



Centre for
Palliative Care

Informing Choice. Enabling Care.

2016 Annual Report



THE UNIVERSITY OF
MELBOURNE



ST VINCENT'S
HOSPITAL
MELBOURNE

A FACILITY OF ST VINCENT'S HEALTH AUSTRALIA

About this report

The Centre for Palliative Care is based at St Vincent's Hospital Melbourne 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 2016 calendar year.

For more details of our activities, visit our website at <http://www.centreforpallcare.org>

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INFORMING CHOICE. ENABLING CARE.

We are **informing** through our education initiatives and the quality of our insights derived from our research. We are **enabling** healthcare professionals, patients, and care givers in making the right choices at the right time.

VISION

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

MISSION

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

VALUES

CARING

Our goal is to ensure patients and their families receive the best possible palliative care. We act with the utmost care when developing our research and education agenda to ensure our work reaches health professionals, patients, care givers and the community. The more we can achieve, the more dignity, choice and support we can provide to patients and their families.

TRANSPARENT

We earn the trust and respect of our supporters, the healthcare community, partners, patients and stakeholders by being transparent. We are clear in our communications, open in discussing our work and accountable for delivering results.

COLLABORATIVE

Our work sees us partner and collaborate with a wide range of stakeholders locally, regionally and internationally. We keep an open mind, share our knowledge, ideas and research to achieve better outcomes. We are an active partner that leads the way, makes decisions and is judged by our outcomes. We know how to listen, encourage teamwork and we demonstrate respect towards all who we work with.

PROGRESSIVE

We are a pro-active organisation that encourages progress and innovation. We seek to deliver the highest standards in education and research to ensure the highest standard of care. Our quest is to deliver the best possible results today, tomorrow and into the future.

DIRECTOR'S MESSAGE

Spreading the message about the value of evidence-based palliative care as a means to enhance 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 2016, we provided training to over 1700 health professionals via a range of educational approaches, including our online introductory course; 'hot topic' seminars; master classes; professional development sessions; mentorship programs; annual lecture and our multidisciplinary post-graduate programs.

We also commenced responsibility for delivery of Victoria's 'Program of Experience in the Palliative Approach', a Commonwealth funded program which aims to improve the understanding of the palliative approach to care delivery amongst generalist health care providers.

Our rich program of research included investigations into new ways to treat symptoms, the impact of family meetings, models of bereavement care and transparent and equitable ways to prioritise limited palliative care resources. Our focus on trying to enhance capacity and build partnerships to foster the evolution of palliative care research across the country was achieved via our facilitation of the Palliative Care Research Network and as hosts of the Australian Palliative Care Research Colloquium. Many of our projects and research initiatives were undertaken as international collaborations with other palliative care experts from around the world.

In recognition that palliative care can be a mysterious concept for the broader community, our Centre also held its inaugural public lecture. We were fortunate to be able to have one of the world's most influential palliative care leaders as our guest speaker. Dr Diane Meier, Director of the US Center to Advance Palliative Care in New York, USA, spoke about Transforming the Care of Serious Illness through Palliative Care.

I sincerely hope that you find our 2016 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.

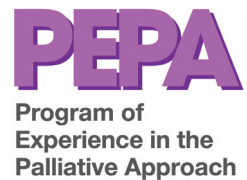


Professor Peter Hudson
DIRECTOR

OUR EDUCATION PROGRAMS

The Centre is developing future leaders in palliative care and increasing the level of expertise within the general health care system. We are developing a range of professional development education opportunities to suit health care services and individual healthcare professionals.

The Centre provides a range of postgraduate palliative care programs and auspices state-wide initiatives including the Victorian Palliative Medicine Training Program (VPMTM), the Victorian Palliative Care Nurse Practitioner Collaboration (VPCNPC), the Victorian Program of Experience in the Palliative Approach (PEPA) and the Victorian End of Life Care Coordinating Program (VEC) initiative.



