative and aged care sectors connect effectively to respond to care needs
- Early discussion, referral, planning and coordination occurs

# Strategic Priority 3 – Coordinating and integrating services

- People
   experience
   services that are
   coordinated and
   designed locally
- The primary, hospital, palliative and aged care sectors connect effectively to respond to care needs
- Early discussion, referral, planning and coordination occurs

# Strategic Priority 4 – Making quality end of life and palliative care everyone's responsibility

- Knowledge is increased across the healthcare sector to provide safe, quality care
- End of life care is consistent across the healthcare system
- Healthcare staff are equipped to communicate and deliver the benefits of palliative care
- Organisations actively support their staff in the delivery of quality end of life
   care

# Strategic Priority 5Strengthening specialist palliative care

- Models of homebased care are effective and efficient
- The specialist workforce is used effectively
- Specialist
   palliative care is
   accessible locally

Emrpcc has worked towards implementing Victoria's End of Life and Palliative Care framework. Coordinating and integrating services and strengthening specialist palliative care has been a strong focus of member organizations for several years, and will continue to be so into the future. Acknowledging the importance of extending our reach into community and community organisations has led to an emphasis on Priorities 1, 2 and 4 during this year.

# **OUR PRIORITIES**

Member Agency	Representative	Consortium	Executive
St Vincent's Health	L Stewart	6/6	3/3
	M Boughey	3/6	
Eastern Health	K Marshall/Leah	2/6	
	Stevens		
	C Johnson	6/6	3/3
	Leeroy William	3/6	
Eastern Palliative Care	J Moody	6/6	3/3
	K Draper	5/6	
Fernlea House	S McIvor	0/6	
RDNS/Bolton Clarke – EMR	J Gray /Leanne	3/6	
	Davey		
North Eastern Melbourne Integrated Cancer	K Simons/ B Zappa	5/6	
Eastern Melbourne Primary Health Network	L Paulin/ L Wright	5/6	
DHHS Box Hill office (ex-officio)	W Molesworth	3/6	
Consortium Manager (ex officio)	K Conte /Barb	6/6	3/3
	Dobson		
Total meetings		6	3

The Consortium met on six occasions during 2018-2019. All meetings were held at EPC. The number of scheduled meetings held during the year ending 30 June 2019, and the number of meetings attended by each of the member agencies is set out in the table above.

# **OUR NEW LOGO**

The original Emrpcc logo was developed in a process with members, and was designed to reflect the three specialist palliative care partners and the support of the



associate members. This was reflective of an original focus on inter communication and service development amongst members. At the beginning of 2019, Consortium members acknowledged the strengths of the partnership that had been forged over several years and shifted the lens outwards, to community. As part of this process it was decided that the Emrpcc logo should visibly respect the Traditional Custodians of the land on which palliative care services are delivered in the EMR.

After consultation with members from the Aboriginal Community and Community leaders, we embarked on a logo competition, inviting submissions from artists across the region to share their ideas. This provided a good talking point and facilitated some valuable discussions in Community about palliative care. We had some lovely entries which highlight the wonderful talents of people in the local area.



Figure 1 Entry by artist Merilyn Duff

Entries revealed a depth of understanding in the community about the nature of palliative care. As fabulous as the art entries were, they could not translate easily into digital format. We then commissioned a local digital artist to develop the themes that are important us which are: to recognise and acknowledge the Traditional lands of the Wurundjeri people on which we all provide services for people at the end of life, the provision of culturally safe palliative care and the eastern region.

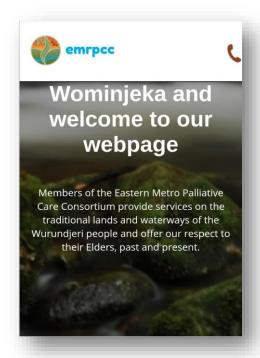
## **OUR NEW LOGO**



Bunjil is a creator deity and ancestral being for Aboriginal people in the EMR. Bunjil is represented in many art forms in the region, including a sculpture at Eastern Heath. In this logo, Bunjil flies over the land watching over all people from Community, and all those who have come to call this region home. Hills, valleys and towns of the eastern region are symbolised and crossed by the waterways, carrying life and spirit from the beginning of life to its next phase after death — which is represented by the warm rays of the setting sun.

