



Calvary

Palliative and End of Life
Care Research Institute

ANNUAL REPORT 2017-2018

Calvary Palliative and End of Life Care Research Institute - about

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Palliative care patients and their families deserve the best possible care that we can give them.

This commitment underpins the establishment of the Calvary Palliative and End of Life Care Research Institute. Projects undertaken at the Institute address the whole arc of the palliative care experience for patients, their families and communities.

To offer the highest quality and safest palliative care we are committed to evidence-based approaches. Collaborations play a vital role in undertaking research and translating the results into practice.

The palliative care services across the Institute care for over 1,200 patients every year. In keeping with the holistic mission of palliative care we undertake research projects to improve the physical symptoms of people in our care and support their psychosocial and spiritual experience. Research undertaken by the Institute has real-world focus, addressing issues and concerns in the different settings that our patients and their families find themselves. Patients' experiences and outcomes are our central concern and we involve them in planning and undertaking our research.

We would like to extend our thanks to the patients, family members and staff from across all Calvary Palliative and End of Life Care Research Institute sites who kindly agreed for their images to be included in this annual report.

Message from Calvary's National Director of Hospitals

I wish to congratulate the researchers at the Calvary Palliative and End of Life Care Research Institute on their first Annual Report.

The Institute was established from the passion of our palliative care clinicians and researchers to deliver high quality, evidence-based care. It reflects the strategic intent of The Little Company of Mary Health Care to build respectful, collaborative relationships with patients, residents, clients, families and community partners from which we can grow compassionate, person centred models of care.

A collaborative framework for researchers from the four specialist palliative care services in Calvary's public hospitals further builds on the vision of clinical excellence founded in our Mission and Values. Partnering with others to anticipate future developments will enable us to be ready to respond to opportunities that will impact upon the communities which Calvary serves.

Research partnerships are of course vital to this process, and the studies in this Annual Report reflect the changing face of health care in our specialist palliative care services, hospitals and residential aged care facilities. Adapting to these changes requires vision and determination. Our researchers are well placed to draw from their clinical experience and possess the diverse knowledge to address national and international standards required to meet health and social needs now and in to the future.

Calvary is one of Australia's largest providers of specialist palliative care. Our 17 residential aged care facilities, 15 public and private hospitals, and 19 community care service centres, offer exciting opportunities and partnerships for the Institute in the areas of growth and development. The delivery of innovative research programs, and the effective and efficient use of our resources, will ensure high quality, evidence based palliative and end of life care to those in need.



Brenda Ainsworth

**National Director of Hospitals, Little
Company of Mary Health Care**

In its first year, the Institute has welcomed contributions from clinicians, academics, consumers and students, whose research and commitment truly reflects the desire to make a difference to patients, residents and clients in our care. Motivated by the spirit of Venerable Mary Potter in 'Being for Others', they have brought a diversity of skills, knowledge and passion to palliative and end of life care research. This inaugural Annual Report shows clearly that the future is bright in palliative and end of life care research at Calvary.

A handwritten signature in dark ink, appearing to read 'Brenda Ainsworth', written in a cursive, flowing style.

Brenda Ainsworth

Message from the Chair

It gives me great pleasure and a sense of purpose and achievement to present the inaugural Annual Report of the Calvary Palliative and End of Life Care Research Institute following its launch in 2017.

The Institute is 'virtual' in nature and connects clinicians and researchers across the four specialist palliative care units at Calvary Health Care Bethlehem, Victoria; Calvary Public Hospital Bruce, ACT; Calvary Mater Newcastle and Calvary Health Care Kogarah in NSW.

The Report highlights the important research conducted at these Calvary sites to manage the common symptoms experienced by our palliative care patients such as pain, nausea, breathlessness and delirium. Much of this innovative and ground breaking research is in collaboration with the Palliative Care Clinical Studies Collaborative. This program of research was initiated by palliative care clinicians here in Australia and is changing palliative care practice around the world.

There are also reports on psychosocial research that investigate the experiences of patients, their families and friends. Studies continue into family meetings, advance care planning, coping and distress along the illness trajectory and then after the death to explore grief, trauma, resilience and growth. Research into planning services, with a focus on particular groups such as those from culturally and linguistically diverse populations and the development of assessment tools, leads to better outcomes for those who come into our care.

Supporting people both living and dying at home is an aspect of palliative care that is greatly affected by social and demographic changes, as families and housing arrangements change, and people live longer, often with more illnesses and frailty. For many people, their place of care and death will be a nursing home - and there are very real challenges to ensure that the care that happens in nursing homes for people who are dying is of the highest quality, consistently. The award winning INSPIRED Project is one example of the ability of the Institute to translate important research outcomes across Sites through the sharing of information and resources.



Professor Liz Lobb

Chair, Calvary Palliative and End of Life Care Research Institute

Palliative care patients and their carers wish to contribute to the research agenda and play a role in the delivery of their health care. We welcome the contribution of consumers in developing our research studies. Increasingly, funding bodies seek out research collaboratives to engage and support and no longer is the single researcher working in isolation a focus. By building on Calvary's values of Hospitality, Healing, Stewardship and Respect the Institute has the ability to bring researchers together to share ideas and experiences, optimise funding, and deliver outcomes.

Calvary is committed to providing the best possible care to our patients, residents and clients, including those who are approaching and reaching the end of life. The Institute has an important role to play to ensure we are delivering evidence-based care in accordance with Calvary's mission and values, as well as national and international accepted best practice. Our goals are to place those people in our care and their families first; to ensure high quality, safe care; and to deliver innovative and integrated care. This first report of the Institute illustrates that with collaboration and goodwill, we can meet these goals now and into the future.

A handwritten signature in black ink that reads "Liz Lobb".

Liz Lobb



Palliative Care Clinical Studies Collaborative (PaCCSC)

The Palliative Care Clinical Studies Collaborative (PaCCSC) is an Australia-wide, member-based research network that aims to improve the wellbeing of people with life-limiting illnesses through:

- The generation of high quality research evidence to support effective palliative care clinical interventions including medications
- Building capacity within the health workforce in the conduct and understanding of high quality palliative care clinical research
- The translation of palliative care research results into clinical practice and policy.

The role of PaCCSC is to engage in high quality research that provides the evidence base to underpin and optimise quality healthcare practice for people with life limiting illnesses. PaCCSC research extends across a number of symptoms being: pain; nausea; breathlessness; fatigue; gut dysfunction; cognitive and neurological disorders and appetite and cachexia. These symptoms are commonly experienced by people with palliative and end of life care needs.

Clinicians across all four of Calvary's PEOLC Research Institute sites have PaCCSC members who are actively involved in PaCCSC studies. Calvary Health Care Kogarah has been recruiting to clinical trials since 2008, followed shortly thereafter by Calvary Mater. More recently, Calvary Health Care Bethlehem commenced the RAPID studies - a quality improvement program looking at the prospective use of medications and non-pharmacological interventions commonly used in palliative and supportive care. In 2018, Calvary Public Hospital Bruce commenced the BEAMS study, a clinical trial investigating low dose morphine for chronic breathlessness which is also open for recruitment at Calvary Health Care Kogarah.



Symptom Management



Symptom Management

There are a range of symptoms that people with advancing illness commonly experience including pain, delirium and breathlessness. A significant amount of research is underway to investigate these symptoms and improve their clinical management and prevention. Much of this research is led by the Palliative Care Clinical Studies Collaborative (PaCCSC). All four Institute sites have been involved in PaCCSC led studies during the past year.

Breathlessness

Breathlessness is a distressing symptom that people with lung disease such as lung cancer or chronic obstructive pulmonary disease (COPD) can experience. Calvary Health Care Kogarah, Calvary Mater Newcastle and more recently Calvary Bruce are participating in a study to understand if a low slow-release dose of morphine can help. Recruitment is ongoing and involves collecting information from carers on their experience of supporting someone who has chronic breathlessness. These sites are also participating in another study to investigate if low doses of morphine can also help with people who have breathlessness from lung disease, sometimes acquired in the workplace by exposure to asbestos.

Delirium

Delirium is a syndrome with one or more underlying physiological causes. It features changes in conscious level and cognition that can appear quite suddenly. Symptoms of delirium, including confusion and disorientation, loss of memory, restlessness, agitation, disorders of perception (for example hallucinations

- seeing or hearing objects which are not there) and illusions (mistaking objects), can range from mild to severe. Delirium can also affect a person's understanding and awareness, as well as their ability to communicate and interact with their environment. These symptoms can be very distressing for the patient and their family.

Prevention of delirium is more effective than trying to reverse it once it has occurred. The strongest evidence for prevention is through non-pharmacological strategies that support essential human needs, such as physical and cognitive activity, sleep, hydration, vision and hearing. Calvary Health Care Kogarah recently completed a pilot study to see if it is possible to involve staff, family members and volunteers in the introduction of strategies that are not drug related to prevent delirium among inpatients in the palliative care ward. A phase three clinical trial is also underway using Melatonin to see if this medication can help reduce the symptoms of delirium and assist researchers to better understand any associated side effects.