SNAPSHOT OF PROGRAM ATTENDANCE DETAILS:



HOT TOPICS

TITLE: How 'hot' is Dementia? Exploring issues for palliative and aged care

PRESENTER: Professor Deirdre Fetherstonhaugh

DATE: 29th June 2016

REGISTRATIONS: 110

Attendee Comment:

Deirdre's comprehensive presentation raised critical dialogue surrounding how dementia impacts both individuals and the family at hand. She also discussed the challenges accompanying a longer average life expectancy coinciding with limited resources, support and training for medical staff.

In tackling these issues, more government funding must be allocated to palliative and aged care.



TITLE: Medicinal cannabis in palliative care: navigating evidence, policy and consumer choice

PRESENTER: Professor Meera Agar

DATE: 6th September 2016

REGISTRATIONS: 102

Attendee Comment:

Professor Meera Agar is a very knowledgeable presenter. As a lawyer, I was very impressed by her understanding of the complex legal frameworks at international, national & state levels.



GUEST LECTURE

TITLE: Improvements to Palliative Care Service Delivery:

New Initiatives and Creating Change.

Insights from the USA's Center to Advance Palliative Care

DATE: 25th February 2016

PRESENTER: Dr Diane Meier

REGISTRATIONS: 105



DEATH HAPPENS! SO LET'S TALK ABOUT HOW WE DIE

Death and dying is often seen as a medical failure rather than a part of life. It is rarely discussed in contemporary society and – as such – our view is often shaped and informed by commercial TV. A lot of people do not understand what palliative care is and what it can offer. Consequently, there are many misconceptions about it.

The Centre for Palliative Care held a public forum, *'Death Happens! So let's talk about how we die'* to debunk commonly held myths about palliative care. It provided a safe forum for people to air their concerns, learn about their options for end-of-life care and establish strategies in order to talk to their respective family about it.



The public forum – which promoted discussions about death, dying and palliative care - was attended by over 400 people. The forum raised the profile of often neglected issues such as the availability of advice, care, services and the support which ensures that we have the best possible opportunity to make independent choices about palliative care.

Dr Gael Jennings, Honorary Fellow at the Centre for Advancing Journalism, The University of Melbourne, was the MC for the event, and we were touched by the screening of *Marmaduke's Story: a family's experience of palliative care*, which was shown before we welcomed carer Simon Waring to the stage.

Mr Waring cared for his young son and wife through their terminal illnesses, and spoke of the vital support palliative care provided for his family.

International key note speaker, Dr Diane Meier, Director of the Center to Advance Palliative Care in New York, USA, spoke about *Transforming the Care of Serious Illness through Palliative Care*.

The forum concluded with a **panel discussion** – which included Dr Meier, Mr Waring, Dr Carolyn Lethborg (Clinical Leader, Cancer & Chronic Illness, St Vincent's Hospital, Melbourne), A/Prof Mark Boughey (Director Palliative Medicine, St Vincent's Hospital, Melbourne), and Carmel Smith (Executive Manager, Goulburn Valley Hospice Care Service Inc, Shepparton).

SPECIALIST AND GRADUATE CERTIFICATES IN PALLIATIVE CARE

In 2016 the Centre in collaboration with the University of Melbourne provided opportunities for **30** more health professionals to gain postgraduate qualifications in palliative care. In addition, 23 health professionals completed one or more of the short course options.

COMMENTS AND HIGHLIGHTS FROM STUDENTS:

“Learning from experts in the field with real time experience! Quality of the presenters.”

“Meeting other students with shared interests and learning from other students about their experience and getting new ideas.”

“I’ve found the mentorship aspect provided to be fantastic and very helpful”

“Pushed me to a limit of learning I did not think I was capable of. The topics I chose to cover in-depth for my assignments were invaluable in my day to day practice.”

THE ORDER OF MALTA



The Order of Malta has been providing an annual academic prize (\$1,000) for the Specialist Certificate in Palliative Care since its inception in 2008. The award is presented to the student who achieves the highest overall academic score for that academic year.

The Order of Malta is a worldwide organisation which is primarily dedicated to providing assistance in hospitals, charitable fields and disaster relief.