The manna gum leaf represents our Traditional owners who care for Country, graciously share culture, and welcome us to the region. The circle symbolises the care we all offer to each other, especially at the end of life.

A change in direction for our website designer meant we needed to engage new designer and website host. This provided an impetus to redesign the <a href="Emrpcc website">Emrpcc website</a> to reflect our focus on community and place. Our website is now mobile accessible and links readers to the sites of our partners and peak bodies.



# THE EASTERN METRO REGION

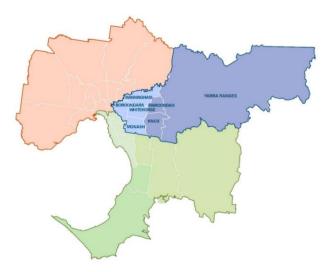
# Regional Profile



The Eastern Metropolitan Region is unique in its inclusion of inner suburban LGAs and Outer LGAs where issues often connected to rurality affect both service access and delivery.

The Eastern Metropolitan region (EMR) is comprised of seven Local Government Areas (LGAs): Boroondara, Knox, Manningham, Maroondah, Monash, Whitehorse, and Yarra Ranges

Collectively the region services over 1015473 people. For integrated service and planning purposes the LGAs are divided into Inner: Boroondara, Manningham, Whitehorse and Monash. and Outer: Knox, Maroondah and Yarra Ranges.



The area has a particular feature of including inner suburban LGAs and Outer LGAs where issues often associated with rurality affect both service access and delivery. There is a significant difference in the demographic, cultural and geographic profiles of the inner and outer areas. Local people identify strongly with a sense of place, their place, whether that is the hills, valleys, small isolated towns or bustling urban communities. People in the outer area, in particular the LGA of Yarra Ranges, experience significant barriers to service access due to distance and isolation. Limited access to public transport impacts on the costs both for individuals and health/wellbeing service organisations in the outer areas. Opportunities for telehealth service models are emerging in the region as viable supports to address these barriers.

# THE EASTERN METRO REGION



Collectively the region embraces cultural and linguistic diversity, with the municipalities of Manningham, Monash and Whitehorse currently having the greatest number of people who speak a language other than English at home.

While there is a growth in the younger work force, the EMR is experiencing the broader Australian trend of an aging population.





The percentage of the population aged 65 and over is expected to grow from 15.5% in 2011 to 18.4% by 2021.

Our 2017/18 Annual report provided a comprehensive outline of the 2016 ABS data. It is available <u>here</u>. The 2020 Census data is on the horizon and we look forward to sharing the updated profile with readers in our next Annual report.

## **Consortium Activities**

The reach of the Consortium across the EMR is facilitated by a range of activities. This includes creating the space for palliative care and end of life conversations with community and organization representatives, attendance at network meetings, key issues forums, and presentations to groups on request. Additional activities include: participation in service planning meetings, project reference groups and supporting initiatives that are important to community. These activities are a current priority focus for the work of the Consortium Manager.

#### Stakeholder Engagement

In late January 2019, the Consortium Manager commenced a stakeholder engagement process. The purpose of this was to reaffirm our connections to existing partners, identify any emerging trends affecting community and to introduce the new Consortium Manager.

Key themes emerging from the stakeholder consultations related to:

- Culturally safe palliative care,
- NDIS,
- VAD, and
- Perceptions of palliative care.

Two key initiatives emerged as a focus for prioritization. These were to:

- review and redesign the website to demonstrate our awareness of, and commitment to, the concerns our local stakeholders.
- strengthen engagement across the eastern community to ensure palliative care service delivery is informed by, and respectful of, social and cultural diversity, in particular with Aboriginal and Torres Strait Islander peoples in the EMR.

#### **Palliative Care Conversations**

Emrpcc hosts a Journal Club for service providers in the EMR. In 2019, membership was open to community working in end of life and palliative care projects. It meets every two months with conversations focused on recent journal publications on topics proposed by the members.

#### Culturally informed practice

Palliative care services in the EMR are committed to learning from Aboriginal leaders and representatives, to ensure cultural safety for Community receiving End of Life Care, and to support Community to understand and access end of life care options. The Consortium Manager developed a project which aims to deepen connection with local Aboriginal communities with a view to entering a reciprocal relationship where there is an ongoing interchange of knowledge.

