



Centre for
Palliative Care

Informing Choice. Enabling Care.

2015 ANNUAL REPORT



THE UNIVERSITY OF
MELBOURNE



ST VINCENT'S
HOSPITAL
MELBOURNE

A FACILITY OF ST VINCENT'S HEALTH AUSTRALIA

Mission

Our cutting edge research and world class education creates awareness, expands knowledge and ensures excellence in care.

Vision

A leading academic authority in palliative care, our pioneering work transforms the lives of patients and families facing advanced illness.

About this report

The Centre for Palliative Care is based at St Vincent's Hospital and is a Collaborative Centre of the University of Melbourne, Australia.

The aim of this report is to give our stakeholders an overview of the breadth and depth of the Centre's education and research activities for the 2015 calendar year. For more details of our activities, visit our website at www.centreforpallcare.org

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Director's message



Professor Peter Hudson

Director

Spreading the message about the value of evidenced-based palliative care in enhancing the quality of life of patients with life limiting illness and their families, is core to our work at the Centre for Palliative Care.

In 2015, our efforts included involving almost 2000 health professionals in a range of palliative care educational opportunities, ranging from an online introductory course through to post-graduate training as well as seminars and mentorship programs.

Our rich program of research included investigations into new ways to treat nausea, the impact of family meetings, and transparent and equitable ways to prioritise limited palliative care resources.

Many of our projects were undertaken as international collaborations with other palliative experts from around the world.

In recognition that palliative care can be a mysterious concept for the broader community, our Centre also underwent a rebranding exercise in preparation for taking a more proactive approach in engaging with the community on palliative care issues.

I sincerely hope that you find our 2015 annual report informative. Our initiatives and achievements could not have been possible without the commitment of our team and the contributions and support provided by numerous stakeholders and collaborators.

OUR WORLD-CLASS EDUCATION PROGRAMS

At a glance

The Centre fosters the palliative care education and training of healthcare professionals by providing a range of postgraduate palliative care programs and auspicing state-wide programs, including the Victorian Palliative Medicine Training Program (VPMTTP), the Victorian Palliative Care Nurse Practitioner Collaboration (VPCNPC), the Victorian Aboriginal Palliative Care Collaborative (VAPCC) and the Victorian End of Life Care Coordinating Program (VEC) initiative.

Hot topics

The Centre held two free information sessions open to anyone interested in current issues facing the palliative care sector.

Euthanasia and physician assisted suicide: pragmatic implications for palliative care
Attendees: 126

Presenters: The Centre's Jennifer Philip, Peter Hudson, & Mark Boughey, Nurse Consultant/Educator Rosalie Hudson, University of Newcastle, NSW, Brian Kelly



Lifting their spirits: Who provides spiritual care at the end of life?
Attendees: 116

Presenter: Dr Bruce Rumbold, La Trobe University, Melbourne

Forums

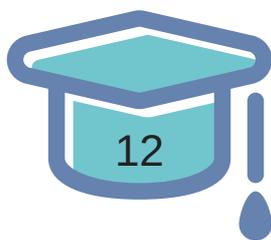
The VPMTTP and VPCNPC hold individual and joint forums.



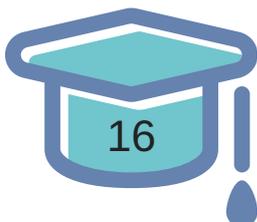
VPCNPC forum attendees: 82

Joint VPCNPC/VPMTTP forums attendees: 54

Post graduate qualifications



Specialist Certificates awarded in Palliative Care

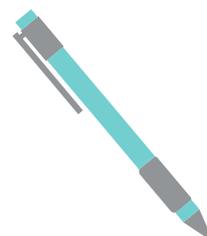


Graduate Certificates awarded in Palliative Care

14 doctors began advanced training in palliative medicine

Customised education

Our education area designs customised outreach training for health services on request.



75 customised education participants

CENTRE'S CUSTOMISED TRAINING UPSKILLS THE SECTOR

Health professionals at Goulburn Valley Health Service (GVHS) are better equipped to assist patients and their families with their palliative care needs after attending a tailored training and education program provided by the Centre.

GVHS contacted the Centre to provide training to their staff in preparation for opening palliative care beds on a general medical ward.