The 2016 recipient of the Order of Malta award was Jeanette Lacey from New South Wales. Jeanette is an end of life care nurse practitioner at John Hunter Hospital, Newcastle. She has been working in the acute care sector for over 20 years, specialising in the critical care areas of Organ and Tissue Donation, ICU, Emergency, and the operating theatres during this time.



Jeanette is passionate about understanding and improving the needs of patients and their families in the terminal phase of life and improving service delivery and care for patients in acute care hospitals at the end of life.

Jeanette is pictured with her husband after receiving her award at the students' annual Graduation and Awards Ceremony.

VICTORIAN PALLIATIVE CARE NURSE PRACTITIONER COLLABORATIVE



A Nurse Practitioner (NP) is a highly-skilled registered nurse who has specialist qualifications to work autonomously and collaboratively in an advanced clinical role. The NP role can see them assessing and managing patients, referring patients to other health care professionals, prescribing medications and ordering diagnostic investigations.

The key objective of the Victorian Palliative Care Nurse Practitioner Collaborative is to support Nurse Practitioners and Nurse Practitioner candidates with educational and networking opportunities that are specific to their advanced practice role.

There are currently 21 palliative care nurse practitioners in the state of Victoria that are employed in both community and hospital services. Three nurses are in health service supported candidate positions, and are working toward meeting the clinical and academic requirements required for their endorsement as nurse practitioners with AHPRA.

PALLIATIVE CARE NURSE PRACTITIONER FORUMS:

Forums are delivered four times a year by the Centre for Palliative Care. Each forum includes an education component, networking, case discussions and relevant updates. The forums are well attended with 94 attendees in 2016.

Each year, one joint forum is held including nurse practitioners from four collaborative practices: oncology, older persons, chronic disease and palliative care. Fifty-one nurse practitioners attended the joint forum in 2016.

Evaluation comments from participants/attendees of the joint forum

"I really appreciate the cross-fertilization across the specialties."

"The joint forum provides for networking with other NPs, a chance to share experiences and expand practice beyond my own area."

"The forum gave me valuable networking, support (professional and personal) as well as an educational opportunity."

Funding: Department of Health and Human Services, Victoria

PALLIATIVE CARE - GETTING STARTED:

Our free online course for health professionals, Palliative Care: Getting Started, serves as an essential introduction to the key palliative care concepts required to provide best practice clinical care. Designed with input from a range of academics, nurses, palliative care physicians, psychiatric and allied health specialists, this evidence-based resource includes a case study that brings the theory to life.



The Online Program developed by the Centre has recently undergone a major review and update. Approximately 100 people per month – representing 67 different countries - registered for the course in 2016. The top 6 countries represented were: Australia (80%) followed by Canada, New Zealand, United States, United Kingdom and India.

EVALUATION DATA:

91% of Delegates thought the module was very effective to extremely effective at introducing Palliative Care concepts.

90% of Delegates thought the module highlighted very well to extremely well, key changes in a person with life threatening illness.

92% of Delegates thought the module was very effective to extremely effective at giving an overview of common symptoms experienced by dying people.

88% of Delegates thought the module was very helpful to extremely helpful to their clinical practice regarding common symptoms.

84% of Delegates thought the module delivered very useful to extremely useful information on grief and bereavement.

VICTORIAN END-OF-LIFE CARE COORDINATING PROGRAM



CARE PLAN
FOR THE DYING PERSON
VICTORIA

The Victorian End-of-Life Care Coordinating Program (VEC) supports the delivery of evidence-based person-centred care during a person's last days and hours of life, irrespective of their diagnosis or the involvement of palliative care services.

VEC does this by supporting organisations and health professionals to use evidence-based, person-centred and sustainable end-of-life care plans (EoLCP) in their care setting by providing them with clinical, educational and management resources.

This year, the Victorian End-of-Life Care Coordinating Program finalised the development of a suite of clinical and educational resources designed specifically for the Victorian acute healthcare sector.

