

Research Report 2019



As an independent Christian charity, HammondCare champions life.



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2019 RESEARCH REPORT

Welcome and Foreword



As we write this, we find our world in the midst of a coronavirus pandemic, which has landed upon us unheralded. We are living in difficult and uncertain times, and now more than ever, medical research is paramount to solving the coronavirus puzzle and saving lives.

Researchers around the world are working collaboratively such as never before to document the timeline of the disease, develop and manufacture rapid testing kits, seek ways to develop vaccines to prevent the disease, and look for treatments to manage the disease when it occurs.

While this is occurring, we are all playing a part in controlling the spread of the virus, by isolation, social distancing, hand hygiene and minimising our travel.

These measures that are currently controlling the spread of the coronavirus have arisen from research that occurred during, and out of, past pandemics, including the 'Spanish flu' just over 100 years ago.

What is the role of HammondCare in the midst of the global coronavirus pandemic?

First and foremost, HammondCare's services are on the frontline, caring for vulnerable people through our residential aged care, hospital, home care, dementia specific, and restorative care services.

Our staff have risen to the challenge, with many going 'above and beyond' in the course of their work, as they develop innovative ways in which to continue to provide care and support in an era of 'social distancing'.

This Research Report is for the 2019 calendar year – a year when no one had heard of COVID-19, and a year when we all thought that toilet paper, tissues, pasta and rice would always be in plentiful supply in Australian supermarkets!

Yet, if we look at the breadth of research that HammondCare researchers were involved in during 2019 we can see how important this

research can be in a 'post-coronavirus' world. Our key research areas speak to many of the areas that will impact the lives of people affected by the coronavirus pandemic.

This included palliative and end-of-life care, and symptom control; understanding the importance of meeting people's spiritual needs; providing the best environments and care models for people living with dementia and their support persons; and of course rehabilitation, restorative care and reablement for people who have experienced functional loss as a result of illness.

The statistics page summarises HammondCare's research efforts for 2019: 48 research projects across seven thematic areas; 82 publications; and 87 conference and other presentations. The stories highlighted for 2019 are across a range of areas, and include projects at different phases of implementation.

Dr Annette Britton and I congratulate all of our research staff and their collaborators, and above all we wish to thank everyone who has participated in these projects. Without the generosity of our research participants, many of the achievements contained in this report would not have been possible.

Dr Annette Britton
HammondCare Board of Directors

Professor Christopher Poulos
Head of Research, HammondCare





2019 RESEARCH UPDATE

Translating research into better care

**Virtual Reality: New hope for spinal
cord injury pain**

**Improving patient pain outcomes
through mHealth training**

**Quantifying the social impact of
dementia support programs**

'My Life My Way': A volunteer's story

**Designing residential care for
older people who are experiencing
homelessness or at risk of homelessness**

Guided by excellence

A guide to good practice

**The Advance Project: Enabling and
equipping general practices in end of
life planning**

Better conversations for end of life care

Virtual Reality: New hope for spinal cord injury pain

The opportunity

Evidence now shows that Virtual Reality is an innovative alternative for people living with persistent pain. It is becoming increasingly affordable and accessible in both clinical and experimental settings. However, despite growing evidence of its benefits, there are currently no studies that examine the effectiveness of Virtual Reality for people living with chronic pain following spinal cord injury.

The research

The effectiveness of existing treatments for the relief of neuropathic pain in people following a spinal cord injury leaves plenty of room for improvement. With recent evidence showing significant pain relief using Virtual Reality in other areas of pain medicine, The Department of Pain Management at Greenwich Hospital embarked on this new project.

The aim of the project was to examine whether a commercially available 3D head-mounted Virtual Reality application and software could result in a significant short-term reduction in neuropathic pain in people with spinal cord injury.

3D Virtual Reality devices now incorporate a realistic multisensory experience that surrounds the user, transporting them to another place. This project aimed to determine if watching an immersive 3D Virtual Reality device provided significantly more pain relief in comparison to using a less immersive 2D Virtual Reality device.

In the study, a group of people living with a spinal cord injury and a diagnosis of chronic neuropathic pain underwent two 20-minute Virtual Reality sessions, separated by a one-hour break.

One session used the immersive 3D head mounted Virtual Reality, while the other used the 2D computer screen. Both approaches allowed participants to explore the same relaxing nature scene.

During each Virtual Reality session, recordings of brain activity were also taken to determine whether Virtual Reality could reverse altered electrical activity in the brain due to spinal cord injury, towards a more normal state.

The outcome

Early results are very promising and show significant reductions in pain experienced by participants during both 3D head-mounted and 2D computer screen Virtual Reality sessions.

Most importantly, participants using 3D Virtual Reality reported an average decrease in neuropathic pain intensity of over 65% compared to a 35% decrease by those using the 2D Virtual Reality.