"We put together a tailored education program to meet their needs," says the Centre's Education

Coordinator, Karen Quinn.

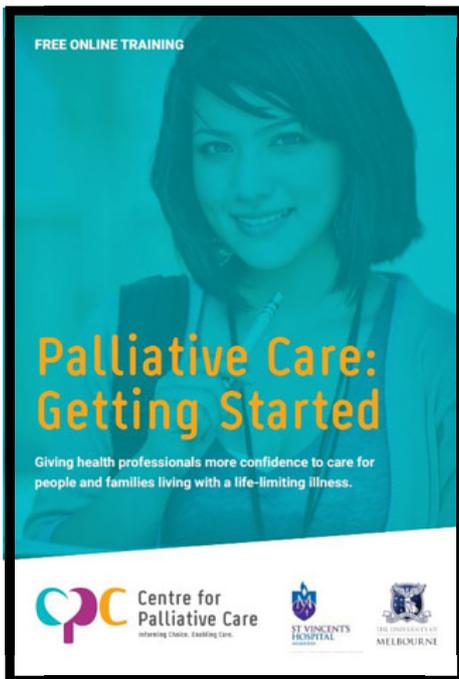
About 75 health practitioners attended the two workshops delivered in Shepparton, the first on physical assessment and the second on conversations and care-planning across the palliative care continuum. Teachers included palliative care medical consultants, a palliative care nurse practitioner, an educator, a psychologist and a clinical nurse consultant.

One hundred per cent of the participants in the physical assessment workshop reported

it had increased their confidence to undertake a clinical assessment of the palliative care patient.

One participant noted: "I enjoyed the less formal approach and how it respected the experience and knowledge within the room."

The Centre provides customised palliative care training and education to health services throughout Victoria, with trainers available from a range of multidisciplinary backgrounds.



*"I have just looked after my first dying patient and wish I had completed the module beforehand as I feel I would have been armed with better knowledge to care for the patient and their partner."
- participant feedback from the online course*

PALLIATIVE CARE 101

In 2015, a total of 1962 health professionals world wide received a sound introduction to caring for people and families living with a life-limiting illness by completing the Centre's free online course.

The course, *Palliative Care: Getting Started*, has a 91 per cent satisfaction rating, with surveyed participants stating it was either 'very helpful' or 'extremely helpful' in increasing their knowledge of common symptoms experienced by the imminently dying.

The course increases health professionals' confidence in caring for people and families living with a life-limiting illness. Taking about two hours to complete, it has been designed with input from a range of academics, nurses, palliative care physicians, psychiatric and allied health specialists.

Embedded short films and an ongoing case study ensure the course is interesting, as well as informative, with interactive quizzes used to confirm participants understanding of the key concepts.

Education program feedback

"I really value the opportunity for networking with colleagues which these forums make possible."

- Nurse Practitioner Candidate on the VPCNPC

"The whole day was very relevant and increased my knowledge and confidence with physical assessments."

- Nurse on the Centre's customised outreach workshop for Goulburn Valley Hospice

"The course is so very well structured and the learning material is relevant."

- Health professional enrolled in one of our post-graduate programs

SUPPORTING EXCELLENT END-OF-LIFE CARE



Almost 50 per cent of all deaths in Australia occur in an acute hospital, which means each year potentially up to 18,000 Victorians will die in hospital.

In 2015, the Victorian End-of-Life Care Coordinating (VEC) Program focused on the development of a suite of clinical and educational resources specifically for the Victorian health sector.

The resources included a new Care Plan for the Dying Person – Victoria; a clinical tool to assist health professionals deliver best practice end-of-life care and support to dying people and their family members and friends.

The resources are expected to be made available in the near future following a review by the Department of Health and Human Services.

To promote discussion about end-of-life care issues across the acute health sector, the VEC Program also hosted a forum attended by representatives from 18 health care services throughout the state.

Participant feedback confirmed the program's key role in providing a central platform for discussions and resource sharing related to quality end-of-life care delivery across Victoria.

CULTURALLY RESPONSIVE PALLIATIVE CARE

Victorian health care leaders have made a series of recommendations to increase Aboriginal people's access to culturally responsive palliative care services, following a three-year collaboration.