The central clinical resources are an integrated, multidisciplinary care plan named the Care Plan for the Dying Person-Victoria (CPDP-Vic) and a consumer brochure that explains care provided during the final days and hours of a person's life.



The resources will be released to the sector in 2017 via a purpose built website (www.vec.org.au)

The website will provide health services access to a range of clinical resources, training materials and information aimed at improving the quality of care provided to imminently dying Victorians in our acute health care settings.

The VEC Program - with assistance from the eight regional Palliative Care Consortia - has begun raising awareness for these important resources across the state. Forums for key stakeholders, which introduce the resources and provide an overview of factors that contribute to a successful health service implementation, will be conducted throughout 2017.

The development and implementation of the CPDP-Vic resources has been funded by the Victorian Department of Health and Human Services. The Department encourages health services to implement the resources in alignment with the Victorian Government's End of Life and Palliative Care Framework and other relevant national accreditation, safety and quality standards.

Funding: Department of Health and Human Services, Victoria

VICTORIAN PALLIATIVE MEDICINE TRAINING PROGRAM (VPMTM)



VICTORIAN
PALLIATIVE MEDICINE
TRAINING PROGRAM

The VPMTM was established to provide a coordinated state-wide palliative medicine training program. It is funded by the Victorian Department of Health and Human Services and they have been building and sustaining a high quality palliative medical workforce since 2007.

2016 was an exciting year where a new format for the VPMTM Education Program commenced. It has a new venue and takes place fortnightly at the Royal Australian College of Physicians offices on St Kilda Road. All registrars in palliative care have protected study time to attend these 2.5hr sessions. Any other doctors who are interested in palliative care are also encouraged to attend.

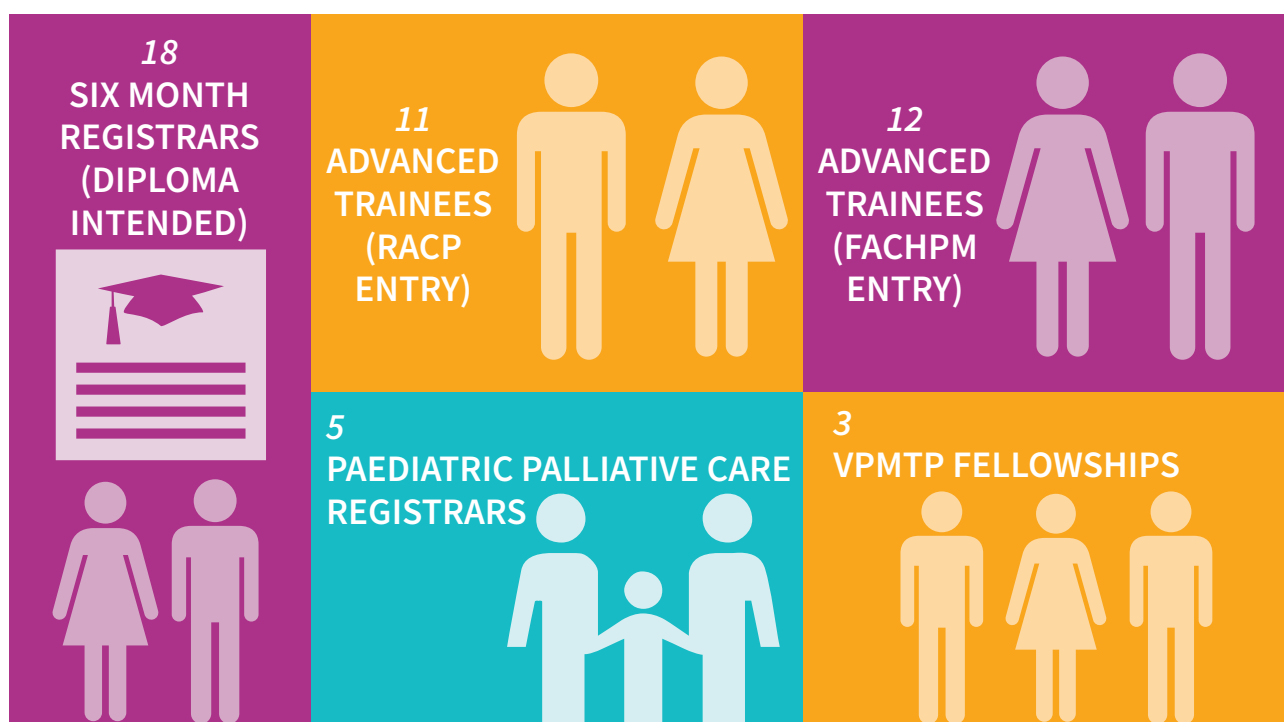
Two registrars commenced advanced speciality training in palliative medicine in Victoria. Upon completion, their intention is to become palliative care specialists.