Medications for symptom management

Easing suffering is of primary importance in palliative care but the burden and potential harm from medications needs to be better understood in this setting to make sure that clinical prescribing does not inadvertently increase suffering and harm a person's ability to function.

Despite the wide use of medicines there is very limited information after drugs are registered for use in humans and rarely is there information available for the medications use in the palliative care population. Calvary Health Care Kogarah, Calvary Mater Newcastle and Calvary Health Care Bethlehem as participating sites in the PaCCSC RAPID Program have been collecting data to understand the net clinical effect (benefits and harms) of medications in the palliative population.



By collecting such information it is hoped to improve patient safety and reduce iatrogenic harms. This work is now being extended to include non-pharmacological nursing interventions. Investigators from Calvary Kogarah are helping to establish this work which will open the doors to other nursing interventions being studied in the future.

Calvary Mater Newcastle also undertook a study to explore the local experiences of people using cannabis for medicinal purposes.

Symptom Management studies include:

- Breathlessness, Exertion And Morphine Sulphate Study (BEAMS): A pragmatic, phase III, multi-site, double-blind, placebo controlled, parallel arm, dose increment randomised trial of regular, low dose extended release morphine for chronic refractory breathlessness
- MILD Dyspnoea Study: A prospective, randomised, placebo-controlled, double-blind, cross-over study of the efficacy of sustained-release low dose morphine in the subjective sensation of dyspnoea as a result of maximally treated mesothelioma or asbestosis or other causes of interstitial lung disease in opioid naïve participants
- Phase II (pilot) cluster randomised controlled trial of a multi-component multi-disciplinary non-pharmacological intervention to prevent delirium for hospitalised people with advanced breast cancer (PRESERVE Study)
- Randomised, double-blind, placebo-controlled phase III trial of oral melatonin for the prevention of delirium in hospital in people with advanced cancer
- RAPID Pharmacovigilance Studies: A prospective observational study – understanding the burden of adverse drug reactions and their impact on symptoms at end of life
- Cannabis Prevalence Study: Exploring the use of Cannabis for medicinal purposes in a Palliative Care population
- Randomised, double blind, placebo controlled phase III trial of oral melatonin for the prevention of delirium in hospital in people with advanced cancer



Residential Aged Care



Integrating specialist palliative care into residential care for older people

All Calvary services are committed to providing high quality palliative and end of life care. This includes acute hospitals, specialist palliative care, residential aged care and community services.

A 'palliative approach' is a term commonly used in residential aged care to describe this care, particularly the period closer to death. The primary aim of a palliative approach is to improve symptom management, comfort and function, and address the holistic needs of a person with a life limiting illness at the end of life. The applicability of a palliative approach and the provision of end of life care is increasingly relevant in aged care settings.

However, there are many barriers to delivering this care. These include limited palliative care capabilities (knowledge, skills and confidence) of staff and attending general practitioners, resource and funding limitations, and a lack of clarity around the roles of both primary and specialist palliative care providers in the delivery of this type of care. All of these factors impact on the capacity of residential aged care facilities to provide optimal care to dying residents. Given that the majority of residents of aged care facilities have high care needs and a proportion may require a hospital transfer, there is a need to develop systems and practices for end of life care particular to the residential aged care setting. The role of specialist palliative care to support this care is of particular interest to Calvary,

A number of initiatives are underway at several Calvary Palliative and End of Life Care Research Institute sites to implement and evaluate new models of care integrating specialist palliative care into residential aged care.

Development of a checklist

The first study sought to generate an evidence-based checklist to support the integration of specialist palliative care clinicians into residential aged care during palliative care needs rounds. Needs rounds are monthly clinical meetings that can help identify and prioritise care for people most at risk



for unplanned dying with inadequately controlled symptoms. The aim was to describe the activities, thought processes and subsequent staff activities that are generated within and from needs rounds, to develop a model that explains what occurs in needs rounds, and from that distil a checklist that can be used in routine practice. Finally, the checklist was developed drawing on feedback from staff in the collaborating residential aged care services.

Palliative Care Needs Rounds

This new model of care - the Palliative Care Needs Round, was then piloted across four residential aged care facilities, which identified residents who were approaching the end of their life and helped develop care plans for their final months. The results were promising - the checklist was found to reduce avoidable time spent in hospital by residents by 67 per cent. The team pictured above was awarded ACT's top award at the 2017 Quality in Healthcare Awards. The awards honour initiatives that are improving the delivery of safe, quality health services to the ACT community.

Gathering further evidence

Following the success of the early pilot study, the model was implemented and evaluated using a randomised control design in 12 residential facilities in the ACT; 1,700 residents were enrolled. The primary aim of the randomised trial is to reduce the time residents spend in acute care, with secondary outcomes focused on improving staff knowledge and confidence in palliative care, better controlled symptoms of people at end of life and increasing people's ability to die in their preferred place. Results are pending.



Care Kogarah with the potential for further translation at Calvary Health Care Bethlehem, as Calvary Research Institute sites continue to be inspired by the INSPIRED trial and related research that has also commenced in the ACT at Calvary Public Hospital Bruce. This research is being embraced across the Institute sites and there has been wide interest both nationally and internationally in this work. We are delighted and excited about the pending trial results and translation of this study, so keep an eye on the Institute's website in coming months for results as they are published.

Translating results

The translation of this research across Calvary Institute sites began with visits from Calvary Kogarah Community Palliative Care team to Canberra's Clare Holland House - Palliative Residential Aged Care team in July 2017. From these meetings came the sharing of ideas and replication of the model, driven by two palliative care nurse practitioners Josh Cohen and Carmen Sanchez pictured above. Some modifications were developed in order to meet particular local needs during implementation including support from a 0.6FTE residential aged care social worker. Cross site collaboration continues as a deeper understanding of the model of care grows with each Needs Round conducted. The checklist is now being incorporated into Palliative Care Needs Rounds facilitated in 11 residential aged care facilities by nurse practitioners at Calvary Health

Residential Aged Care studies include:

- Improving specialist palliative care in residential care for older people: A checklist to guide practice
- Integrating specialist palliative care into residential care for older people: A stepped wedge trial (INSPIRED trial)
- Integrating Palliative Care Needs Rounds into rural residential aged care: A mixed methods study



Caregiving



Caregiving

For specialist palliative care services, care of the family during the illness and death of the patient, as well as provision of bereavement support following that death, are an integral part of their mission. Several studies have been undertaken to understand the needs of carers during the caring phase but also into the bereavement phase after the patient's death.

Caring and high grade gliomas

Professor Liz Lobb at Calvary Health Care Kogarah has been an investigator on a program of research for the past 12 years with colleagues in Western Australia investigating the needs of carers of patients with high grade glioma (HGG, a type of brain cancer).

Studies on caring for patients with brain cancer conclude that relatives of these patients found caring 'overwhelmingly exhausting'. Care needs were high and were associated with sustaining hope, emotional support, managing symptoms and side effects, and accessing support and information.

The research team has previously reported that the top five unmet needs for carers of HGG patients at the time patients were receiving chemo-radiotherapy were: accessing prognostic information, accessing financial support and government benefits, accessible hospital parking, impact of caring on usual life and reducing stress in the patients' life. Recent work also demonstrated that carer distress and psychological morbidity (anxiety and depression) is highest close to diagnosis, but remains high over time, with distress and psychological morbidity being highly correlated. Following a Grant from Cancer Australia a nurse-led intervention to provide tailored information to carers and support is being tested at five Cancer Centres in NSW and WA.

Mapping grief

There is growing need to understand the impact of grief on family caregivers. It is known that, overall, caregivers are at significantly greater risk of getting sick or dying after the death of their spouse or family member. Bereavement issues demonstrated in the palliative care caregiver population include anxiety/depression, prolonged grief disorder, and demoralisation. Some situational factors, cognitions, and coping factors including pessimistic thinking, stressful life events in the life of the caregiver, pre-bereavement mental distress including depression and perceived lack of social support after the patient's death have been identified. Yet it is not known how to identify

those most vulnerable to poor bereavement outcomes, or whether and how palliative and supportive care services may be able to minimise these risks.

The Mapping Grief Study (led by Dr Jane Mowl) aims to understand the experiences of care, grief and adjustment of family members. Extensive interviews were undertaken over 22 months and questionnaires collected information on the symptoms of grief over this time. A second study is investigating the development of a risk assessment tool to identify carers who may be at risk of prolonged grief disorder.

Sleep and caregiving

Sleep disturbances have been noted as a common concern among many caregivers. Poor sleep not only affects caregivers' health and wellbeing, but also compromises their ability to provide effective care. Studies suggest 72-100% of caregivers of patients with advanced cancer have moderate to severe sleep disturbances. Significantly, this is almost double that reported in the general population. No studies have been undertaken in an Australian palliative care population.

A significant doctoral program of research is being undertaken at Calvary Kogarah, Sacred Heart Health Service and Hammond Care Greenwich Hospital to: a) explore the sleep of caregivers of Australian palliative care patients; b) identify the causes and consequences of sleep disturbances in this population; and c) understand the role of health professionals in identifying strategies to optimise caregivers' sleep. The study aims to inform approaches and interventions for health professionals to optimise caregivers' sleep.