Project activities are guided by Community representatives at HICSA, Eastern Health Aboriginal Health Team (EH AHT) and Mullum Mullum Indigenous Gathering Place (MMIGP).

The key message to share in relation to service reorientation relates to connectedness and commitment. The visibility of acknowledgement plaques and artwork in our services is appreciated and a good start, however it needs to be matched by an investment of time in developing strong relationships based on trust.

The palliative care sector cannot enter into the end of life care of an individual if they have not been engaged in, or at least aware of, the significant issues that affect Community life. Reciprocity in this relationship requires engagement by health care service representatives with local communities to ensure they are known and trusted. This requires being present at significant events, being aware of, interested in, and up to date with major social influences that are affecting Community.

To date, as outcomes of this project Emrpcc has:

 Refocused the design of our website to demonstrate our commitment to our First Nation peoples.

- Endorsed the Consortium Manager membership of the Yarra Ranges Council (YRC) Indigenous Advisory Committee (IAC) and its activities
- Partnered with PEPA to organize a workshop at HICSA for Aboriginal and Torres Islander workers in the East
- Attended MMIGP PAG group to yarn about "What is palliative care?"

- Supported YRC Reconciliation event on May 30 where over 180 people were engaged in presentations on Walking the Line.
- Committed to regular attendance at Community Lunch at HICSA
- Commenced engagement with MMIGP to look at co designing future end of life learning activities
- Consulted with representatives of the EH AHT
- Contributes to and attends the FDA1000 network

#### Public Health Palliative Care in the East

Early in 2019, the Consortium Manager was invited to facilitate a workshop to further the ideas of establishing a collaborative process for working together in the EMR on end of life care. Invited participants at the workshop included

- Yarra Ranges Council
- CHAOS (Neighbourhood House Collective) Be The Ripple project sponsors
- Eastern Metropolitan Region Palliative Care Consortium
- La Trobe University HPPCU

Key issues to emerge from the workshop include identified needs for:

- A systems approach to social change e.g. embed forward planning, communication and decision making on end of life matters into social structures, reaching beyond the health sector into broader social systems such as education and law.
- Ongoing staff training across sectors that is integrated into a processes of recruitment, orientation, supervision and professional development
- Stronger integration of palliative care into public health/health promotion
- Sustained capacity building and information sharing in local communities

The Consortium Manager and participants devised a draft plan which, once authorising approvals have been received, will inform the community initiatives, capacity building and resource strengthening for End of Life and Palliative Care in the EMR. The plan includes the establishment of an area based network for community and health professionals working in palliative care that will foster closer connections between the sectors, including health, public health, law and community. Emrpcc is offering leadership for the establishment of the network.

# **Engaging Young People in Death Education**

For palliative care to become 'everyone's business' there needs to be a shift in several things:

- integration of palliative care across the service sectors;
- intersectoral engagement and service planning;
- community preparedness to embrace conversations about death and dying;
- workforce development and,
- integration of death/cycle of life education into the school curriculum.

In a meeting of Consortium representatives, it was acknowledged that if we are to shift societal attitudes to death and dying, and prepare people for decision making related to their end of life wishes, we need to engage young people in age appropriate conversations and experiences.



The Consortium Manager prepared a background paper which summarized research data and the results of previous initiatives in this area. This highlighted that projects where opportunities for individual experiences, reflection and learning were provided, impacted positively on participant thinking, improved confidence to engage in conversations about death, and improved understanding of palliative care. A systemic approach would comprise integration of cycle of life themes into the existing curriculum, professional development and resource support for teachers and appropriate undergraduate course material for emerging teachers. There was no doubt that a similar project replicated in the eastern region would also have similar impacts on the students involved.

Members of the Consortium acknowledged the need for an initiative of this kind, however, given existing resource limitations and uncertainty relating to the outcomes of the Consortium review, it was decided this level of initiative may be better served with leadership from our State and National bodies.

#### Dying to know day 2018

The Consortium Manager joined with other organisations to be part of a small expo event for Dying to Know Day 2018. This event involved exhibitors from community support services including a general practitioner, funeral directors, and grief and bereavement services. A café area where attendees could sit, enjoy refreshments, ask questions or simply chat about information they had received was provided alongside the exhibitors. The expo was attended by approximately 50 people, including carers (informal and formal), community support workers, and members of the public.