Three doctors were admitted to Fellowship through the Chapter of Palliative Medicine. This followed three years of specialist training.

Sixteen doctors completed a six-month rotation of adult palliative care in 2016. Their intention is to use these skills in their chosen specialties; e.g. general practice, oncology and geriatrics.

In 2016, the VPMTM produced its first specialist in Paediatric Palliative Care. Dr Bronwyn Sacks has joined Associate Professor Jenny Hynson as the second physician working with the Victorian Paediatric Palliative Care Program.

Funding: Department of Health and Human Services, Victoria



THE PROGRAM OF EXPERIENCE IN THE PALLIATIVE APPROACH



The Program of Experience in the Palliative Approach

The Program of Experience in the Palliative Approach (PEPA) is a Commonwealth funded program and has been managed in Victoria by the Centre since January 2016. PEPA aims to enhance the capacity of the generalist health and aged care workforce to deliver a palliative care approach through their participation in either clinical placements in specialist palliative care services or interactive workshops.

There are three main elements to the PEPA program:

1. Workshops:

The PEPA program delivered 45 workshops attended by 795 people. One of the highlights of this extensive workshop program has been the introduction of palliative approach workshops for the acute healthcare sector. Seven tertiary level hospitals hosted a palliative approach workshop with 128 people attending. For the first time, PEPA collaborated with Victorian Aboriginal Community Controlled Health Organisation (VACCHO) in order to take their highly regarded Aboriginal and Torres Strait Islander cultural safety training program to regional areas. This was also the first year in which PEPA in Victoria offered, in conjunction with Palliative Care Victoria, culturally responsive palliative care workshops.



2. Placements:

PEPA arranged 111 placements for health practitioners across Melbourne and regional Victoria. A PEPA placement was also promoted for the first time to nurse practitioners, resulting in five aged care nurse practitioners undertaking a PEPA placement.

3. Post Placement Support:

PEPA took a new approach in the delivery of post placement support in 2016 as part of this revamped program. Post placement support workshops covering contemporary issues in palliative care were developed and delivered across metropolitan Melbourne and regional Victoria and all eight workshops were attended by 172 participants.

PEPA also offered - for the first time - the opportunity for previous PEPA participants to undertake an advanced practice workshop in pain management and symptom assessments - 78 participants registered for these two workshops.

Funding: Department of Health, Australia

OUR RESEARCH

Our researchers collaborate with other leaders - within Australia and overseas. We are continually contributing to the global evidence base by publishing results in peer reviewed journal articles and presenting findings at national and international conferences.

The focus of the Centre's research is on improving the outcomes of patients with a life-limiting illness and their families.