Caregiving studies include:

- Confidence to Care: A multistate randomised controlled trial of structured nurse led, home based support and education for caregivers of people with high grade glioma
- Improving outcomes for bereaved individuals: A longitudinal study to develop an early risk identification tool
- The experiences of care, grief and adjustment for family members bereaved after a coronial or palliative care death: A mixed method longitudinal study
- Supporting the provision of care in the home: A trial of distance learning materials for informal palliative carers
- The SAC Study: Sleep in Australian Caregivers: Evaluating the sleep of adults caring for a person living with advanced cancer in the community: A mixed methods study

Culturally and linguistically diverse populations



Culturally and linguistically diverse populations

Rising population trends in ageing, chronic illness, and migration have significant implications for the provision of palliative care. These global trends have led to ageing populations within countries defined by growing cultural heterogeneity and numbers of people who do not speak the dominant language. The increase in these culturally and linguistically diverse (CALD) populations corresponds with growing recognition of the need for planning and delivery of palliative care services to address the needs of this patient group.

Palliative care teams are at the coalface of navigating the complex space of providing good end of life care and support to patients from CALD backgrounds.

A number of studies have been undertaken in this patient population.

Barriers to access

Using a chart audit methodology the clinical journeys of 100 patients from the specialist palliative care service at Calvary Kogarah were reviewed. These patients were from culturally and linguistically diverse backgrounds who had transitioned from acute care facilities to either community or inpatient care. Inpatient and community palliative care team members were also asked about their perceptions of providing care to this population.

Results showed that the overarching approach to providing care was that death is difficult in any language. This reflected a perception that concerns related to approaching the end of life were universal and that cultural and linguistic backgrounds need to be considered within individualistic care.

Understanding the role of palliative care

Research studies indicate that in most developing Asian countries, members of the public do not really understand the functions of palliative care. Based on traditional Chinese culture, elderly patients in terminal stages of illnesses are usually taken care



of by the family members, rather than relying on palliative care services. In Australia, Chinese migrants experience cultural and linguistic barriers in using mainstream healthcare services. Also, the topic of palliative and end of life care remains a taboo in Chinese culture, especially when death is not imminent. As such, the relevant information is often unknown to the Chinese Australians. A second study aimed to develop information and service strategies to improve the quality palliative service and end of life care for cancer patients and their families with Chinese background. Information sessions were held and participants' understanding of palliative care was canvassed by surveys. From this process information packs on palliative care in Cantonese and Mandarin languages were developed.



Understanding pain

Across cultures, pain is one of the most feared cancer symptoms and affects half of all cancer patients. Despite the availability of cancer pain management guidelines and effective analgesics, unrelieved cancer pain persists and remains a serious issue in Australia. Culture is one factor that can significantly influence patients' pain experience, coping behaviours and adherence to a recommended pain management plan. A project undertaken by a UTS PhD student explored Chinese migrants' perceptions of the influence of culture on their cancer pain management needs. The study also explored cancer and palliative care nurses' experiences and perceptions of Chinese migrants' cancer pain management needs. By conducting focus groups with patients and carers and sending surveys to nurses, insights were gained into the perceived barriers to achieving good pain control.

CALD population studies include:

- Identifying barriers to access to palliative care services at Calvary Health Care Kogarah by CALD communities
- Light in the Darkness: Information and Resources for Palliative Care Cancer Patients and Their Families with Chinese Background
- Chinese Migrants Cancer Pain Management Project (UTS PhD study)



Communication



Communication

Addressing conflict

Conflict is a significant and recurring problem in health care. Commonly identified causes or triggers of conflict include breakdown in communication, relatives' involvement in decision-making, patient and family mistrust of the healthcare system, religious beliefs and cultural differences about treatment goals, refusal of treatment and misunderstanding of prognosis.

Calvary Bruce undertook a study to understand staff and relatives' perspectives on the characteristics of conflict and disagreement in adult palliative care, including triggers, risk factors and the impact on themselves and clinical care. Participants from 52 family meetings completed pre/post questionnaires, and 13 relatives participated in an interview.

Communication was frequently cited as a cause of conflict. Further, different understandings regarding disease process, syringe drivers and providing nutrition and hydration caused conflict. Staff applied empathy to moderate their responses to conflict. Relatives' reactions to conflict followed a trend of anger or frustration followed by explanations or justifications of the conflict. Relatives identified systemic rather than interpersonal issues as triggering conflict.

The study concluded that family meetings may fruitfully be applied to prevent and de-escalate conflict. Clinical audits may be useful to identify and provide support to families where there may be unresolved conflict impacting grief processes.

Family meetings



Family meetings are increasingly used within palliative care, with guidelines directing practice to improve support to families. Family meetings are a structured

collaborative communicative approach to family support, involving discussions among clinicians, relatives, and patients. They have been shown to result in decreased distress for relatives and to facilitate discussing goals of care, diagnosis and management, and identifying the supports needed for relatives.

Investigating the role of empathy in family meetings

Calvary Bruce undertook a study to examine the role of relational empathy as an outcome of routinely held family meetings in a palliative care inpatient ward. They theorised that perceived empathy would be improved by family meetings. 25 staff and seven bereaved relatives from a multidisciplinary specialist palliative care setting were interviewed.

Families reported more empathy from staff after a family meeting. Some families with relatives who were not speaking with each other reported that meeting facilitators were unable to manage the pre-existing dynamics. The study concluded that family meetings improve reported empathy. It would be beneficial to have more specific preparation and planning by the clinical team for meetings with people who have a history of familial conflict, and those where the staff's agenda is around discharge planning. Published guidelines could be adapted to better support staff to run meetings where there are complex family dynamics. Adoption of family meetings in outpatient settings has the potential to improve perceptions of empathy with a larger patient group.

Patient-centred family meetings

Usually family meetings are initiated by health professionals and they set the agenda. Calvary Health Care Kogarah conducted a quality improvement project that took a different approach to family meetings. This project was designed to improve communication with patients and their families through a new approach of patient-centred family meetings.

This style of meeting creates an opportunity, with no clinician-determined agenda, for newly admitted patients and their chosen family members and supporters to meet the palliative care team, early in their first admission for inpatient palliative

care. In this model, the clinicians' task is to facilitate conversations about any issues the patient and/or family identify, assisting them to talk about the future as they wish, and then to hear, acknowledge, and where appropriate respond to patient and family concerns. The project found that patient-centred family meetings in palliative care are feasible and acceptable for staff, patients and family members. Many patients and families spontaneously shared end of life concerns.

The next stage of this project is the VOICE Study - Valuing Opinions, Individual Communication and Experience: Building the evidence base for undertaking patient-centred family meetings in palliative care: A mixed methods study.

Recruitment is underway at Calvary Kogarah, Sacred Heart Health Service and Hammond Care Greenwich Hospital.

This PhD student initiated project will determine the broader acceptability and feasibility of providing patient-centred family meetings in a specialist inpatient palliative care unit by comparing this new model with standard care. The study will help to further understand the benefits and burden of participating in family meetings from the patient, family and clinicians perspectives.



Patient reported outcomes

Understanding each individual's needs is central to palliative and end of life care.

One of the essential components of palliative care is 'Care is based on the assessed needs of the patient, carer and family'. Calvary Kogarah routinely collect satisfaction data from patients, but has little information

on their experience of care. Kogarah received a Grant from the Agency of Clinical Innovation to help understand our patients' experience of care and support in our specialist palliative care unit. Patient Reported Outcome Measures (PROMs) were administered when patients were discharged and the feedback received was used to inform future policy and models of care.

The Patient Dignity Question

Failure to acknowledge personhood is often the cause of patient and family dissatisfaction. The Patient Dignity Question was developed as a simple means of enquiring about personhood: "What do I need to know about you as a person to give you the best care possible?" It is based on the premise of whole person care -that we treat the whole person not just their disease.

A study eliciting personhood through the use of the Patient Dignity Question within clinical practice, and the effects on patients, families and health care providers (HCPs) found that 90% of HCPs indicated they learned something new from it; 64% that they were emotionally affected by it; 59% that it influenced their sense of empathy and 44% that it influenced their care.

In this study, during a brief 5 - 10 minute interview soon after admission to Calvary Health Care Kogarah, each patient is asked the dignity question. The patient's response is summarised and entered into the patient's record. Importantly, it is then integrated into patient care - it is shared at both the Interdisciplinary Meeting and at nurse handover, thereby directly influencing patient care.

Communication studies include:

- Translating the Palliative and End of Life Care Blueprint into practice in a specialist palliative care unit: A pilot study using patient reported outcomes
- Family Meetings in Inpatient Specialist Palliative Care: A Mechanism to Convey Empathy
- The Nature of Conflict in Palliative Care: A Qualitative Exploration of the Experiences of Staff and Family Members
- VOICE Study. Valuing Opinions, Individual Communication and Experience: Building the evidence base for undertaking patient-centered family meetings in palliative care: A mixed methods study

Planning



Planning

Validation of modified Life-Space Assessment for palliative care populations



The level and degree of engagement in the environment is an important consideration for palliative care patients whose ability to participate in society is influenced by a number of variables, such as: their symptom burden; degree to which their symptoms are managed; and their physical and functional capabilities.