Participants who used the 3D Virtual Reality and reported the greatest reduction in pain intensity also experienced a greater sense of immersion, stating that the scene felt more real as they were less aware of the environment around them.

These findings are particularly encouraging, as all the 3D Virtual Reality equipment is commercially available with relatively affordable, downloadable, “off the shelf” software. This gives 3D Virtual Reality the potential to be a highly accessible, safer and immersive source of potential pain relief beyond opioids and other medications.

‘Early results are very promising and show significant reductions in pain experienced by participants ...’





Improving patient pain outcomes through mHealth training

The opportunity

Pain is almost universally experienced by people who are living with cancer at some stage in their illness trajectory. Despite all the guidelines and evidence underpinning effective pain management, people living with cancer continue to experience unacceptable levels of pain at various times throughout their cancer journey.

The research

HammondCare, in partnership with IMPACCT (Improving Palliative Aged and Chronic Care through Clinical and Translational Research) at University of Technology Sydney, embarked on a new project in May 2019 utilising a wait-listed, randomised control trial design.

The aim of the trial was to improve cancer and palliative doctors' and nurses' pain assessment capabilities through a targeted inter-professional clinical education intervention: mHealth.

The intervention was delivered via the online QStream platform directly to participants' mobile devices (via a free app) or email, and designed to help them address and reduce unrelieved cancer pain.

The trial was conducted across six Australian Cancer and palliative care sites, including three HammondCare palliative care sites. It focused on delivering authentic case-based cancer pain assessment scenarios directly to participants' mobile devices.

Once participants completed their individual assessments, they were given immediate feedback as to whether the answers they provided were correct. They then received online links to an evidence-based clinical decision support system (CDSS).

Assessment questions that were answered incorrectly were re-sent via email to participants at a later date and retired once answered correctly on two separate occasions, to promote learning.

The project team, led by Professor Jane Phillips, was a collaboration between Professor Tim Shaw, Professor Melanie Lovell, Professor Patricia Davidson, Professor Frances Boyle, Professor Lawrence Lam, Dr Nikki McCaffrey, Professor Paul Harnett, Ms Nicole Heneka and Mr John Stubbs.

The project was supported by funding from Cancer Australia - Priority-driven Collaborative Cancer Research Scheme.

The outcome

Assessment of pain is vital to successful pain management. If the mHealth intervention is found to be effective, it will improve pain assessment capabilities of cancer and palliative staff, and lead to more effective treatment planning for cancer patients.

The project team are currently working on preliminary data analysis to examine the effect of the intervention, and assess the change in pain screening, assessment, and documentation in participants. A final report will be distributed to participating sites in mid-2020.





Quantifying the social impact of dementia support programs

The opportunity

Age NI, the leading charity for older people in Northern Ireland, commissioned HammondCare to undertake an evaluation of its 'My Life My Way' project that supports older people with dementia and their carers. The approach taken was Social Return on Investment (SROI) analysis.

The research

Much of the value associated with activities that take place in the real world is not easily measured in financial terms – things like happiness, dignity, respect. This can mean that outcomes which are important to people are overlooked, or discounted. SROI analysis aims to assign monetary values to these outcomes and impacts, relative to the cost of the activity.

The 'My Life My Way' project is delivered by 'Community Navigators' who connect with isolated, older people living with dementia and their carers. A network of volunteers then works with those individuals offering support and providing tailored information about care options and entitlements.

The aim of the project is to empower older people at high risk of losing their independence or facing life-changing decisions during transitions between home, hospital and residential care, by facilitating personal choice, control and influence over decisions about their life.

CASE STUDY

'My Life My Way': A volunteer's story

Led by Dr Julie Christie, Associate Professor Colm Cunningham and Oonagh Thompson-Bradley, HammondCare's approach to the evaluation using SROI was to leverage HammondCare's unique combination of dementia knowledge, evidence-based practice, and co-production experience with people living with dementia.

This was achieved by meeting with a range of people who have experienced change as result of the project, and exploring these changes in detail, including taking account of other factors that could have contributed to the changes. For example: What would have happened in the absence of the programme? How long the changes can be expected to last. And what were the costs of providing existing services to deliver similar changes.

With this information, the researcher was able to assign monetary values to these outcomes and impacts and describe them in financial terms relative to the cost of the activity.

This was all within the context of the personal stories of change, as shared with the researcher, by people living with dementia, their carers and their families.

The outcome

A series of specific positive outcomes were identified for the people living with dementia, their carers and the volunteers who were involved in the 'My Life My Way' project. These outcomes were analysed and linked back to the specific inputs and activities that people had experienced.

This information enabled the researchers to calculate The Social Return on Investment which demonstrated that a total investment of approximately £668,000 (AUD \$1,339,941) generated an estimated social value of approximately £3,665,000 (AUD \$7,343,927).

This means that for every £1 (AUD \$1) invested in the 'My Life My Way' project, approximately £5.49 (AUD \$10.98) of social value was created in return.