Special thank you to Heather Widjaja-EPC Volunteer (pictured above), who assisted on the day.



#### Participating Organisations

Consortium Manager

The Compassionate Friends of Victoria

Call on Clare

**Uniting Care** 

Life Assist

Natural Grace Holistic Funeral

Donate Life

A big thank you to Uniting East Burwood for hosting the event at the Burwood Heights Uniting Church Hall and for generously providing tea and coffee for all.

#### **Clinical and Community Networks**

#### Palliative Care Clinical Network PCCN

Safer Care Victoria – Palliative Care Clinical Network supports the Victorian palliative care sector by partnering with clinicians and consumers to support quality safety improvement at the local level. The Emrpcc interfaces with Safer Care Victoria- Palliative Care Clinical Network (PCCN) in a number of ways. A/Prof Mark Boughey, Director at St Vincent's Health, is the Clinical Lead of the PCCN. Barb Dobson, Manager EMRPCC is an invited guest of the PCCN Governance Committee. Barb provides an interface between all Victorian Palliative Care Consortia Mangers and the PCCN. Previously, Karen Conte (previous Manager Emrpcc) was a member of this committee. Dr. Leeroy William (Clinical Director of Supportive & Palliative Care, Eastern Health) and Jeanette Moody (CEO, EPC) are also members of the PCCN INSIGHT committee. Prof Claire Johnson was a member of this group until March 2019.

The Emrpcc has also worked with the PCCN to commence the review of palliative care guidance documents, and many of our consortia member health services are involved in improvement projects currently underway in the PCCN. These include improving triage in palliative care, care of the dying person, recognition and response to life limiting illness, and work to develop statewide guidance for anticipatory medicines.

To promote Emrpcc community engagement, increase awareness of, and access to, palliative Care, the Consortium Manager regularly attends and/or contributes to the following:

- Community lunch Healesville Indigenous Community Services Association (HICSA)
- Yarra Ranges Council Indigenous Advisory Committee (YRC IAC)
- Be the Ripple (BTR) project reference group
- Wantirna Health Palliative Care Journal Club
- FDA1000 outer east network
- Palliative Care Research meeting Wantirna Health
- End of life Care Expert Advisory Committee (EAC) meeting Eastern health
- Eastern Melbourne Primary Health Network (EMPHN) End of Life Care Working Party

Boroondara Aged Care Service Providers network

2018 – 2019 saw a significant change in the EMR network landscape. Two significant, longtime networks ceased:

- EMR Alliance
- EMR Aboriginal Health and Wellbeing Network

#### **EMR Alliance**

The EMR Alliance (the Alliance) was established by the Eastern Metropolitan Region's (EMR) Department of Health & Human Service in September 2010 to support the implementation of the Active Service Model (ASM) across the region. Over time the Alliance evolved to incorporate Diversity Planning & Practice and provided an important platform for communication between the health sectors. A final meeting of the EMR Alliance was held on June 18<sup>th</sup>.

#### EMR Aboriginal Health and Wellbeing network.

This provided an important local platform for improving culturally competent service delivery, service coordination, peer support, improved referrals and information sharing. Its final meeting was held in October 2018. The Consortium Manager, and the Manager Nursing and Medical Services from EPC, had been long term members of the network.

The Consortium Manager now attends the First 1000 Days Australia (FDA1000) network meetings. The focus of this work is whole of life from birth to end of life. It involves working together at all levels of Community, and across sectors, to ensure healthy babies are born who become healthy elders who can pass on their cultural legacy, and then enter the end of life surrounded by well supported Community. The Consortium Manager presence at this network is a powerful visual presence of palliative care and end of life being included in Community life.

The Consortium Manager works across the EMR to increase collaboration across the member sites and the visibility of the Emrpcc in the community. With the redevelopment of Caritas Christi in Kew, it was decided to suspend weekly attendance onsite until the new building is completed. A minimum of one day per week is allocated to Wantirna Health and EPC.

#### Research

In the 2018 Annual Report details were shared about a collaborative research project titled "Planned and unplanned respite admissions to inpatient specialist palliative care units: a comparative study of clinical profiles and outcomes with lessons for future service planning".