Palliative care aims to minimise the impact of end of life symptoms, optimise physical functioning, and support people to engage with the activities they find meaningful for as long as possible. Being able to detect subtle changes in the degree to which patients receiving palliative care interact within their environment is an important outcome measure.

This study aims to validate a Palliative Care Life-Space Assessment (PC-LSA) for use in community dwelling palliative care populations using a short-time frame follow up.

Participants will be asked on a weekly basis to recall their movement over the past week. After four weeks, participants will be asked to recall their movement over the past month, using the expanded LSA. Assessing how reliably a palliative population can actually recall their movement over a 4 week period will help determine if the PC-LSA is sensitive enough to be reliably used with community palliative care populations using a shorter follow up, such as weekly or fortnightly as opposed to every four weeks.

Bereavement counselling outcome assessment tool

(The BOAT Study)



The effectiveness of bereavement counselling as determined by consumers accessing palliative care services has largely been determined anecdotally or by clinician-based review. However, these processes are generally variable and idiosyncratic, and cannot be applied beyond the individual context. Client ratings of the alliance are far better predictors of outcome than therapist ratings. Therapists, then, cannot assume that their evaluation of the quality of therapy correlates with their client's perception.

In the current consumer-based and inclusive healthcare climate it is essential to hear the voice of consumers on their experience of such services via a consultative process. This is particularly true in the area of bereavement counselling services in palliative care. However, this area lacks any evaluation tools for gathering such information in a systematic, routine and user-friendly manner.

This project seeks to develop a tool for evaluating outcomes of Calvary bereavement counselling services in the palliative care setting.

A standardised and validated tool will be a significant addition to palliative care practice in that it will provide outcome and process based information to assess the effectiveness of bereavement counselling services and to further develop bereavement counselling services – currently no such tool exists.

Preventing emergency department presentations

Multiple Emergency Department (ED) visits can be considered markers of sub-optimal care, and can cause distress to patients and carers. Studies of nursing home residents' use of EDs report high rates of admission, despite easy access to medical care, notably for pneumonia and urinary tract infections. This study seeks to understand why patients in receipt of specialist palliative care out-patient services attend the ED and to develop alternate care pathways. This is a mixed method study, with retrospective case-note audit of medical records combined with prospective qualitative data from clinician and patients. The study is highly likely to lead to a change in practice across the ACT in reducing preventable presentations to the ED.



Ambulance Care Plans

Authorised care plans are provided by NSW Ambulance for individual patients who require care that is outside standard NSW Ambulance protocols. A specific type of authorised care plan has been developed for patients with palliative care needs (Ambulance Palliative Care Plans or APCPs). They are intended to support paramedics' decision-making when called to attend palliative care patients in crisis, documenting pre-determined and agreed palliative and end of life wishes, for instance if patients want to die at home. They potentially provide a link between home and hospital in the advance care planning

process. APCPs aim to allow patients to receive care at their chosen location wherever possible, thereby reducing unnecessary and avoidable ED presentations, and burdensome or inappropriate treatments. APCPs allow treating clinicians to document a plan for patients who would not benefit from or do not wish to have cardio-pulmonary resuscitation.

The APCPs communicate these wishes to attending paramedics who would otherwise be expected to perform life-saving measures. Funded by the Australian Government, DIISR Collaborative Research Network through the University of Notre Dame we evaluated the acceptability of these plans for patients, caregivers and clinicians, and patients' experiences of decision-making associated with putting a plan in place.

Supporting end of life discussions in rural and remote Australia

Calvary Public Hospital Bruce is working with Palliative Care Australia (PCA) and the Royal Flying Doctors Service (RFDS) to undertake a pilot project on end of life care planning in RFDS clinics. This study will investigate patients' and health professionals' satisfaction with and acceptability of tools and resources developed specifically for the project from the well known Dying to Talk initiative.

Planning studies include:

- Validation of Modified Life-Space Assessment for palliative care populations
- Bereavement Counselling Outcome Assessment Tool (The BOAT Study)
- Preventable presentations at Emergency Departments by patients receiving specialist out-patient palliative care in the Australian Capital Territory
- Supporting end of life discussions in rural and remote Australia
- A study of the impact of Ambulance Palliative Care Plans on patterns of care, treatment and hospitalisation, and on palliative care patients' and caregivers' experiences of crisis
- Dying to talk: Advance care planning for people with dementia
- Specialist palliative care clinicians' and health service managers' perceptions and experiences of opioid errors within their service: A mixed methods study (The PERISCOPE Study)

Palliative Neurological



Palliative Neurological Research



Calvary Health Care Bethlehem (CHCB) is the site of the Statewide Progressive Neurological Diseases Service (SPNDS) and, as such, receives referrals from across Victoria to provide care for people living with complex progressive neurological diseases.

A core activity of SPNDS is ongoing research into progressive neurological diseases. CHCB is a leader in research into complex neurological disorders, particularly Motor Neurone Disease (MND) and Huntington's Disease (HD). Research activities have focused on both clinical trials of potentially disease modifying agents as well as qualitative projects that have examined the impact of disease on both patients and caregivers. More recently, collaborative projects have focused on specific end of life care for people living with progressive neurological diseases.

Dr Susan Mathers has led the neurological research at CHCB for nearly 30 years. Current trials include a range of Phase 1 through to Phase 3 clinical international trials evaluating the use of agents that may slow progression of diseases including MND and HD.

More recently, some research projects have focused on the unique needs that people living with progressive neurological diseases face as they approach the end of life.

Current collaborations include a project exploring the process of decision-making for people living with MND. This project aims to examine the impact that

progressive communication and cognitive deficits have on a person's ability to actively engage in decision-making over time. The project is a mixed methods study and involves progressive interviews with patients and carers.

Other current and developing projects include: exploring the end of life care wishes and concerns for people with Huntington's disease and their carers; detailed clinical audit exploring the terminal phase for people with MND; exploring the symptoms and needs of people with advanced multiple sclerosis and evaluating the impact of referral to a neuro-palliative clinic for this group of patients.



The team of new and established researchers based at CHCB are committed to ongoing collaboration to further explore and define the unique challenges faced by people with progressive neurological diseases as the illness progresses. The team hope to be able to find new and effective ways to deliver targeted neuro-palliative care to this vulnerable group of patients in order to maximise quality of life.

Palliative Neurological studies include:

- Motor Neurone Disease: What happens in the terminal phase of the illness? A retrospective, inpatient, clinical audit
- Communication and decision-making in Motor Neurone Disease
- End of life wishes and concerns for people living with Huntington's Disease and their caregivers

Institute Research Activity by site

The Calvary Palliative and End of Life Care Research Institute includes four lead sites which are each engaged in clinical research in addition to quality improvement, service development and more. The Academic Research Units (Calvary Public Hospital Bruce and Calvary Health Care Kogarah) have formal relationships in place with one or more local universities as well as dedicated research positions and a professorial position. Other clinicians also lead and conduct research in addition to their clinical work. At the Clinical Research Units (Calvary Health Care Bethlehem and Calvary Mater Newcastle), clinicians also have formal relationships with local universities however they do not have designated research positions. At these sites, clinicians lead and conduct research on top of their usual clinical load.



Academic Research Centres

Calvary Public Hospital Bruce



About our Researchers



Professor Nicholas Glasgow - Emeritus Professor at the Australian National University. Acting Head of the Calvary Centre for Research in Palliative Care

Research interests: health service research in palliative care and clinical research particularly through the PaCCCS network and BEAMS study. **Inspiration:** a conviction that good research leads to better health services, better patient care, and better outcomes for people and populations.



Liz Forbat - Professor Palliative Care (Allied Health)
Head of the Calvary Centre for Research in Palliative Care to May 2017

Liz Forbat was a foundation member of the Research Institute. She is an experienced psycho-oncology researcher and clinician specialising in palliative care. Liz has recently returned to the UK and her contribution to the Institute continues.



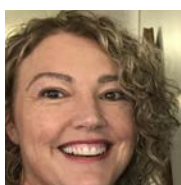
Dr Suharsha Kanathigoda - Medical Director Palliative Care ACT & CHH
Site Investigator

Research interests: Suharsha is actively developing research capacity within Clare Holland House, with a specific focus on the PaCCSC BEAMS and RAPID studies, and the further development of multidisciplinary research within the service.



Dr Suzanne Rainsford - Palliative Medicine Specialist, General Practitioner
Site investigator; Research Fellow at the Australian National University

Research interests: Suzanne is an accomplished qualitative researcher and continues to build on her work looking at “good death” in rural settings, as well as actively contributing to the BEAMS study. **Inspiration:** Good research can make a difference to the end of life experience. And, it's fun!



Nikki Johnston - Palliative Care Nurse Practitioner
Site Investigator

Research interests: Integrating specialist palliative care into residential aged care. **Inspiration:** Examining the impact of trauma on people living with life limiting illness and collaborating with others.