In addition to the SROI calculation, the research team reviewed further data, identifying welfare benefits representing an additional financial value of approximately £562,000 (AUD \$1,122,819).

Des Donnelly first reached out to become a volunteer at Age NI, Northern Ireland's leading charity for older people, in 2013 after reading an article about the 'My Life My Way' project online. He was 63 at the time.

He remembers that the article painted a stark and confronting picture of just how isolated older people in Northern Ireland were feeling from their local communities. And that this isolation was felt particularly acutely by people living with dementia.

During that time, Des recalls that there had also been lot of discussion by politicians, the media, and the public about the hidden epidemic of loneliness in today's society, especially for older people.

But the thing he says really galvanised him into action, to personally get involved in his local community, was a speech given by then UK Health Secretary Jeremy Hunt about the plight of loneliness in older people.

Mr Hunt highlighted the tragedy of the many older people that died a "lonely death" and that "Each and every lonely person has someone who could visit them and offer companionship." This resonated deeply with Des, and the 'My Life My Way' project seemed a perfect opportunity to play his part.

Still a passionate volunteer for the 'My Life My Way' project today, Des describes how he finds the experience an incredibly rewarding and enriching experience.

"I see the volunteering I do as just being a good neighbour really. It takes up less than 2% of my week," he says.

"And for those not sure if they can help, you don't need any particular skill or expertise, just some basic training, a little of your time and just being yourself. I'm already thinking about giving more of my time to Age NI," says Des.

"We are all growing older and I hope that there will always be volunteers to support projects like 'My Life My Way'."

When you volunteer, you don't just give back, you definitely 'get back' too."



Designing residential care for older people who are experiencing homelessness or at risk of homelessness

The opportunity

A qualitative research study was undertaken to support the planning for HammondCare Darlinghurst, a newly built residential care home for older people who are currently experiencing homelessness or at risk of homelessness. The aim of study was to help inform the care home's model of care, referral pathways and admission criteria.

The research

The Darlinghurst Aged Care Service research project was led by HammondCare and University of New South Wales academics in 2019. It was funded by Perpetual Trustees IMPACT Philanthropy Program.

A number of organisations that provide services to older people who are experiencing homelessness were invited to participate. These services include accommodation, health, social policy and research.

The exploratory study reviewed the impact of homelessness on older people, the pathways that led to homelessness, and what principles are important in delivering best practice residential aged care. It also involved a literature review and data collection on homelessness in older people and service provision for older people experiencing homelessness.

Key issues found from the literature review were: a history of loss and trauma, often from childhood abuse and neglect; difficulty in interpersonal relationships and regulating emotions; alcohol and drug dependence; experiences of violence throughout the life course leading to acquired brain injuries; mental health difficulties; poor physical health status due to the circumstances of homelessness; socioeconomic disadvantage; and loneliness and lack of social support.

The review also found that Aboriginal and Torres Strait Islander people are over-represented in homelessness statistics and the above conditions. This group is one of the more vulnerable that may be referred to HammondCare Darlinghurst.

30 organisational stakeholders from the homelessness, aged care, health and mental health sectors participated in the interviews or focus groups (including government, non-government, research agencies and HammondCare staff). The staff roles represented were across management, policy, research, direct care, and case management/casework roles, across the range of organisations.

The interviews explored the needs of older people experiencing homelessness; models of residential care; care home management issues; operational and design issues; staff considerations including recruitment, training and support; systemic and policy issues in addressing homelessness; interagency referral pathways; and future directions for agency collaboration.

The outcome

Vital information was gathered from the study to help inform HammondCare management and staff in preparing to welcome and care for the residents at HammondCare Darlinghurst.

Research participants were also generous in sharing their experience and learning curves in working with this vulnerable population. Suggestions included sources for staff training, resources for residents, and referral and assessment options.

From the research literature and data collected, it was clear that HammondCare's current model of care is highly applicable to HammondCare Darlinghurst, with the inclusion of an understanding of the impacts of trauma for older people who are experiencing homelessness.

A trauma-informed approach, as advocated and used by many services within the homelessness sector, will support consistency in care and the relationships built between staff and residents. In addition, it will further strengthen HammondCare's existing model of care.

This model of care will also take into account both health needs (such as mental health, substance dependence and acquired brain injury) and significant losses through the life course of people who have experienced homelessness.

Pictured: HammondCare Darlinghurst



Guided by excellence

The opportunity

An opportunity arose to evaluate the extent to which Dementia Support Australia (DSA) consultants' recommendations and advice are informed by evidence and best practice using the Clinical Practice Guidelines and Principles of Care for People with Dementia.

The research

Dementia Support Australia (DSA) is a national service established by the Australian Government to respond to and support people living with dementia and their supporters through a telephone and face-to-face consultative service.