The results of the study aligned with the literature which has proposed the term 'respite admission' is ambiguous in clinical practice and is frequently used when there is disease progression and increasing care needs. In the study, the use of the term 'emergency respite' was strongly correlated with inpatient mortality, higher symptom severity scores and performance status measures. Hence, the greater incidence of 'urgent respite' commonly appeared to be a reflection of the burden of symptom instability and/or pre-terminal disease being managed in the community.

The final report on the study made the following recommendations:

- Eastern Metropolitan Region services collaborate on defining the use of the term respite
- Planning for care includes a discussion of expected symptoms and capacity building for carers who have agreed to support the PSOD at home.
- Contribute to further policy development in the area of palliative care respite
- Advocate for additional resources to support carers in managing preferred site of death at home.

Consortium members have responded to the recommendations in range of ways. In recognition of the increasing needs of carers at the pre-terminal to terminal phase, EPC has initiated a project to provide additional carer support to manage when the preferred site of death is home. For more details please see the member activity section.

Members have also considered the need to achieve consistency in the use of terminology. Work on this aspect has commenced. The expectations are that the terminology will provide a clear understanding of the reason for an admission, promote increased consistency of practice and enable equitable resource allocation at the Specialist Palliative Care Units.

#### VAD service capabilities

Many services began preparation for the introduction of VAD in 2018. Preparations intensified throughout 2019 as organizations undertook processes to determine their response to VAD implementation.

EPC held staff information sessions and conducted workshops to ensure staff members were supported with accurate information and to be clear about the EPC policy and its implications for practice. EPC's electronic database, PalCare, has been modified to capture information relevant to data processing when a client has indicated VAD is part of their end of life plan.

Eastern Health undertook a survey of all health professional staff to help inform the Board of staff views and service capability. EH has developed a model and pathways for patients to access VAD throughout the Health Service with the exception of Supportive and Palliative Care. However, Supportive and Palliative Care will continue to provide palliative care for all patients who require it.

The Emrpcc recognizes the need for ongoing palliative care support for patients whose end of life plan includes VAD. In practice, the need for sufficient resources particularly for psychospiritual and social support is acknowledged, given that the most frequently cited reasons for accessing VAD in other countries relates to social, existential and psychological concerns.

#### **Eastern Health**

Eastern Health's Supportive and Palliative Care service consists of specialist doctors, nurses and allied health professionals (physiotherapists, social workers, occupational therapists and spiritual carers) whose role is to provide assistance in the management of complex symptoms, expertise in supporting patients, families and staff across the spectrum of End of Life care. The 32 bed inpatient Specialist Palliative Care Unit, located at Wantirna Health, provided interdisciplinary care for 745 patients in 2018/19. A further 2060 patients were referred to the Hospital Based Palliative Care Consultancy Service (HBPCCS) from general services throughout Eastern Health - Box Hill - 1104, Maroondah - 642, Angliss – 314.

Eastern Health was pleased to inform partners in the eastern region of the appointment of A/Prof Leeroy William to the role of Clinical Director of Supportive & Palliative Care.

#### Dying at home research project

Eastern Health has worked to build on the Memorandum of Understanding signed with EPC in 2016/17, with a collaborative research project to support patients to fulfill their wish to die at home. Selected patients were discharged from Wantirna Health with enhanced palliative medicine input, in conjunction with support from EPC and the patients' GPs. Between August 2017 to August 2018, over 80 patients received additional support through this project.

Out of those who consented for their data to be published anonymously, 21% changed their preferred site of death from hospital to home. In comparison, none of the patients discharged between November 2015 to July 2017 had this change in their preference. Additionally, patients were spending an average of 15 (27%) of their remaining days in hospital, while those who received additional support only spent 7 (14%) of their remaining days in hospital, though this was not statistically significant. Analysis of feedback from GPs and Specialist Community Palliative Care clinicians sharing care identified themes of improvement in clinical management confidence, inter-professional collaboration, continuity of care, patient and their families' choices and appreciation.

#### Eastern Palliative Care Association Incorporated

#### What an exciting and busy year we have had!

EPC provides a diverse group of disciplines, all working together to support our clients and their families. But many in the community also do not understand the breadth of EPC services and that we also work with the person's immediate family, carers and friends – whoever is important to the client. There is clearly a need to encourage and assist our community to be more aware of palliative care and what it has to offer. Responding to this need is part of our current strategic plan for EPC, and we envisage that ongoing work in this area will be required.