OUR THREE KEY PROGRAM AREAS ARE:

Psychosocial

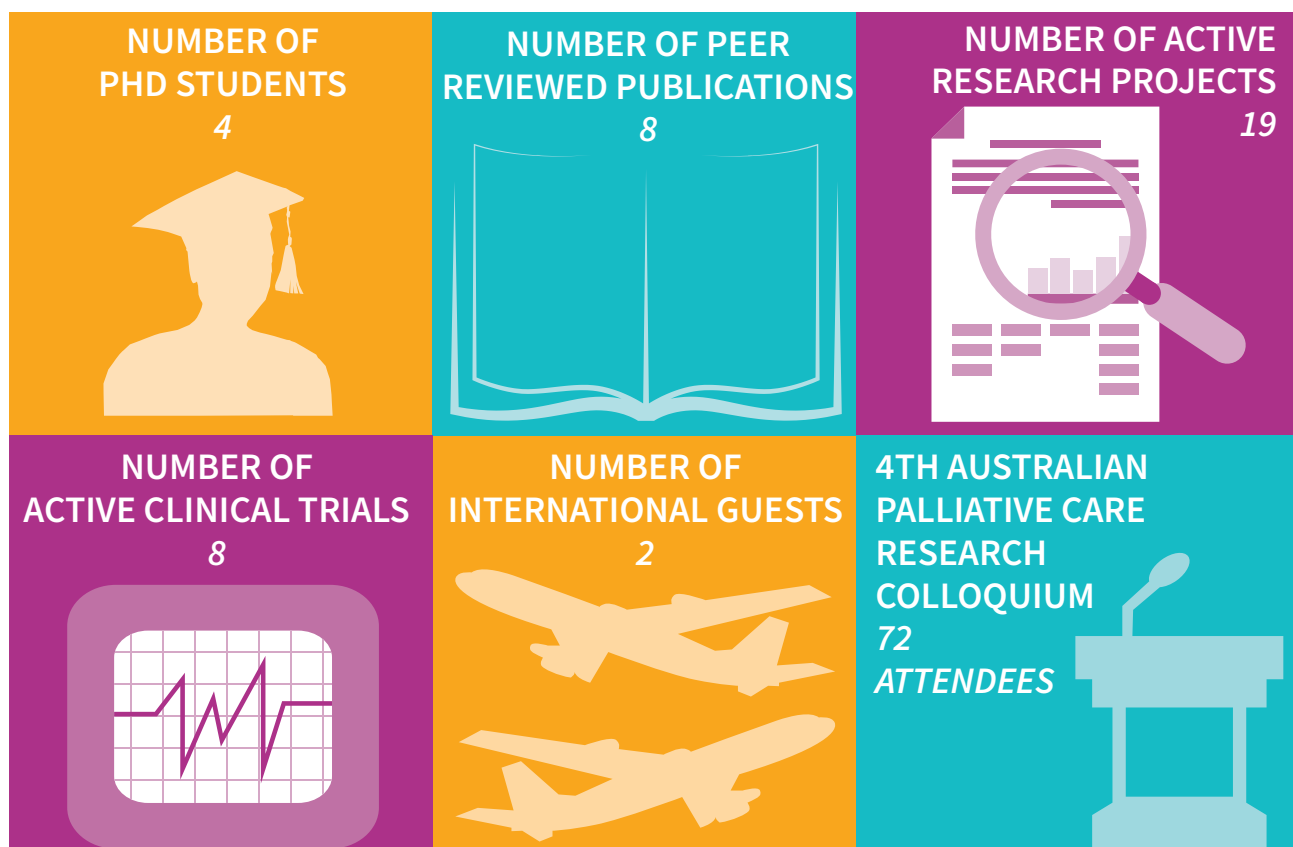
Being diagnosed and experiencing a life-limiting illness, or caring for a loved one in that situation, can have a wide ranging impact on the patients' and carers' physical and mental health, their ability to function on a day-to-day basis and their overall quality of life.

Health Services

The Centre's Health Services research assesses the current provision of palliative care. We develop and rigorously evaluate novel models of palliative care provision with the aim of improving patient outcomes.

Clinical Trials

The Centre's clinical trials research contributes to improved treatment and care of palliative care patients and their families. Our clinical trials research program takes a holistic approach to improving evidence-based palliative care practice.



FAMILY MEETINGS IN PALLIATIVE CARE: An essential tool for improving care and support for families

The Centre is leading a multi-site study to evaluate the benefits and resource implications of including structured family meetings as part of routine palliative care.