Other clinicians and health professionals involved in research in 2017-2018 included:
Julie Kulikowski, Mary Waterford and Pip Davies.

Research Activity 2017/18

Research Studies

Integrating Specialist Palliative Care into residential care for older people; A Stepped wedge trial (INSPIRED)

Johnstone, N., Lovell, C., Parker, D., Agar, M., Forbat, L., Lam, L., Liu, W., Chapman, M.

Dying to Talk in the Bush

Glasgow, N., Rainsford, S., Kanathigoda, S.,

Literature search looking for research already published around empathic distress, compassion fatigue and resilience in health professionals

Waterford, M.

Rural RAC needs rounds

Rainsford, S., Johnson, N., Liu, W., Glasgow, N., Forbat, L.

Individualised gym program for inpatient palliative care patients for fatigue levels and functional status

Davies, P.

Preventable presentations at Emergency Departments by patients receiving specialist out-patient palliative care in the Australian Capital Territory

Forbat, L., King, S., Maher, K., Chapman, M., Ranse, K., Kamrani, S.

Family meetings in in-patient specialist palliative care: A mechanism to convey empathy

Forbat, L., Francois, K., O'Callaghan, L., Kulikowski, J.

The nature of conflict in palliative care: A qualitative exploration of the experiences of staff and family members

Francois, K., Lobb, E.A., Barclay, S., Forbat, L.

Publications

Carolan, C., Smith, A., Davies, G., Forbat, L. (2018). Seeking, Accepting and Declining Help for Emotional Distress in Cancer: A Systematic Review and Thematic Synthesis of Qualitative Evidence *European Journal of Cancer Care* 2, doi: 10.1111/ecc.12720

Chapman, M., Johnston, N., Lovell, C., Forbat, L., Liu, W. (2018). Avoiding costly hospitalisation at end of life: Findings from a specialist palliative care pilot in residential care for older adults *BMJ Supportive and Palliative Care* 8, 102 - 109 doi: 10.1136/bmjspcare-2015-001071

Forbat, L., Robertson, J. and McNamee, P. (2018) Couple therapy following prostate cancer surgery: A manual to guide treatment *Journal of Family Therapy* 40, 86 - 110 doi: 10.1111/1467-6427.12129

Rainsford S., MacLeod R.D., Glasgow N.J., Wilson D.M., Phillips C.B., Wiles R.B. (2018). Rural residents' perspectives on the rural 'good death': a scoping review *Health and Social Care in the Community* 26, 273-294 doi: 10.1111/hsc.12385

Rainsford S., Glasgow N.J., MacLeod R.D., Neeman T., Phillips C.B., Wiles R.B. (2018). Place of death in the Snowy Monaro region of New South Wales: A study of residents who died of a condition amenable to palliative care *Australian Journal of Rural Health* 26, 126 - 133 doi: 10.1111/ajr.12393

Rainsford S., Phillips C.B., Glasgow N.J., Macleod R.D., Wiles R.B. (2018). Dying at home in rural residential aged care: A mixed-methods study in the Snowy Monaro region, Australia *Health and Social Care in the Community* doi: 10.1111/hsc.12583

Du, W., Glasgow, N., Smith, P., Clements, A., Sedrakyan, A. (2018). Major inpatient surgeries and in-hospital mortality in New South Wales public hospitals in Australia: A state-wide retrospective cohort study *International Journal of Surgery* 50, 126 - 132 doi:10.1111/hsc.12583

Rainsford, S., Phillips, C., Glasgow, N.J., MacLeod, R.D., Wiles, R.B. (2018). The 'safe death': An ethnographic study exploring the perspectives of rural palliative care patients and family caregivers. *Palliative Medicine* doi: 10.1177/0269216318800613

Forbat, L., Chapman, M., Lovell, C., Liu, W., Johnston, N. (forthcoming) (2017). Improving specialist palliative care in residential care for older people: a checklist to guide practice. *BMJ Supportive and Palliative Care* 8, 347 - 353 <http://dx.doi.org/10.1136/bmjspcare-2017-001332>

Forbat, L., Robinson, R., Bilton-Simek, R., Francois, K., Lewis, M., Haraldsdottir, E. (2017). Distance education methods are useful for delivering education to palliative caregivers: A single arm trial of an education package (PrECEPT) *Palliative Medicine* 2, 581 - 588 doi: 10.1177/0269216317712849

Francois, K., Barclay, S., Lobb, E., Forbat, L. (2017). The Nature of Conflict in Palliative Care: A Qualitative Exploration of the Experiences of Staff and Family Members *Patient Education and Counselling* 8, 1459 - 1465 doi: 10.1016/j.pec.2017.02.019

- Forbat, L., Kunicki, N., Chapman, M., Lovell, C.** (2017). How and why are subcutaneous fluids administered in an advanced illness population: A systematic review *Journal of Clinical Nursing* 9(10), 1204 - 1216 doi: 10.1111/jocn.13683
- Forbat, L., Simons, J., Sayer, C., Davies, M., and Barclay, S.** (2017). Training paediatric health care staff in recognising, understanding and managing conflict with patients and families: Findings from a survey on immediate and six-month impact *Archives of Disease in Childhood* 102(3), 250-254 doi: 10.1136/archdischild-2016-310737
- Rainsford S., MacLeod R.D., Glasgow N.J., Phillips C.B., Wiles R.B., Wilson D.M.** (2017). Rural end of life care from the experiences and perspectives of patients and family caregivers: A systematic literature review *Palliative Medicine*, 31, 895 - 912 doi: 10.1177/0269216316685234

Book Chapters

Rainsford S. 2018 Palliative care in rural settings *Textbook of Palliative Care* MacLeod R.D., Van den Block, L. Springer p1-15

Presentations

Rainsford, S. & Phillips, C.B. An interview is not a consultation: The dual role of clinician-researcher. Lessons from an ethnographic study exploring rural patients and family caregivers' perspectives on the 'good death' 22nd International Congress on Palliative Care, Montreal Canada Oct-18 Oral presentation of qualitative work arising from PhD thesis exploring patient and carer perspectives on good death in a rural setting.

Conference Posters

Rainsford, S., Glasgow, N.J., Phillips, C.B., MacLeod, R.D., Wiles R.B. (2018). The influence of rural culture on place of death: An ethnographic study exploring the experiences of patients and family caregivers 22nd International Congress on Palliative Care, Montreal Canada.

Rainsford, S., Glasgow, N.J., Phillips, C.B., MacLeod, R.D., Wiles R.B. (2018). Dying in a safe place is more important than dying at home. An ethnographic study of rural patients and family caregivers. 10th World Research Congress of the European Assoc. of Palliative Care, Bern, Switzerland.

Rainsford, S., Phillips, C.B., Glasgow, N.J., MacLeod, R.D., Wiles R.B. (2018). "This is Mum's home now". Residents' and families' experiences on dying in rural residential aged care 10th World Research Congress of the European Assoc. of Palliative Care, Bern, Switzerland.

Rainsford, S., Phillips, C.B., Glasgow, N.J., MacLeod, R.D., Wiles R.B., Wilson D. (2017). Place of death does not determine the 'good death' for rural family caregivers. An ethnographic study. European Assoc. of Palliative Care Congress, Madrid, Spain.

Rainsford S., Glasgow N.J., MacLeod R., Phillips C., Neeman T., Wiles R. (2017). "I want to stay home and die on the farm." The actual place of death in a rural setting. European Assoc. of Palliative Care Congress, Madrid, Spain

Committees

Professor Nicholas Glasgow

RACP Curriculum Advisory Group
Member (For AChPM)

Australian Pharmacy Council
Councillor

Review of Medical Intern Training Steering Committee Member

Canberra Region Medical Education Council Member

External Ministerial appointment ACT Minister of Health

ACT Palliative Care Clinical Network Member

PaCCSSC Member

Dr Suzanne Rainsford

McGrath Foundation, Expert Reference Group - Breast Cancer Nursing Model of Care Member

Advisory Group; Palliative and end of life care in southern NSW. Co-ordinaire Primary Care Network Member

Expert Reference Group; Project to develop a palliative care bereavement support model 2017-2018. Southern NSW Local Health District Member

PaCCSSC Member

Dr Suharsha Kanathigoda

PaCCSSC: Member

PaCCSSC in Calvary/CHH: Principal Site Investigator

ACT Palliative Care Clinical Network: Member

Life Extinct Certification ACT wide working group: Member

RACP regional committee NSW/ACT: Deputy Chair

Chapter of Palliative Medicine: representative in the RACP regional Committee in NSW/ACT

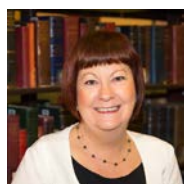
Shanthi Foundation Australia: Founder & Chairman

Academic Research Centres

Calvary Health Care Kogarah



About our Researchers



Professor Liz Lobb - Professor of Palliative Care (Allied Health)

Head of Research, Calvary Health Kogarah, Adjunct Professor; University of Notre Dame, Sydney and University of Technology, Sydney.