The Department of Health and Human Services funded the Victorian Aboriginal Palliative Care Collaborative in 2013 as part of its *Strengthening palliative care: Policy and strategic directions 2011-2015* project.

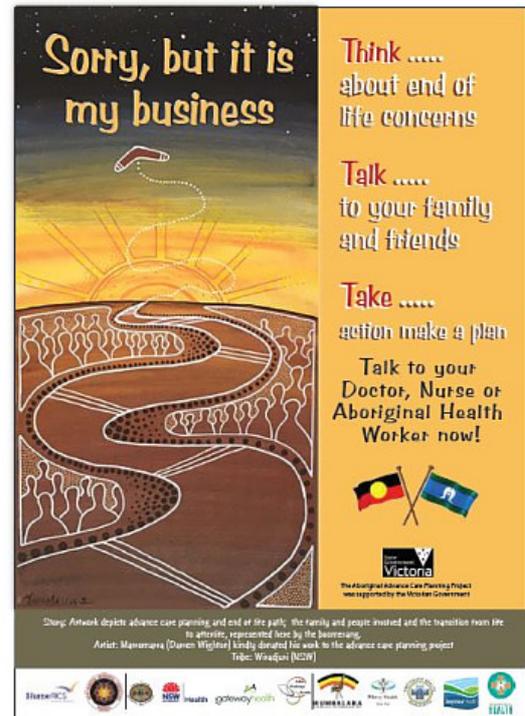
Led by the Centre, the collaborative brought together key organisations, including Aboriginal Community Controlled Health Organisations (ACCHO) and mainstream palliative care providers.

The collaborative highlighted three key issues impacting on Aboriginal people's access to palliative care. These were a lack of shared understanding of potential cultural differences as well as what constitutes palliative care; health workers' limited clinical knowledge and inter-agency networking; and, inadequate systems and processes to ensure culturally-appropriate care.

It then supported three Victorian health services to run projects that tackled those issues.

Those projects informed the collaborative's recommendations to the State Government on ways to improve Aboriginal people's access to specialist responsive palliative care in Victoria, including:

1. establishing a unit of competency in Aboriginal palliative care for Aboriginal health workers
2. exploring best practice examples of advance care planning tools
3. establishing dedicated roles for Aboriginal people in palliative care teams
4. fostering trust and respect through meaningful and dynamic partnerships
5. establishing a mechanism to monitor cultural responsive palliative care in Victoria.



"Aboriginal people are reluctant to engage with mainstream health services, and rarely with palliative care services. We wanted to know why."
- Steve Kirkbright, Project Officer

DOCTORING THE NUMBERS

It was a busy year for the Victorian Palliative Medicine Training Program (VPMT) in 2015, with 14 doctors, like Dr Danielle Ko (story below) beginning their three-year advanced training in palliative medicine.

The program coordinates palliative care medical training throughout the State, with funding provided by the Department of Health and Human Services.

Since it was established eight years ago, the program has steadily increased the number of palliative medicine specialists trained in Victoria.

Beginning with five advanced trainees in 2008, 29 doctors have completed this training and become specialists.

In addition, since 2008, 75 doctors have completed a six-month training position in palliative care, enabling them to bring their newfound

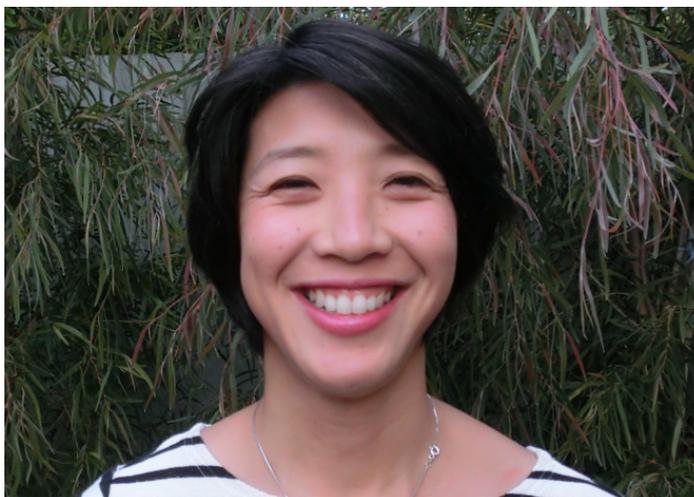
knowledge and experience to their own specialties and work towards gaining the Royal College of Physicians Clinical Diploma in Palliative Care.