Operated by HammondCare since 2016, DSA seeks to offer an evidence-based, best practice service to provide advice and recommendations to people who care for someone with dementia where behaviours are impacting their care.

In 2016, Australia's first Clinical Practice Guidelines and Principles of Care for People with Dementia were released. The clinical guidelines include 109 recommendations for health and aged care staff to apply to support the needs of a person living with dementia and their carers, providing an independent benchmark of best practice for DSA consultants.

To evaluate the extent to which DSA recommendations are informed by the Clinical Practice Guidelines and Principles of

Care for People with Dementia, over 400 DSA recommendation reports were scrutinised and rated by a panel of four auditors.

32 DSA staff and 25 residential aged care staff across Australia were also interviewed to establish what helps or hinders the implementation of DSA recommendations.

The outcome

The evaluation indicated that over 98% of consultant recommendations were supported by the Clinical Practice Guidelines and Principles of Care for People with Dementia.

A review of the change of behaviour after delivery of a DSA consultation report showed a significant decrease in reported behaviours.

Interviews also revealed that carers who made a referral to DSA benefited from the service. This was due to the DSA consultant providing them with a better understanding of what causes certain behaviours associated with dementia and practical ways to manage those behaviours.

CASE STUDY



A guide to good practice

For many people who are living with dementia, they may begin to behave in ways that other people find difficult to understand, especially as the disease progresses.

As a Dementia Consultant for Dementia Support Australia (DSA), Renee Smith's main role is to offer support, advice and practical assistance to carers and people living with dementia. She does this by providing a better understanding of the cause of certain behaviours, as well as non-pharmacological solutions to help manage them.

"We find that people living with dementia can sometimes communicate the frustration they experience in the form of aggression, particularly during personal care. This can take the form of punching, hitting, pinching, and verbal abuse," says Renee.



“Often, the way care homes cope with this behaviour is to have more people come into the room to subdue and to try and help the patient, which unfortunately, can confuse and upset them further.”

To help understand changed behaviours as calmly and effectively as possible, Renee first identifies the possible causes and triggers of agitation in the person living with dementia.

“We work through why the person is reacting to specific stimuli in certain ways, and thereby focus on how to manage behaviour by addressing this stimulus and their wider environment,” says Renee.

“We often find that a person’s behaviour correlates to specific timelines and events. The negative behaviour tends to peak when a person is new to a care home – usually within their first week.”

According to Renee, this is largely due to sensitivity to change, as people living with dementia have difficulty adjusting to new environments because it is harder for them to learn new things. As a result, they become overwhelmed and scared, leading to fight or flight responses.

“More often than not, carers in care homes are so busy that it becomes difficult for them to see the resident as more than their behaviour,” says Renee.

“In line with the Clinical Practice Guidelines, we aim to support carers and family members to genuinely connect with the person who is living with dementia by gathering as much information about them and their past as possible. By truly getting to know the person and the life they have lived, we are able to bring the human back into the care equation.”



The Advance Project: Enabling and equipping general practices in end of life planning

The opportunity

HammondCare, in partnership with leading health organisations and universities, led the development of the Advance Project toolkit and multi-component training program. This program aims to equip General Practitioners (GPs) and General Practice Nurses (GP Nurses) to support patients in more effective planning for end-of-life care and the assessment of palliative and supportive care needs.

The research

Primary care has been identified for some time as an ideal setting to initiate discussions surrounding early advance care planning and palliative care. HammondCare was initially funded by the Australian Government to develop a suite of resources and multi-component training to support this.

The Advance Project aimed to support GP Nurses to initiate conversations about advance care planning with older or chronically ill patients during routine health assessments, and to assess patients' and carers' palliative and supportive care needs.

The training components included online modules, practical workshops, rural scholarships and one-on-one mentoring which have been delivered nationally. The program was evaluated with pre and post participant surveys and qualitative interviews.

823 GP Nurses across Australia enrolled in online training and 536 GP Nurses completed online training and workshops. 27 workshops were also held across Australia with 182 regional and rural participants. 585 pre-training, 384 post-training, and 125 follow-up surveys were completed and 20 GP Nurses were interviewed.

The outcome

Evaluation of Phase 1 of the program found that GP Nurses rated the quality and relevance of the resources and training to their practice highly. They felt it added real value to their patients. They also stated that it bridged the gap between existing resources and training for GP Nurses.

The evaluation showed strong and significant improvements in GP Nurses' confidence, comfort,

knowledge and attitudes towards initiating advance care planning conversations and palliative care assessments post-training.

Further funding from the Australian Government has enabled the expansion of the Advance Project to support GPs, GP Nurses and practice managers to use a systematic and team-based approach to initiating advance care planning.

The online training for GP Nurses has been revised to incorporate feedback from Phase 1 of the program. One-on-one mentoring is now available to support individual primary care clinicians and general practices to implement the resources in clinical practice.