Research Interests: Loss, grief and bereavement in carers, in particular prolonged grief disorder.

Inspiration: Participating in research that translates directly to patient care and support for carers; supporting clinical staff to turn their clinical questions into a research concept and watching the next generation of PhD and Masters students flourish.



Dr Caitlin Sheehan - Palliative Care Physician

Site investigator PaCCSC.

Research Interests: Symptom management in palliative care; research at very end of life; consent in palliative care. **Inspiration:** To improve overall end of life care for patients



Dr Safrina Thristiawati - Senior Research Officer

Researcher and data analyst for PEoLC Research

Research Interests: Psycho-social-cultural dimensions of palliative and end of life care. **Inspiration:** Providing equal opportunity for patients with terminal illnesses and their carers for optimum quality of life



Ruth Dunleavy - Registered Nurse

Clinical Trials Nurse

Coordinating clinical studies including recruiting patients on to trials, supporting them through the clinical trial process, collecting data, ongoing liaison with regulatory bodies and Ethics Committees, submission of new clinical trial protocols.

Research Interests: Clinical and nursing issues in palliative care. **Inspiration:** A drive to improve our knowledge base in palliative care and hence our quality of care.

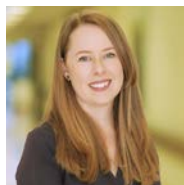


Dr Chris Sanderson - Palliative Care Physician

Site Investigator

Research Interests: Patient and family experiences of end of life care, bereavement outcomes for families of palliative care patients. Health care team decision-making.

Inspiration: The patients and the families that I care for inspire me. My colleagues in palliative care inspire me. The opportunity to improve the experience of people who are dying and to give them some choices and control.



Kristin Bindley - Research Officer

Recruitment, data management and initial analysis for the Mapping Grief Study

Research Interests: Bereavement, social and structural inequity, public health approaches to palliative care. **Inspiration:** To increase understanding of experiences of marginalised populations in the context of end of life care and bereavement.

Other clinicians and health professionals involved in research in 2017-2018 included:

Dr. Jane Mowll, Dr. Jan Maree Davis, Dr. Jodie Ellis, Jane Graham, Carmen Sanchez, Josh Cohen, Kirstin Maltby, Philippa Cahill, Mei Lau, Natalia Jerzmanowska, Margo Green, Ann Johnson, Erin Thompson

Research Activity 2017/18

Research Studies

Research participation by older people with impaired decision-making capacity: a scoping review of consumers' perspectives and experiences

Hosie, A.; Kochovska, S., Ries, N., Caplan, G., Agar, M., Gilmore, I., Sheehan, C., Parker, D., Sinclair, C., Collier, A., Visser, M., Xu, X., Chye, R., Lobb, E.A., Sheahan, L., Brown, L., Lee, W., Sanderson, C., Amgarth-Duff, I.

Funding: SPHERE-AAA-CAG

A cross-sectional study to identify the supportive care and health literacy needs of cancer patients undergoing chemotherapy treatment in a private cancer centre.

Monterosso, L., Lobb, E.A., Bulsara, M. Funding: Australian Government, DIISR Collaborative Research Network, University of Notre Dame

Confidence to Care: A multistate randomised controlled trial of structured nurse led, home based support and education for caregivers of people with high grade glioma

Halkett G.K.B., Nowak A, Lobb E.A., Agar M., Miller L., Moorin R., Shaw, T.

Funding: Cancer Australia

The effect of a nurse-led haematology survivorship clinic on patient reported anxiety and unmet informational needs : A multi-site Phase II randomised controlled trial

Monterosso, L., Lobb, E.A., Bulsara, M.

Funding: Australian Government, DIISR Collaborative Research Network, University of Notre Dame

Translating the Palliative and End of Life Care Blueprint into practice in a specialist palliative care unit: a pilot study using patient reported outcomes

Lobb, E.A., Graham, J., Lau, M., Davis J. M.

Palliative Care: Translating evidence into action to improve outcomes for palliative care patients and their care givers

Phillips, J., and Lobb E.A., Funding: Australian Government, DIISR Research Collaborative Research Network University of Notre Dame

A study of the impact of Ambulance Palliative Care Plans on patterns of care, treatment and hospitalisation, and on palliative care patients' and caregivers' experiences of crisis

Sanderson, C., Lobb, E.A. Funding: Australian Government, DIISR Collaborative Research Network, University of Notre Dame

Phase II (pilot) cluster randomised controlled trial of a multi-component multi-disciplinary non-pharmacological intervention to prevent delirium for hospitalised people with advanced breast cancer

Agar, M., Hosie, A.M., Davis, J.M. et al

Breathlessness, Exertion And Morphine Sulphate Study (BEAMS) A pragmatic, phase III, multi-site, double-blind, placebo controlled, parallel arm, dose increment randomised trial of regular, low dose extended release morphine for chronic refractory breathlessness

Sheehan, C (CI at Calvary Kogarah) PaCCSC

Randomised, double blind, placebo controlled phase III trial of oral melatonin for the prevention of delirium in hospital in people with advanced cancer.

Sheehan, C. (CI at Calvary Kogarah) PaCCSC

Light in the Darkness - Information and Resources for Palliative Care Cancer Patients and Their Families with Chinese Background.

Man, S., Graham, J.

The Life Space Validation Study Phillips, J, Sheehan, C

A pilot study of the implementation of a palliative care medical consultative service into RACFs in SESLHD

Davis, JM, Lobb, E.A., Graham, J.

Identifying barriers to access to palliative care services at Calvary Health Care Kogarah by CALD communities.

Lobb, EA, Green, M., Ellis, J.

Publications

- Green, A., Jerzmanowski, N., Green, M., Lobb, E.A.** (2018). Death is difficult in any language”: A qualitative study of palliative care professionals’ views on providing end of life care to patients from Culturally and Linguistically Diverse backgrounds. *Palliative Medicine*. 32(8) 1419-1427. Editor’s Choice – September 2018
- Green, A., Jerzmanowski, N., Thristiawati, S., Green, M., Lobb, E.A.** (2018). Culturally and Linguistically Diverse palliative care patients’ journeys at the end of life. *Palliative & Supportive Care* 1-7. <https://doi.org/10.1017/S1478951518000147>.
- Andriessen, K., Mowll, J., Lobb, E.A., Dudley, M., Draper, B., Mitchell, P.B.** (2018). “Don’t bother about me”. The grief and mental health of bereaved adolescents. *Death Studies*. 42(10), 607-615. <https://doi.org/10.1080/07481187.2017.1415393>
- Lobb, E.A., Schmidt, S., Jerzmanowska, N., Swing, A., Thristiawati, S.** (2018). Patient Reported Outcomes of Pastoral/Spiritual Care in a Hospital Setting. *Journal of Health Care Chaplaincy*. <https://doi.org/10.1080/08854726.2018.1490059>
- Andriessen, K., Lobb, E.A., Mowll, J., Dudley, M., Draper, B., Mitchell, P.B.** (2018). The help-seeking experiences of bereaved adolescents. *Death Studies*. <https://doi.org/10.1080/07481187.2018.1426657>
- Phillips, J., Lobb, E.A., Piza, M., Austin, P., Mohacsi, P., Currow, D.** (2018). Identifying systems barriers that may prevent bereavement service access to bereaved carers: A report from an Australian specialist palliative care service. *Collegian* 25 39-43 doi: <https://doi.org/10.1016/j.colegn.2017.03.004>
- Green, A., Jerzmanowski, N., Green, M., Lobb, E.A.** (2018). “Death is difficult in any language”: A qualitative study of palliative care professionals’ views on providing end-of-life care to patients from Culturally and Linguistically Diverse backgrounds” *Palliative Medicine*, 32(8), 1419-1427. Editor’s Choice – September 2018
- Green, A., Jerzmanowski, N., Thristiawati, S., Green, M., Lobb, E.A.** (2018). Culturally and Linguistically Diverse palliative care patients’ journeys at the end-of-life. *Palliative & Supportive Care*, 1-7. <https://doi.org/10.1017/S1478951518000147>
- Stomski, N., Petterson, A., Kristjanson, L., Lobb, E.A., Phillips, M., Williams, A., Morrison, P., Joske, D.** (2018). The Effect of Self-Selected Complementary Therapies on Cancer Patients’ Quality of Life and Symptom Distress: A Prospective Cohort Study in an Integrative Oncology Setting. *Complementary Therapies in Medicine*, 37, 1-5
- Snowden, A., Lobb, EA., Schmidt, S., Swing, A., Logan, P., McFarlane, C.** (2018). “What’s on your mind”. The only necessary question. *Journal for the Study of Spirituality*, 8(1), 19-33. <https://doi.org/10.1080/20440243.2018.1431031>
- Cahill, P., Philips, J., Lobb, E.A., Sanderson, C.** (2018). The VOICE Study Valuing Opinions, Individual Communication and Experience: Building the evidence base for undertaking patient-centered family meeting in palliative care: A mixed methods study. *Pilot and Feasibility Studies*, 4(51). doi: 10.1186/s40814-017-0225-9
- Halkett, G.K.B., Lobb, E.A., Miller, L., Shaw, T., Moorin, R., Long, A., King, A., Clarke, J., Fewster, S., Nowak, N.K.** (2017). Do carer’s levels of unmet needs change over time when caring for patients diagnosed with high grade glioma and how are these needs correlated with distress? *Supp. Care in Cancer*. 26(1), 275-286
- Sanderson, C., Johnson, A., Cahill, P., Phillips, J., Lobb, E.A.** (2017). Patient-centered family meetings in palliative care: Exploring a different approach to communication with patients and families at the end of life. *Annals of Palliative Medicine*, 6(2), 195-205. doi: 10.21037/apm.2017.08.11
- Maltby, K., Sanderson, C., Lobb, E.A., Phillips, J.** (2017). Investigation of sleep disturbances in caregivers of advance cancer patients: A systematic review. *Palliative & Supportive Care*, 15, 125-140
- Hosie, A.M., Agar, M., Lobb, E.A., Davidson, P., Phillips, J.** (2017). Improving delirium recognition and assessment for patients receiving palliative care: A mixed-methods meta-synthesis. *International Journal of Nursing Studies*, 75, 123-129
- Monterosso, L., Lobb, E.A., Krishnasamy, M., Yates, P., White, K.** (2017). Living with multiple myeloma: A focus group study of concerns and unmet needs. *Journal of Patient Experience*, 1(10). doi: 10.1177/2374373517715011
- Monterosso, L., Taylor, K., Platt, V., Lobb, E.A., Krishnasamy, M., Yates, P., White, K., Johnson, C., Musiello, T., Bulsara, C., Stratton, K., Addiscott, T., Joske, D.** (2017). A qualitative study of the post-treatment experiences and support needs of survivors of lymphoma. *European Journal of Oncology Nursing*, 28, 62-68
- Francois, K., Lobb, E.A., Barclay, S., Forbat, E.** (2017). The Nature of Conflict in Palliative Care: A Qualitative Exploration of the Experiences of Staff and Family Members. *Patient Education & Counselling*, 100(8)1459-1465. doi: 10.1016/j.pec.2017.02.019