In April we honoured our generous supporters with a Donor Appreciation High Tea and Expo. This was a first for EPC as not only did we provide a lovely afternoon tea, a heartfelt and informative speech from the CEO plus a goody bag to take home, we also added an extensive Expo. This involved information tables manned by around 20 staff representing each of the disciplines at EPC. All are experts in their field and shared their knowledge one on one with our guests, and had lots of information to give away. We had nurses, family support workers, music therapists, massage therapists, occupational therapists, volunteer coordinators and more.

Many conversations took place and it was a great opportunity to explain what home based community care looks like and the many services we actually offer. It was a very successful day with around 60 people attending with very positive feedback. This event will now be repeated every year.

In May we held a Death Café as part of National Palliative Care Week. We had not done this for a few years and we put a fresh spin on it by advertising more widely and setting the room up beautifully to encourage a relaxed and respectful conversation. Around 50 members of the public attended which is a record for EPC and certainly more than most organisations manage to achieve for this type of event. We ensured that a Family Support Worker was on each table to gently guide conversations and enable everyone to have their say. We had very positive feedback with many people wanting to know when we would hold this event again.

#### Some Statistics and achievements over the past year

Referrals were up 7% with a total of 1935 clients cared for by EPC over the year. In May 2019 we had the highest number of clients referred in one month ever – 244 referrals. In March 2019 we also had the greatest number of clients supported by EPC in one month - 468 clients. The average number of clients supported by EPC has grown over the past 3 years from 372 to 441 clients per month. This growth has been achieved by the significant grant increases provided to EPC by the Department of Health and Human Services. This shows that there is still a great need for more education in our community on the benefits of home based specialist palliative care.

EPC's support into aged care has continued to increase with referrals for clients in aged care up an amazing 17%. Many of these clients die within 24 hours of referral as many facilities are recognising dying very late in the journey. Sometime EPC can respond quickly but at other times this cannot happen. EPC continued to provide education into aged care facilities and our registered nurse and personal care attendant courses have been very well attended over the past year.

Eight percent of clients had a lung cancer, six percent has breast cancer and five percent of clients had prostate disease, three present had ovarian cancer. Clients came for 91 different countries and spoke 36 languages. The top 5 countries of birth being Australia, Italy, Greece, England and China.

EPC commenced a number of pilot programs over the past 12 months. These included:

- Increased medical services hours to better support clients to remain at home as long as possible: to improve GP support and to support carers. EPC now has special physician five days per week.
- Overnight registered nurse respite in the clients own home when they are they are in the terminal or deteriorating phase. To the ends of June EPC provided more than 50 nights of respite for clients who were in the terminal phase of their illness so that the carer could have support and a rest.
- Trail of Personal Care Attendants. Many EPC client are unable to access services quickly
  enough as their illness progresses very quickly. EPC has been trialing the provision of
  Personal Care Attendants to support these clients. The trial will end in February 2020.
- Community Education Review. We have experienced an increase in demand of our Community Education courses. EPC is currently undertaking review of Community Education to better meet with demand.
- Occupational Therapy (OT) hours. We have significantly increased the Occupational Therapy hours to meet client demand. This commenced in February 2018, OT demand has steadily increased each month since.
- Consumer Advisory Committee. In recognition of the need to have consumer input into EPC, in the past year we have created a Consumer Advisory Committee. Their role is evolving but a keystone is keeping EPC connected to our clients and carers and their needs. There are around 17 carers who have nominated to assist EPC in the future and we will continue recruitment as necessary. This committee is critical to ensuring we ensure we understand and respond to community demands.

#### 24 Hour Service

EPC has continued to have nurses on duty form 8:30 am to 11 pm each day Monday to Friday And 8:30 AM – 5 PM Saturday and Sunday. After these hours EPC has a call services (Triage Service) that supports clients but nurses can be called out to visit clients as needed. The Triage Service is designed to prevent clients and carers from calling an ambulance or attending a hospital emergency department where they may or may not be known. It also provides education and support.

#### Data analysis

Once again we note that seventy-five percent of calls occurred between the hours of 5 PM and midnight. Most calls come from a son/daughter (41%) closely followed by the partner (35%).