Four 'champion' Primary Health Networks in three Australian states are currently being supported with grants and train-the-trainer support, to deliver face-to-face training and guide

implementation locally. In addition, 19 general practices across Australia are participating in an evaluation of the Advance Project resources with patients and their families, to inform ongoing improvement of the program.

'The evaluation showed strong and significant improvements in GP Nurses' confidence, comfort, knowledge and attitudes towards initiating Advance Care Planning conversations ...'

CASE STUDY

Better conversations for end of life care

Ten years ago, Palliative Care Clinical Nurse Consultant, Kelly Arthurs, was involved with a patient undergoing active chemotherapy as a result of a lung cancer diagnosis.

During the time of his chemotherapy, his family's focus was unsurprisingly solely on his treatment. There had been no conversations around his final wishes nor had his preferences regarding dying been formally discussed or recorded.

When a sudden crisis arose, he was admitted to hospital and the situation quickly escalated. Without an agreed advance care plan, further treatment and considerable distress was experienced by the patient and his family. Sadly, he died in hospital days after being admitted.

According to his wife, he would never have chosen to die that way in hospital. These would not have been his wishes. But because a conversation surrounding his end-of-life care was never had, the decisions were not made by the patient and his family in the manner they would have preferred. Ten years on his wife still becomes emotional when discussing this.

"Unfortunately this is not an unusual situation," says Kelly. "People need to know their options and have the opportunity to express what is important to them prior to having to make significant medical decisions. Once we know that, we can plan accordingly. That's what advance care planning is all about," she says.

As an experienced palliative care nurse, Kelly can relate to the significant challenges health care professionals face when discussing end-of-life



care. These challenges include approaching the subject in the first place, knowing the right questions to ask, and how to ask them in a sensitive manner.

Often a patient's wishes on end-of-life care aren't addressed until someone is brought into the emergency department or enters palliative care or residential aged care.

"That's why the Advance Project has such an important role to play," says Kelly. "GPs and practice nurses are often the people who patients and families trust and turn to. It equips them to have these conversations with patients and their families early, so people have the opportunity to reflect, and discuss their preferences."

For Western Australian Primary Health Alliance (WAPHA), one of the projects' champion networks that extends across WA, the Advance Project has been like a 'huge light switch'. Rose Adamson, the Advance Care project lead at WAPHA says "It's given GPs, nurses and patients some amazing resources on how to have those difficult conversations, and also also where they go to from here. The focus is on how a patient's wishes, values and preferences can be articulated and honoured."



2019 RESEARCH UPDATE

Research projects

Key research areas

An overview

Grants and statistics

Successful grant applications
& grants with continuing funding

Palliative care

Four new projects in 2019
& continuing projects

Dementia

Eight new projects & continuing projects

Ageing, restorative care and reablement

Three new projects & continuing projects

Rehabilitation

Three new projects & continuing projects

Pain management

Two new projects & continuing projects

Advance care planning

Continuing projects

Spiritual aspects of care

One new project & continuing projects

Key research areas



Palliative Care

HammondCare is involved in a broad range of research in palliative care. Our research program aims to improve the quality of life and well-being for people living with life threatening illness and their families. We conduct mixed methods and health services research to inform development of interventions to improve provision of palliative care in a variety of settings, as well as support families in their bereavement. One example is a recent study to investigate the communication-related experiences and needs of families for older people living with advanced dementia receiving end-of-life care.

We also do translational research projects to embed evidence in practice – for example, pain guidelines, an anxiety and depression pathway, and a toolkit and national training program to facilitate team-based initiation of palliative care in general practice.

In addition, we supervise PhD students' research in several areas including pain management. We are active partners in the Palliative Care Clinical Studies Collaborative (PaCCSC) and the Cancer Symptom Trials group: an international research network that aims to generate high quality research evidence to support the use of medicines and other interventions at the end of life to better manage or alleviate symptoms such as pain, confusion, breathlessness, appetite loss and gastrointestinal problems.

We collaborate with several national and international experts to enable the conduct of multi-disciplinary, team-based, high quality and clinically valid research to improve outcomes for this vulnerable population of patients and their families.



Dementia

The Dementia Centre conducts research with a significant focus on understanding and addressing the causes of dementia behaviours, drawing on the expertise of the national Dementia Support Australia (DSA) program. DSA is a partnership led by HammondCare that brings together dementia expertise from across the aged care industry. It provides the Dementia Behaviour Management Advisory Service (DBMAS), Severe Behaviour Response Teams (SBRT) and the Needs Based Assessment Program for determining eligibility for Specialist Dementia Care Programs (SDCP) nationwide.

Other areas of research from the Dementia Centre include environmental design, technology use, palliative care for people living with dementia, music engagement, sensory changes and other evidence-based interventions. The Dementia Centre aims to deliver a practical viewpoint in the often complex world of aged care service provision.