Halkett, G.K.B., Lobb, E.A., Miller, L., Shaw, T., Moorin, R., Long, A., King, A., Clarke, J., Fewster, S., Nowak, N.K. (2017). "Feasibility testing and refinement of a supportive educational intervention for carers of patients with high-grade glioma A pilot study" *Journal of Cancer Education*, doi:10.1007/s3187-017-1125

Halkett, G.K.B., Lobb, E.A., Shaw, T., Rogers, M., Miller, L., Hovey, E., Nowak, N.K. (2017). Distress and psychological morbidity does not reduce over time in carers of patients with high grade glioma. *Supportive Care in Cancer* 1(7), 25(3), 887-893. doi: 10.1007/s00520-016-3478-6

McSpedden, M., Mullan, B., Sharpe, L., Breen, L.J., Lobb, E.A. (2017) The presence and predictors of complicated grief symptoms in peri-natally-bereaved mothers from a bereavement support organization. *Death Studies*. 41, 112-117. doi: 10.1080/07481187.2016.1210696

Presentations

Lobb, E.A., Davis, J.M., Lau, M., Graham, J., Thristiawati, S. 'What do I need to know about you as a person to give you the best care possible?': Implementing the Patient Dignity Question into a specialist palliative care service. Palliative Care NSW Biennial State Conference, Kiama, November 2018

Lobb, E.A., Davis, J.M., Lau, M., Graham, J., Thristiawati, S. You don't know if you don't ask: A pilot study using patient reported outcomes in a specialist palliative care service. Palliative Care NSW Biennial State Conference, Kiama, November 2018

Sanderson, C., Comans, T., McPherson A., Lobb, E.A. The impact of ambulance palliative care plans on the use of services by community palliative care patients: A health economics assessment. Palliative Care NSW Biennial State Conference, Kiama, November 2018

Lobb, E.A. Bereavement: An update on complicated grief. Palliative Care Network EAPC – International Conference, November, 2017 (Invited speaker)

Lobb, E.A. Is home the ideal place of care and death? IPOS, Hong Kong, October/November 2018 (Invited Plenary speaker)

Halkett, G., Lobb, E.A., Phillips, J., Hudson, P., Miller, L., King, A., Clarke, J., McDougall, E., Attwood, R., Nowak, A. What support are carers requiring over time during nurse-led support provided as part of the Care-Is study? COGNO Scientific Meeting, Brisbane, October, 2018

McCormick, D, Halkett, G, Lobb, E.A., Clarke, J., McDougall, E., Attwood, R., Nowak, A. Exploring the carer's experience of looking after a person diagnosed with primary brain cancer: an exploration of carers' experiences during nurse-led phone interviews for the intervention 'Care-Is'. COGNO Scientific Meeting, Brisbane, October, 2018

Lobb, E.A. Palliative Care Services and a Good Death International Work Group on Death Dying and Bereavement, London, Ontario. June, 2018 (Invited speaker)

Agar, M., Hosie, A., Lobb, E.A. Workshop title: Delirium in people receiving palliative care. 12th Asia-Pacific Hospice Conference, Singapore, July 2017

Lobb, E.A. Research to Drive Change and Service Improvement. 12th Asia-Pacific Hospice Conference, Singapore, July 2017. Invited presentation

Lobb, E.A. Translating Research into Clinical Practice. Catholic Health Australia, Research Symposium, St. Vincent's Hospital, 30th June, 2017. Invited Presentation

Sanderson, C., Mowll, J., Bindley, K., MacLeod, R., Lobb E.A. "Death at home and the complex negotiation of "best care": Learning from the Supportive Palliative Care Packages (SPCP) in NSW. Palliative Care Australia Conference, Adelaide, 2017

Mowll, J., Bindley, K., Lobb, E.A., Sanderson, C. 'Like a groundhog day': A narrative perspective on multiple loss in the context of coping with grief". International Conference on Grief and Bereavement, Lisbon, Portugal, 12th July 2017

Mowll, J., Bindley, K., Sanderson, C., MacLeod, R., Lobb, E.A. 'Navigating the path to care and death: the experience of bereaved family carers in palliative care' International Conference on Grief and Bereavement, Lisbon, Portugal, 12th July, 2017

Mowll, J., Bindley, K., Sanderson, C., Lobb, E.A., Mowll, J., Bindley, K., Sanderson, C., MacLeod, R., The experience of viewing the body in the context of palliative care and death of a family member at home or hospital. International Conference on Grief and Bereavement, Lisbon, Portugal, 12th July, 2017

Mowll, J., Bindley, K., Sanderson, C, MacLeod, R., Lobb, EA. “You’ve got to integrate it into your life”: Growth and resilience in the context of expected and unexpected bereavement. European Association for Palliative Care, Madrid, Spain, 2017

Mowll, J., Bindley, K., Sanderson, C, MacLeod, R., Lobb, EA. ‘I’ll never stop having flashbacks of that for the rest of my life:’ Experiences of trauma in palliative care. European Association for Palliative Care, Madrid, Spain, 2017

Committees

Professor Liz Lobb

PaCCSC Cognitive and Neurological Disorders Symptom Node Sub-Committee Member

PaCCSC Qualitative Research Sub-Committee Member

Research & Ethics Committee - Calvary Health Care Kogarah Chair

Research Protocol Review Committee - Calvary Health Care Kogarah Chair

Cunningham Centre for Palliative Care – New Studies Working Group, Sacred Heart Hospice Member

ACI Palliative Care Network Executive Committee member

Bereavement Resource Working Group – ACI Member

Palliative Care Home Support & Education Steering Committee - HammondCare Member

Doctor Caitlin Sheehan

PaCCSC Scientific Committee Member

PaCCSC Trials Management Committee Member

PaCCSC Gastrointestinal disorders Symptom node subcommittee Member

PaCCSC Cognitive and neurological symptom node subcommittee Member

Clinical Research Centres

Calvary Health Care Bethlehem



About our Researchers



Dr Scott King - Palliative Care Specialist

Institute site lead

Research Interests: Community palliative care service provision and development.

Inspiration: To provide excellent care to our patients and to provide the evidence base to support that care is what drives me to develop the research capabilities of our service.



Dr Fiona Runacres - Palliative Care Specialist

Clinician and site investigator

Research Interests: include early integration of palliative care for patients with progressive neurological diseases, and exploring the perspectives of clinicians. **Inspiration:** Seeing how the discipline of palliative care has evolved, and the role that the increasing evidence base plays in this expansion and integration into traditional treatment models.



Dr Heidi Gregory - Palliative Care Physician

Clinician and site investigator

Research Interests: Residential aged care, Motor Neurone Disease, Huntington's Disease. **Inspiration:** Discovering innovative ways to deliver specialist palliative care to some of the most vulnerable groups of people living with life-limiting illness

Other clinicians and health professionals involved in research in 2017-2018 included:

Doctor Susan Mathers, Dr Alexandra Burke and Mark Heenan.

Research Activity 2017/18

Research Studies

The role of specialist palliative care in geriatric care: a knowledge, attitudes and practices survey, Runacres, F., King, S., Lustig, J., Ugalde, A.