The average number of calls per month was 237 up from 217 in the previous year December had the lowest number of calls at 186 while June had the highest number of calls at 306.

The average number of call outs was 28.6 with the lowest month being 18 in May and the highest 38 in April.

#### St Vincent's Health (SVHM) Palliative Care Services

#### Caritas Christi Site Redevelopment

St Vincent's Hospital Melbourne is committed to providing the best possible palliative care for our community. To meet this goal and cement our position as a leader in palliative care, we are redeveloping our palliative care hospice Caritas Christi in Kew.

To make way for our major redevelopment, palliative care services were relocated from the Caritas Christi campus on 15 February 2019, with the last patient moved to our purpose-designed palliative care ward at St Vincent's Hospital Melbourne, Fitzroy.

With the redevelopment of Caritas Christi, two major milestones will be achieved: a new, premium quality 120-bed residential aged-care home at the rear of the property and a new 26-bed palliative care facility at the front of the property. The new, patient-centered hospice will support St Vincent's Health Australia's strategic priority of



driving excellence in palliative care, reflecting our focus on education, thought leadership, advocacy, workforce reform and the advancement of new models of care.

The redevelopment will enable a cross-divisional approach to end-of-life care. Our patients will have access to innovative models for palliation that are not currently available in most residential aged-care facilities. The new, purpose-built facility will support greater integration between the traditional hospice environment, the residential aged-care facility and our ancillary programs. It will particularly benefit patients who have end-stage dementia, as well as their families and loved ones. This is an exciting opportunity to provide leading, person-centred aged and palliative care – respectful, compassionate, culturally safe and competent – to a vulnerable group of patients, who entrust their care to us during a particularly vulnerable point in their lives.

#### **End of Life Care**

The End of Life Care (EoLC) working group at SVHM is an organization wide representative committee. The main achievements have included developing an EoLC policy and framework for SVHM within the context of the Department of Health and Human Services definitions and informed by the Australian Commission on Safety and Quality in Healthcare's Essential Elements for Safe and High-Quality End-of-Life care (Consensus Statement), and now the new accreditation standards. A major piece of work has been the governance around and implementation of the Care Plan for the Dying Person – Victoria (DHHS endorsed) to ensure all those dying at SVHM consistently receive the best care possible. Implementation is almost complete, and we are monitoring, evaluating, and reporting on its use to ensure the tool is maximally effective by engaging staff and embedding it in morbidity and mortality practice.

#### Advance Care Planning and Voluntary Assisted Dying

The future of Advance Care Planning (ACP) is stepping into a new era in the presence of Voluntary Assisted Dying (VAD). Over the last 18 months a great deal of consideration has been given to establish an organisational response which incorporates the ethical, legal and clinical implications to end of life care. Although an Advance Care Directive (ACD) does not include a request for VAD as someone needs to remain competent through the entire VAD process, an ACD is a crucial vehicle to ensure an individual's autonomy and self-determination at a vulnerable time in their life.

Advance Care Directives and the Medical Treatment Decision Maker (MTDM) have become legislative clinical directives ensuring health professionals engage with patients and their families aligning medical treatment with the patient's values and wishes. The Patient Risk

Assessment Tool (PRAT) has been initiated in the emergency department at St Vincent's Hospital (SVHM) to start the identification and discussion around an ACD and MTDM as early as possible. Additional education for health professionals and community have become an important initiative to promote better understanding around end of life choices and health literacy. Currently Level 1 and 2 ACP workshops have been conducted to engage with internal staff at SVHM as well as health professionals across Victoria including: general practitioners, surgeons, practice nurses, managers, pastoral care workers, allied health professionals and palliative care clinicians.

SVHM's ethic of care precludes the provision of VAD yet highlights the imperatives of high quality end of life care (EoLC) for our community, especially our most vulnerable groups. SVHM has a long tradition in EoLC dating as far back as 1890 and is committed to continuing this tradition under the leadership of Professor Mark Boughey and the End of Life Liaison Service (ELLS) as they respond to individual's fears on dying and end of life options.