The Dementia Centre is perfectly situated between research and operations within HammondCare to drive a working model of ongoing research knowledge translation and implementation. The Dementia Centre's overall aim is to improve the lives of people living with dementia, their families and staff by providing training, consultancy and evidence-based interventions.



Rehabilitation

As the number of people with disabilities increases rapidly, especially with our ageing population, HammondCare maintains our focus on translating rehabilitation research into providing high-quality rehabilitation services. A landmark paper about cancer rehabilitation, recently published in the European Journal of Cancer Care, examined both perceived stress and fulfilment in our staff, in the context of maintaining a strong team ethos, essential to understanding how such services can be provided in a way that is sustainable in the long-term.

Key research areas



Ageing, Restorative Care and Reablement

While population ageing means that, overall, people are living longer, it doesn't mean that everyone experiences good health, free of disabling conditions as they age. HammondCare's research in ageing recognises this, and our focus is helping people gain the most from their ageing experience, taking a 'whole person' approach, and looking at ways that help maximise people's functional ability and well-being across multiple domains. The research is best described as translational – meaning that we take evidence of what works, and apply that 'in the field', through practical and sustainable service delivery models.

Some specific areas of our research on ageing are caregiver wellness, helping people achieve positive ageing through active participation in the arts, community-based restorative care programs for older people with frailty and chronic disease, and reablement programs for people living with dementia.



Pain Management

By nature, the problem of pain is multi-dimensional and reaches across many clinical conditions – involving and impacting people physically, emotionally and spiritually. In line with this, pain management research at HammondCare is looking at wide-ranging aspects of pain – from the physiology of brain and spinal cord pathways that help control pain, through to the existential and spiritual impact of pain on a person's sense of identity, meaning and purpose.

Through collaborations with colleagues in diverse disciplines such as palliative care, rehabilitation and dementia care, these projects build on the existing strengths within HammondCare to help us contribute to the better management of pain, and to become recognised thought and practice leaders in our specialist areas of expertise.



Advance Care Planning

Sensitive and timely communication about end-of-life issues is one of the most important components of quality care at the end of life for patients and their families. Yet, talking about death and dying can be difficult for everyone involved. Taking part in Advance Care Planning (ACP) well before a patient reaches the terminal phase of their illness can help prepare them and their family for what lies ahead.

HammondCare is leading and collaborating in several research projects aimed at improving ACP for people with a range of different life limiting illnesses in diverse settings. This research is looking at ways to overcome the obstacles to ACP, developing and testing practical tools to help health professionals start conversations about ACP and team-based strategies to embed ACP in routine care.



Spiritual Aspects of Care

At HammondCare, we recognise that spirituality is a fundamental element of human experience. It encompasses each individual's search for meaning and purpose in life.

When facing pain, rehabilitation, mental health issues or a disabling or life-threatening illness, people often struggle to make sense of what is happening to them.

Spirituality also encompasses the connections one makes with other people, nature, the sacred, including – but not exclusively – connections made within traditional religions. Viewed in this way, spirituality can be a key factor in how people cope with illness. We are interested in how people express their spirituality and are keen to find ways to better provide care in this essential dimension of health.

Successful grants and continuing funding

Successful grant applications

Christie J, Thompson-Bradley O, Yates-Bolton N, Cunningham C. The Life Changes Trust, Scotland. *Evaluation of the Life Changes Trust Funded Dementia-Friendly Communities.* Awarded \$267,694.11 from July 2019 to June 2021.

Kizawa Y, Mori M, **Clayton J.** Japanese Government fund for the Promotion of Joint International Research, Grants in Aid for Scientific Research (KAKENHI, multi-year fund). *The development and effectiveness of culturally-adapted advance care planning interventions: Building an Asian collaborative palliative care research network.* Awarded 18,460,000 Yen (equivalent to \$245,000 AUD) from October 2019 for six years.

Lovell M, Austin P. Sydney Vital Translational Cancer Research Centre. *The effects of virtual reality on pain intensity in people with cancer pain.* Awarded \$50,000 from April 2019 for 12 months.

Lovell M, Boyle F. Friends of the Mater Grant. *Updating the Australian Cancer Pain guideline.* Awarded \$50,000 from July 2019 for 12 months.

O'Connor C, Poulos C. AAG RM Gibson Research Fund Grant. *Developing an assessment guide for practitioners implementing reablement programs for people living with dementia.* Awarded \$7000 from July 2019 for 18 months.

Siddall P, McCabe R, Dong S, Clifton S, **Kok C.** icare Foundation. *Restoring hope: fostering connections, engagement and purpose following a spinal cord injury.* Awarded \$414,699 from 15 September for 30 months.

Siddall P, Middleton J, Craig A, Wrigley P, Tan Y. Australian and New Zealand College of Anaesthetists. *The effects of virtual reality on pain intensity and brain activity in people with neuropathic pain following spinal cord injury.* Awarded \$68,327 from 15 March 2019 for 12 months.