Regional support



In 2015, VPMT also completed the Victorian Regional Rural Project in Palliative Care, which explored and identified the professional and social supports needed to build regional and rural physician workforce capacity in Palliative Care.

Ethical issues appeal to ex-lawyer



VPMT advanced trainee in palliative care, Dr Danielle Ko

Dr Danielle Ko's interest in palliative care was piqued as an intern when she repeatedly witnessed seriously ill and deteriorating patients being subjected to intensive and invasive medical treatment with little thought given to the patient's overall health status, values or health goals.

Over the years, she noted that palliative care teams were a counteracting force to the medical culture of trying to fix things just because it was possible, and

that patients' and families' experiences of this phase of life could be vastly different and often peaceful.

Danielle moved to Boston after her GP training and completed a palliative care clinical fellowship at Massachusetts General Hospital, and undertook an ethics fellowship at Harvard Medical School.

After returning to Australia at the end of 2012, Danielle has been undertaking her palliative care speciality training through the Royal Australian College of Physicians and VPMT and is on track to complete her training in 2017.

Drawing upon her interest in bioethics and previous experience as a lawyer, Danielle is a current member of the RACP ethics committee as well as a member of the RACP Euthanasia and Assisted Dying Working Party.

In the future, Danielle hopes to work as a palliative care specialist and a bioethics consultant.

"I have come to realise almost every medical decision has an ethical component and there's a lot of grey in palliative care – I love the grey."

- Dr Ko

THE CENTRE'S GLOBAL FOOTPRINT

Collaborations

The Centre welcomed numerous academic and clinical visitors in 2015 with the aim of establishing collaborations, strengthening existing ties and presenting work within research and clinical forums.

Our rich program of research projects is focused on adding to the global knowledge base on the provision of quality palliative care. Our three research program areas are:

1. provision of palliative care – exploring systems and approaches to improve direct care
2. psychosocial supports for patients and families
3. clinical studies to enhance symptom management.

Peer reviewed publications

OUR GUESTS

Prof Philip Larkin, President of the European Association of Palliative Care.

Prof Joachim Cohen, End-Of-Life Care Research Group of Ghent University and Vrije Universiteit Brussels.

Prof Sam Porter, Chair of Nursing Research and Head of School of Nursing and Midwifery, Queens University Belfast.

Dr Kevin Connaire, Director of Education, St Francis Hospice, Dublin

Ms Karen Charnely, Head of Institute, All Ireland Institute of Palliative Care.

Prof Marion Haas, Professor of Health Economics, Centre for Health Economics Research and Evaluation, University of Technology, Sydney.

CONFERENCE PRESENTATIONS

Total presentations: 21
5 International
9 National
7 Victoria

5 PhD students

Peer reviewed publications: 23

Active research projects: 21

REAL WORLD RESEARCH OUTCOMES

Benefits and resource needs of family meetings:

Maximising opportunities for patients and families to communicate and plan their palliative care needs

John was devastated when diagnosed with advanced cancer. All he wanted to do was get home from hospital and spend time with his grandchildren. His wife Mary was worried about how she would cope and if she would be able to look after him properly. John's palliative care team suggested that John, Mary and their family set aside some time for a family meeting to discuss what would be involved in caring for him at home and how Mary could be supported to look after him.

Family meetings enable health professionals, family carers and patients, to discuss goals-of-care, site-of-care options, and physical, emotional and social support needs. Family meetings are recommended as standard practice, but are not currently provided routinely or necessarily in line with the best available evidence.

This study's primary aim is to assess the effect of a structured family meeting on patient and family outcomes, and to determine the most appropriate time for a meeting.

Carer outcomes examined will include quality of life, psychological distress and preparedness to

care. Patient outcomes will focus on the appropriateness of end-of-life care provision, access to supportive care services and whether the patient died in their chosen place of death.

It also aims to determine the resources required to routinely implement structured family meetings into clinical practice.