#### After Hours 2018-2019

Eastern Palliative Care Association Incorporated (EPC) and Caritas Christi Hospice (CCH), Kew, developed a specialist After Hours Triage support model in the 1990's. The service is provided by SVHM. In the EMR, EPC clients and carers are provided with an After Hours phone number which connects them to Caritas Christi inpatient palliative care unit. The senior nurses (Triage Nurses) at Caritas Christi receive and respond to calls backed up by access to the client's electronic medical record. The Triage Nurse adds to the record when phone calls are received providing integrated support to the client and carer.

At EPC this is backed up with on call specialist palliative care nurses employed by EPC who will visit clients in their homes, out of hours, if the issue cannot be resolved over the phone. In the past 12 months 1578 calls were received by the Triage Service for clients on the Eastern Palliative Care program of which 19% of calls required a nurse to visit. All calls to the Triage Nurse are followed up next day by Eastern Palliative Care nurses.

Generally, there are multiple issues when clients and families ring the Triage Nurse. Most times there will be a combination of advice given, medication instruction/advice, education or a request for specific follow up the next day. Where symptoms are complicated the Triage Nurse may ring the EPC Nurse who will in turn contact either the GP or the EPC Doctor on call. Contact with medical practitioners usually occurs while the nurse is in the home supporting the client.

#### **Bolton Clarke**

Bolton Clarke, the new face of RSL care and RDNS, is one of the largest Australian owned and operated not-for-profit providers of healthcare offering At Home Support, Residential Aged Care and Retirement Living.

The Bolton Clarke Model of Palliative and End-of-Life Care, 2018, is an overarching, evidence and standards based approach to care, staff development and support. The model provides the foundation for the provision of quality, holistic and person centred care with a generalist/palliative approach focus.

In June 2019, Bolton Clarke were successful with a submission for the Eastern Melbourne Primary Healthcare Network (EMPHN) 'Enhanced palliative care at home project'. The project aligns with the Bolton Clarke Model of Palliative Care, covers the outer East of Melbourne and aims to:

- Incorporate a palliative approach as part of standard practice for clients with a life limiting illness
- Recognise and plan for end-of-life including advance care planning
- Provide/facilitate palliative approach education and training for staff
- Strengthen relationships with and referral to specialist palliative care & General Practitioners
- Prevent hospital admissions

The project will span 12 months from the 1<sup>st</sup> of September 2019 with the final evaluation planned for completion in November 2020.

#### Eastern Melbourne Primary Health Network

Greater Choices for At Home Palliative Care measure

Eastern Melbourne PHN is one of 11 Primary Health Networks developing initiatives to improve access to home based palliative care, support service integration, generate and use data to improve services and use technology to enhance service delivery. EMPHN has provided additional funding for Enhanced Palliative Care at Home projects that will provide additional support for carers, after hours specialist advice, development of end of life care videos from the

perspective of carers and early identification of people who would benefit from end of life care planning by home care nurses. EMPHN is also engaging with RACFs to enhance end of life care and reduce unnecessary hospitalisation.

#### **HealthPathways**

HealthPathways Melbourne is a website developed for General Practice to be used at point of care with the aim to assist health professionals to appropriately assess, manage and refer patients to secondary, tertiary and community health services. It aims to promote better health outcomes for local patients by improving access to the right care, in the right place at the right time. Palliative related pages include palliative care, caring for dying patient at home and in a RACF, certification of death, emergencies in palliative care, new palliative care patient, pain management and pain medications, symptom control, terminal phase management, GP palliative care resources and referral to palliative care services.

#### **EMPHCC End of Life Care Working Group**

The Eastern Melbourne Primary Health Care Collaborative established an End of Life Care working group with representation from the collaborative and key palliative care stakeholders to understand the service delivery gaps that may prevent people dying in their place of choice. A workshop in 2017 identified some key themes, and from this the group identified unmet carer needs and baseline data about end of life preferences and needs. Initiatives to come from this work include a project to upskill nursing staff working with patients in the community to improve rates of advance care planning and early identification of those with palliative care needs; and development of innovative workforce roles in community palliative care to support carers.

#### Emrpcc website activity 2018/2019

The website contains relevant and up to date information for specialist palliative care and non-specialist services and service users. We continue to receive requests from people who access the website for information on training opportunities, and support for specific application of the Opioid Conversion Guidelines. The Manager, Nursing and Medical Services at EPC provides clinical support to these enquiries. With the redevelopment of the website we look forward to reporting on its impact in the 2020 Annual Report.