Continuing grants

Butow P, Andrew G, Girgis A, Kelly B, Hack T, **Clayton J,** Price M, Beale P, Viney R, Kirsten L. Cancer Institute NSW Translational Program Grant. *A sustainable and supported clinical pathway for managing anxiety and depression in cancer patients: developing and evaluating components and testing implementation strategies.* Awarded \$3,643,992 from July 2015 for five years.

Christie J, Thompson-Bradley O. *Evaluating the Impact of the Dementia Dog Programme.* Life Changes Trust Scotland. June 2018 to April 2020.

Christie J, Thompson-Bradley O, Cunningham C. *Age UK 'My Life, My Way' Program.* Funded by Age NI, Northern Ireland until October 2019.

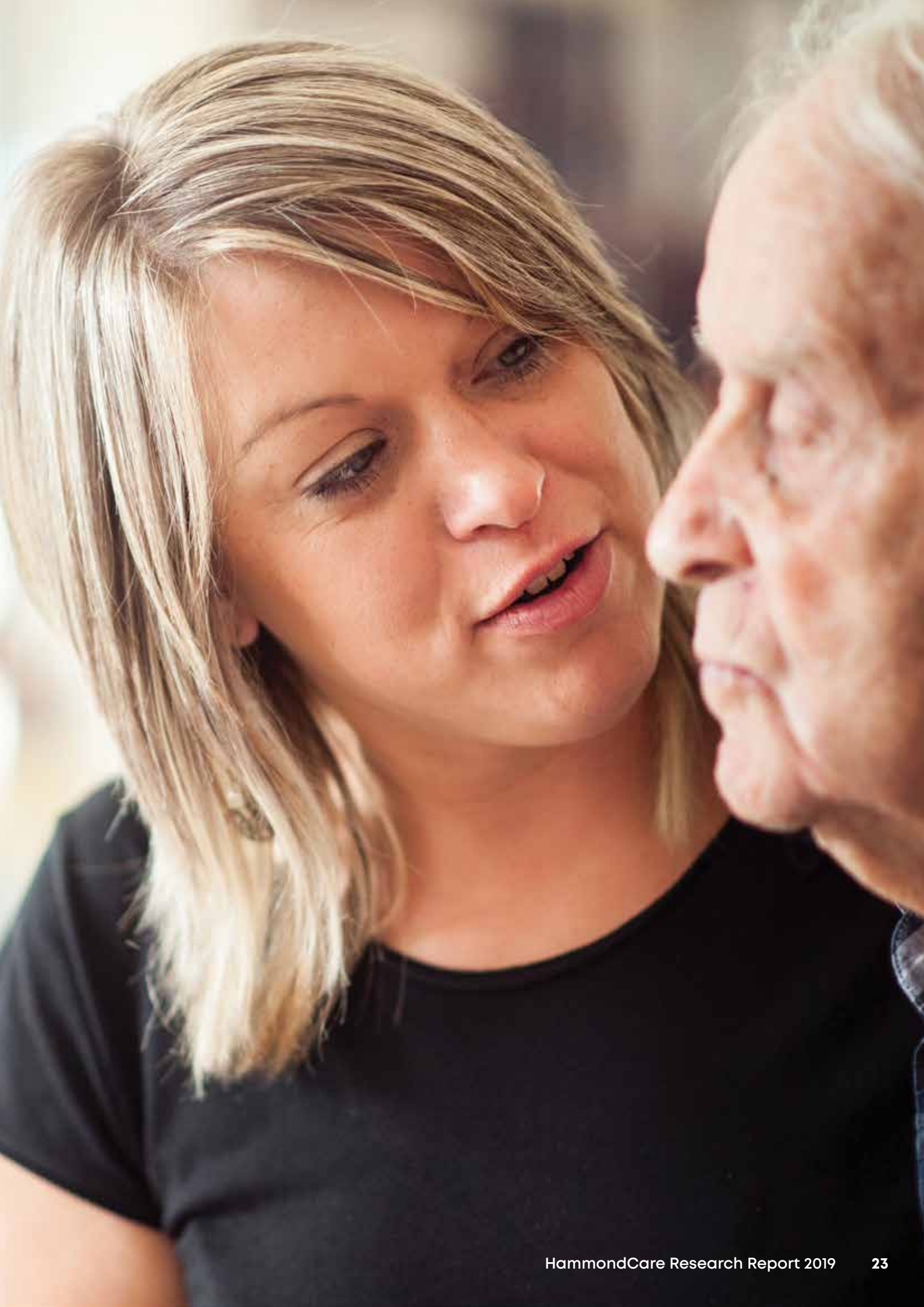
Clayton J, Rhee J, Tieman J, Detering K, Mitchell G, Phillips J, Halcomb E, Morton R, Lewis V. Australian Government, Department of Health National Palliative Care Project. *The Advance Project: Initiating palliative care and advance care planning through training and resources for primary care clinicians.* Awarded \$2 million from August 2017 until end of June 2020.