This multi-site project involves 200 participants from St Vincent's, the Royal Melbourne and the Austin Hospitals with over 100 participants recruited in 2015.

Funding: Victorian Cancer Agency

Nausea symptoms:



Sonja has ovarian cancer and is struggling with persistent nausea.

Sonja's doctors were uncertain of the best way to treat her nausea and needed to try several different medications before they found one that was effective for her.

What is the best way to treat nausea in cancer?

The Centre is involved in testing a number of different medications to improve symptoms (such as nausea) in conjunction with Palliative Care Services at St Vincent's Hospital Melbourne.

One of these studies is a randomised controlled double blind study of oral methotrimeprazine versus oral haloperidol in patients with cancer and nausea that is not related to anticancer therapy.

Funded by the National Health & Medical Research Council, and coordinated by researchers at the Queensland University of Technology, this study is one in a series of studies that is building and contributing to the evidence base of nausea control internationally.

Funding: National Health & Medical Research Council

Prioritising the needs of palliative care patients

An ageing population and an increasing community awareness of the benefits of palliative care early in cancer care and for conditions beyond cancer has fuelled a growing demand for palliative care services.

However, services are struggling to prioritise demand due to the lack of an efficient, transparent and equitable process to triage patients according to the urgency of their needs.

“At the moment there is no standardised way to triage referrals, which means services may be inadvertently allocated unfairly, sometimes even more by chance than by need,” says palliative care physician Dr Beth Russell.

“Services are receiving greater numbers of referrals from multiple sources, including GPs, community nurses, specialists and nursing home staff.”

Research shows that patients with certain diseases and patients from particular demographic groups are disadvantaged by the lack of a robust assessment process.

“For instance, we know that patients with haematological malignancies (cancers of the blood), patients with non-cancer diseases, patients from regional areas and patients from certain ethnic groups are missing out,” Dr Russell says.

The Victorian Government has responded to the issue by funding a research project entitled, *Responding to urgency of need in palliative care: The development and evaluation of a decision aid for palliative care triage*.

As co-ordinating investigator, Dr Russell says the first stage of the project involved a literature review and focus groups with health professionals



“We are trying to develop an evidence-based, simple, and fair process to determine which patients’ needs are most urgent.”

- Dr Beth Russell, Palliative Care Physician & Investigator

and carers to learn about their experiences of assessing and caring for patients with urgent palliative care needs.

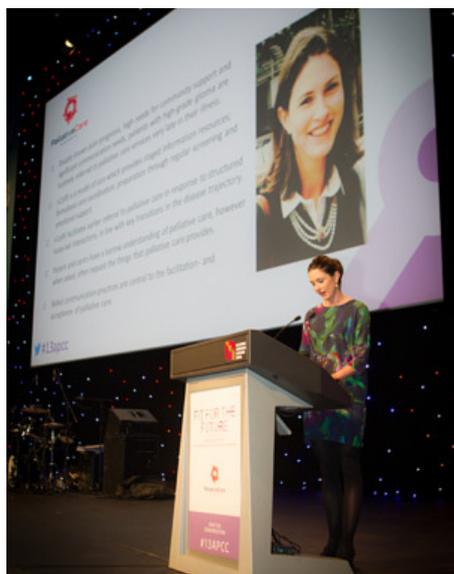
The information gathered has informed the development of a preliminary triage decision aid that includes the various factors that need to be considered when assessing a patient’s urgency.

The next stages of the research will determine the comparative weighting to give to each of those factors and then test the performance of the tool in everyday practice.

“There’s a lot of international interest in this research,” Dr Russell says. “This is an issue being faced by palliative care services around the world.”

Funding body: Victorian Department of Health and Human Services

Emerging researcher acknowledged for work on innovative model of care



PhD student Anna Collins

The Centre's PhD student Anna Collins was honoured with Palliative Care Australia's 2015 Emerging Researcher award for her work into a model of care that supports families and patients facing terminal illness.

The award recognises the outstanding contribution to palliative care by a researcher in the first five years of their research career.

Anna was the Principal Research Fellow within a team that developed the I-COPE project, which provides support and early palliative care intervention to patients with high-grade glioma – a type of brain cancer.