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

To date, over 260 participants have enrolled in the study across three metropolitan palliative care inpatient services. The study involves recruiting participants to either a control group (standard care) or intervention group (standard care plus structured family meeting). Data are collected during the patient's illness experience, and the family member is followed up two months after the death of their relative.

By collecting such comprehensive data over a significant period of time, we will be able to ascertain whether the introduction of a structured family meeting soon after referral to palliative care improves both the patient's care and family carer's wellbeing.



In order to deliver the intervention, over 20 clinical staff have been trained in conducting structured family meetings in accordance with the multidisciplinary guidelines that were previously developed by the Centre. We look forward to analysing the data and presenting the results of this large scale research trial.

Funding: Victorian Cancer Agency

Auspiced by: Palliative Care Research Network

THE BEREAVEMENT MODEL

Bereavement care is recognised as a national health care priority, and is an indicator of the quality of end of life care provided. Following a patient's death, family caregivers have an increased risk of physical and psychological morbidity, associated financial disadvantage and social isolation. Bereavement support can protect against these predisposed risks. While grief will typically resolve without specialist intervention, a significant proportion of people will continue to experience severe levels of psychological distress and/or symptoms indicative of complicated or prolonged grief for up to 13 months post bereavement.



Although quality standards exist, the enactment through a planned bereavement care model is lacking in most health services.

This represents an important public health issue, with Australian data indicating that up to 50% of deaths nationwide occur in acute hospitals, equating to approximately 75,000 deaths annually. At St Vincent's Hospital Melbourne (SVHM), over 900 people die annually while receiving care, demonstrating the need for appropriate SVHM focus to be given to bereavement care provision. Although bereavement support for family caregivers is a core function of the specialist palliative care provision, high demand and limited resources may limit the availability of support. In addition, approximately half of all deaths occur outside of the palliative care setting where there may not be standardised approaches to bereavement care. Given this background, we are in the process of developing an evidence based model of bereavement care for SVHM which may be applicable for other acute hospitals in Australia.

Funding: St Vincent's Hospital Melbourne Research Endowment Fund.

BEAMS STUDY: Breathlessness, Exertion And Morphine Sulphate

For many people, breathlessness can be a frightening and overwhelming problem that is challenging to treat. It often occurs while a person is resting or conducting a routine activity like showering or preparing meals. Evidence from a number of clinical studies suggests that a small, regular dose of morphine helps to reduce the sensation of breathlessness. However, research has not been carried out to show what the best dose of morphine is and which people are most likely to benefit from it.

The BEAMS study is conducted for participants with chronic obstructive pulmonary disease (COPD).

The important questions it aims to answer include:

- Are regular, low doses of morphine at four possible doses over three weeks more effective than placebo medication (containing no active ingredient) at improving breathlessness?
- Does increasing the dose in people who already are experiencing some benefit provide even greater reduction in their worst breathlessness experiences?
- Does the medication have any effect on daily activity and quality of life?
- What are the common or serious side effects of this intervention?
- Does the benefit from the medication outweigh the side effects it produces?
- Are there specific characteristics of people who are more likely to receive benefit from extended release morphine?

During this study, participants receive once daily extended-release morphine or a placebo, in addition to their usual medication for up to three weeks at increasing doses.

The CPC Clinical Trials Group is currently conducting and recruiting for a number of phase 2 and 3 multi-site studies. BEAMS is one example, and part of our collaboration with the Australian Palliative Care Clinical Trials Collaborative (PaCCSC), the world's first and largest national, multi-site phase III clinical trials group.



Funding: The Palliative Care Clinical Studies Collaborative (PaCCSC)

You can support us to continue our work

The Centre for Palliative Care's work in furthering our research and education in order to improve the care of people with a life-limiting illness relies on the generous support of the community. 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 <https://www.centreforpallcare.org/donations>

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.



Centre for Palliative Care
PO Box 2900, Fitzroy, Victoria, 3065
T: +61 9416 0000
E: centre.palliativecare@svha.org.au
W: www.centreforpallcare.org