Delirium prevalence, management and prevention in an inpatient palliative care unit Runacres, F., King, S., Heenan, M.

Communication and decision-making in Motor Neurone Disease. Paynter, C., Mathers, S., Gregory, H., Cruice, M., Vogel, A.

Publications

Bloomer, M., Botti, M., Runacres, F., Poon, P., Barnfield, J., Hutchinson, A. (2018) Communicating end of life care goals and decision-making among a multidisciplinary geriatric inpatient rehabilitation team: A qualitative descriptive study *Palliat Med ePub* 10.1177/0269216318790353

Bloomer, M., Botti, M., Runacres, F., Poon, P., Barnfield, J., Hutchinson, A. (2018) End of life care for older people in subacute care: a retrospective clinical audit *Collegian* 1(6) <http://dro.deakin.edu.au/view/DU:30108688>

Dredge, A., Oates, L., Gregory, H., King, S. (2017) Effective Change Management in an Australian Community Palliative Care Service *British Journal of Community Nursing* 22 536-541 10.12968.bjcn.2017.22.536

Runacres, F.I., William, L., Ingram, A., Franco, M., Yoong, J., Poon, P. (2017) Tuberculosis at the end of life *European Journal of Palliative Care* 24(1) 7-Oct

Yoong, J., Chandra, R. V., William, L., Franco, M., Goldschlager, T., Runacres, F., Poon, P. (2017) Percutaneous sacroplasty for painful bone metastases: A case report *Pain Practice* 7(7) 945-951

Runacres, F.I., Gregory, H., Ugalde, A. (2017) The horse has bolted I suspect: A qualitative study of clinicians' attitudes and perceptions regarding palliative rehabilitation *Palliative Medicine* 31(7) 642-650

Book Chapters

Yoong, J., Runacres, F. (2018). Trajectory of performance status and symptom scores for patients with cancer during the last six months of life - 50 Studies Every Palliative Care Doctor Should Know Hui, D., Reddy, A. & Bruera, E. New York Oxford University Press 51-56

Conference Posters

King, S., Sulaksana, T., Runacres, F., Curtis, C., Gregory, H. Opioid Rotation from Targin to OxyContin in Palliative Care Australian Palliative Care Conference (2017).

Runacres, F., Heenan, M., King, S. Delirium prevention, diagnosis and management in a palliative care unit: a point prevalence audit and key recommendations DECLARED delirium conference (2018).

Gregory, H., Hearn, R. Establishing a neuro-palliative clinic: Patterns, outcomes and what next? ANZSPM Conference (2018).

Paynter, C., Mathers, S., Gregory, H., Cruice, M., Vogel, A. Communication impairment and health care decision making in MND: a narrative review AUSMND conference (2018).

Committees

Dr Scott King

Palliative Care Australia - Clinical Advisory Committee

Palliative Care Clinical Network Victoria - Governance Committee

Palliative Care Clinical Network Victoria - Co-chair Anticipatory Medicine

Clinical Research Centres

Calvary Mater Newcastle



About our Researchers



Ludmilla Sneesby - Nurse Practitioner

Research interests: improving and supporting end of life care provision in residential aged care facilities as well as exploring ethical issues/challenges experienced in this setting. **Inspiration:** Always wanting to do the best for our patients, and being part of a process that drives ongoing improvement.



Naomi Byfieldt - Research Coordinator/Registered Nurse

Naomi spent 8 years coordinating Calvary Mater involvement in national, state and local palliative care research initiatives. Naomi's passion for her work has aided translating research projects into clinical practice. Naomi left Calvary in August 2018 for a new career direction.

Dr Rachel Hughes - Director and Staff Specialist

Research interests: value adding to community outreach palliative care service. Current initiatives include implementation of an outreach triage system to initiate early activation of relevant service disciplines to address patient need.

Dr Mark Mather - Staff Specialist

Research interests: developing and implementing telehealth palliative care clinic to support outlying areas of the local health district. This has now been operational since January 2018. **Inspiration:** seeing an idea become something tangible.

Dr Gareth Watts - Post Graduate Fellow

Gareth has been involved in supporting national research work (via PaCCSC) as well local service based projects looking at patient care issues. Gareth moved from Calvary in May 2018 to take up a palliative care consultant position.

Research Studies

Breathlessness, Exertion And Morphine Sulphate Study (BEAMS) dyspnoea study, PaCCSC

MILD dyspnoea study, PaCCSC

RAPID pharmacovigilance study, PaCCSC

Prevalence of cannabis for medicinal purposes in a palliative care population, Hayes, C., Byfieldt, N., Stabler, J.

A Review of Specialist Palliative Care in Residential Aged Care Facilities, Hayes, C, Byfieldt, N, Stabler, J

Consumer feedback - Bereavement support group, Harris, F

Implementing a triage process in SPC, Wallis J., Maher, J., Compton, V., Byfieldt, N.

Outreach and inpatient equipment storage and cleaning area re-organisation, Gleeson, J, Baird, E, Davis, J, Atkinson, J, Collins-Morgan, L., Bagley, B.

Seating options for hospice inpatients, Davis, J., Collins-Morgan, L., Bagley, B., Gleeson, J., Atkinson, N., Baird, E.

ADL equipment in hospice, Bagley, B., Davis, J., Gleeson, J., Collins-Morgan, L.

Pressure care equipment guidelines, Davis, J., Gleeson, J., Atkinson, N., Collins-Morgan, L.

Publications

Clark, K., Lam, L., Talley, N.J., Watts, G., Phillips, J.L., Byfieldt, N., Currow, D. (2018) A pragmatic comparative study of palliative care clinician's reports of the degree of shadowing visible on plain abdominal radiographs *Supportive Care in Cancer* 26 (11): 3749-3754

Glare, P., Watts, G., Louw, S., Martin, P., Clark, K., Agar, M., Fazekas, B., Currow, D. (2018) Management of anorexia in people with cancer. A randomised double blind, controlled trial of megestrol acetate, dexamethasone or placebo *Journal of Clinical Oncology* 36 (Supplement) Abstract 10020.

Currow, D., Watts, G.J., Johnson, M., McDonald, C.F., Miners, J.O., Somogyi, A.A., Denehy, L., McCaffrey, N., Eckert D.J., McCloud, P. (2017) A pragmatic, phase III, multisite, double-blind, placebo-controlled, parallel-arm, dose increment randomised trial of regular, low-dose extended-release morphine for chronic breathlessness: Breathlessness, Exertion And Morphine Sulfate (BEAMS) study protocol *British Medical Journal* 7(7) e018100

Lucas, C. J., Patel, J., Martin, J. H. (2017) Predicting drug interactions in addiction treatment *Internal Medicine Journal* 47(8) 872-878

Patel, J., Martin, J. H., Lucas, C. J. (2017) Comment on a paper by Dupoirion et al. A phase III randomized controlled study on the efficacy and improved bowel function of prolonged release (PR) oxycodone/naloxone (up to 160/80 mg daily) versus oxycodone PR *European Journal of Pain* 21(10) 1772-1773

Hourn, M.M., Quinn, R., Waller, A., Boyle, K., Jordan, L.A., Salaris, M., Byfieldt, N., Shaw, L., Marsden, D. (2017) Exploring current inpatient practice in transitioning people after stroke from acute to palliative care and in advance care planning: The Plan Assess Understand Survival after Stroke (PAUSE after Stroke) Project *International Journal Of Stroke* 12(23)

Clark, K., Willis, A., Byfieldt, N. (2017) An Observational Study to Explore the Feasibility of Assessing Bereaved Relatives' Experiences Before and After a Quality Improvement Project to Improve Care of Dying Medical Inpatients *American Journal of Hospice and Palliative Medicine* 34(3) 263-268

Presentations

Patel, J. Laxative use in inpatients on oxycodone/naloxone prolonged release and oxycodone prolonged release for cancer and non-cancer pain. ANZSPM Conference 2018. (Authors: Patel, J., Lucas, C., Margalit, M., Martin, J.)

Conference Posters

Watts, G., Byfieldt N., Compton,V., Wallis, J., Maher, J., Hughes, R. (2018). The Implementation and Evaluation of a multi-professional triaging process for referrals to a community specialist palliative care service. BMJ International Forum for Quality and Safety in Healthcare. Melbourne.

Poon, M., Byfieldt, N., Watts, G. (2018). Use of Prognostic tools in assessing eligibility for palliative home oxygen therapy. ANZSPM Conference, Sydney

Glare, P., Watts, G., Louw, S., Martin, P., Clark, K., Agar, M., Fazekas, B., Currow, D. (2018). Treating Anorexia in People with Advanced Cancer. A Randomised, Double Blind, Controlled Trial of Megestrol Acetate, Dexamethasone or Placebo. ASCO Annual Meeting. Chicago.

Hayes, C., Stabler, J., Byfieldt, N. (2018). Exploring the use of cannabis for medicinal purposes in a palliative care population. ANZSPM conference



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Continuing the Mission of the Sisters of the Little Company of Mary