Anna's PhD work builds on this research to consider best methods for integrating palliative care into usual quality care in advanced cancer.

INTEGRATING CARE FOR COPD

Chronic Obstructive Pulmonary Disease (COPD) is an incurable lung illness that causes distressing breathlessness and a reduced quality of life. Yet, despite palliative care's well-recognised benefits, few COPD patients receive any palliative care.

A Consultant Respiratory Physician at the Royal Melbourne Hospital, Dr Natasha Smallwood, is completing her PhD, supported by a scholarship from the Palliative Care Research Network of Victoria, to further the understanding of current practice and attitudes to palliative care and explore a new model of integrated respiratory and palliative care for COPD patients.

Dr Smallwood is examining whether COPD patients receive palliative care as their illness progresses and



Dr Natasha Smallwood

in the final stages of their illness; the beliefs and attitudes of doctors around the use of palliative treatments for COPD patients; and, whether the Royal Melbourne's new model of care, The Advanced Lung Disease Service, which integrates specialist palliative care into routine respiratory

outpatient care, improves patient outcomes, access to palliative care and provides opportunities for advance care planning.

Dr Smallwood's project will be completed over three years, however the preliminary findings indicate about 87 per cent of patients managed through the Royal Melbourne's new model have discussed or completed a written advance care plan, up from 11 per cent.

Additionally, 65 per cent of patients managed under the new model died outside of an acute hospital bed – a previously significant change, given 72 per cent of COPD deaths in Victoria occur in an acute hospital bed.

Funding body: Palliative Care Research Network Victoria

COLLOQUIUM TACKLES THORNY RESEARCH ISSUES

Delegates from across Australia and New Zealand registered for the Centre for Palliative Care's third Australian Palliative Care Colloquium, held over two days in October at the Rendezvous Grand Hotel in Melbourne.

The colloquium brings together researchers to discuss methodologies and issues inherent in palliative care research and facilitates networking and collaboration.

The program is informed by input from the Scientific Advisory Committee, which comprises of academics from around Australia.

The audience includes a broad range of academics and health care practitioners involved in multi-disciplinary palliative care research or related fields.

Following an early career researcher breakfast sponsored by the Palliative Care Research Network of Victoria, the international keynote presenter Professor Philip Larkin, the president of the European Association for Palliative Care, opened the event by making an engaging case for more collaboration in palliative care research.

Other highlights included: a journey into (and out) of the jungle of current

controversies in statistics; a workshop espousing the importance of consumer participation in palliative care research; and, a session on the trials and tribulations of multi-site clinical trials.

Key sponsors were Mayne Pharma and the Victorian Comprehensive Cancer Centre, which awarded a Scientific Committee Meeting grant to the Centre's Head of Operations, Ms Soula Ganiatsas.

Sincere thanks to Dr Chi Li for allowing us to adapt his blog <https://palliverse.com/2015/11/03/3rd-australian-palliative-care-research-colloquium/>



Ms Anne McKenzie AM, Consumer Advocate, The University of Western Australia

"I think that stats session was (unexpectedly) fabulous - and I think that controversy in stats is a great topic."

- Colloquium delegate

Bereavement model



Researchers from the Centre for Palliative Care are investigating the best model of universal bereavement support and care for St Vincent's Hospital Melbourne (SVHM).

Whilst SVHM commonly provides bereavement care and support in the palliative setting, it does not have an organisation wide model of bereavement care.

This project, which has been funded by the hospital's Research Endowment Fund, is expected to develop and recommend a universal model of bereavement care for the hospital that takes into account ongoing costs and current service capacity.

Funding: St Vincent's Hospital Melbourne Research Endowment Fund

You can support us to continue our work

The Centre for Palliative Care's work in furthering research and education to improve the care of people with a life-limiting illness relies on the generous support of the community and we are proud to acknowledge the support we receive from individuals and organisations throughout Victoria.

You can assist us in our efforts by making a personal donation at
www.centreforpallcare.org/foundation

Your support is greatly appreciated.

The Centre for Palliative Care acknowledges the traditional owners of this land, the Wurundjeri people, and all the members of the Kulin nations. We pay our respect to their elders, past and present.

For further information about any of the Centre's programs or initiatives, please visit our website at www.centreforpallcare.org

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