Cunningham C, Brodaty H, Draper B, Low L, **Macfarlane S, Alford M, Baird H, Morris T,** Jessop T, Chenoweth L. Australian Government Department of Health. *Review and adaptation of the '7 tiered model of BPSD' - informing future policy and practice.* Awarded \$300,000 from 22 June 2018 for 12 months.

Cunningham C, Kurrle S, **Gresham M,** De Bellis A, Crotty M, Martin S, **Macfarlane S.** Australian Government Department of Health. *Guided by Excellence: Strengthening service capacity to support people living with BPSD.* Awarded \$612,780 from 1 June 2018 for 13 months.

Phillips J, Shaw T, **Lovell M,** Davidson P, Boyle F, Lam L, McCaffrey N. Cancer Australia Grant ID: PdCCRS 1127011. *Improving Patient Reported pain Outcomes through mHealth Practitioner Training (I-PROMPT): A phase III wait-listed randomised control trial.* Awarded \$342,483 from 2017 for three years.

Piguet O, Fisher A, **O'Connor C.** Charles Perkins Centre Active Ageing Research Node Seeding Grant. *Positive Behaviour Support for individuals with frontotemporal dementia: a family education program.* Awarded \$20,571 from 2018 to 2019.





Statistics January 2019 to December 2019



48 research projects

12 Palliative Care	15 Dementia	5 Ageing, restorative care & reablement	5 Rehabilitation
5 Pain management	3 Advance care planning	3 Spiritual aspects of care	



82 publications

11 Books and chapters	47 Journal articles	16 Industry and magazine articles	8 Technical and other reports
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114 education, grants & awards

2 Awards	1 Higher research degrees	9 Academic degree supervisions	7 Successful grant applications
8 Grants with continuing funding in 2020		87 Academic conferences and industry seminars	

Palliative care

Communication-related experiences and needs of families for older people living with advanced dementia receiving end-of-life care: A systematic review and meta-synthesis of qualitative research

| New in 2019



Researchers: Dr Jacob Kwok, Professor Josephine Clayton, Professor Chris Poulos, Dr Alison Ritchie, HammondCare; Dr Tim Luckett, University of Technology Sydney; Professor Jennifer Tieman, Flinders University



Sites: HammondCare Greenwich Hospital and Pallister House



Duration: Jan 2019 to Jul 2020



Project Partners: University of Technology Sydney; CareSearch, Flinders University



Funding Source: In researcher's own time and in-kind support

Family members of older people living with advanced dementia experience complex caregiver burdens and require support from health professionals.

In this project, we will explore the end-of-life communication-related experiences and needs of families of older people living with advanced dementia. A systematic review and meta-synthesis of qualitative research will be conducted. The findings will provide evidence for health professionals communicating with family members to utilise a family-centred approach.

Analysis and write up of this systematic review is in progress. An abstract has been accepted for oral presentation at the 2020 International Dementia Conference.

Study Status: In Progress

A retrospective study looking at outcomes of patients considered for discharge to residential aged care facilities from a palliative care unit and factors associated with survival | New in 2019



Researchers: Dr Gillian Meyer, Professor Josephine Clayton HammondCare; Dr Odon DeMontiero, Fairfield Hospital



Sites: HammondCare Braeside Hospital



Duration: Feb 2019 to Jul 2020



Project Partners: Fairfield Hospital



Funding Source: In researcher's own time

Palliative care units (PCUs) are a limited resource and with our ageing population living longer and accumulating more illnesses, the demand for this resource is likely to continue to grow.

This study strives to obtain more information surrounding the discharge of patients from a PCU to residential aged care facilities (RACFs). The aim is to identify the outcomes of patients in whom RACF discharges are discussed and effected, and factors associated with survival for these patients. This in turn could lead to better identification of patients in whom nursing home discharges should be considered.

Patients admitted to a PCU over a 2-year period who underwent a family conference to discuss a RACF discharge will be included. Data collection has been completed at Braeside Hospital and analysis is in progress.

Study Status: In Progress

Palliative care

The effects of virtual reality on pain intensity in people living with cancer pain | New in 2019



Researchers: Professor Melanie Lovell, Dr Philip Austin, Professor Philip Siddall from HammondCare and University of Sydney



Site: HammondCare Greenwich Hospital



Duration: Jun 2019 to Dec 2020



Project Partners: University of Sydney



Funding Source: Sydney Vital

Cancer pain is very often severe, poorly controlled and impairs quality of life for both patients and family members.

Cancer pain is thought to be due to a combination of inflammatory, neuropathic and ischaemic factors due either to cancer cell activity or the body's reaction to cancer. Given the ongoing prevalence of cancer pain, despite currently available treatments, there is a need to find alternative therapeutic approaches. The use of virtual reality (VR) devices currently show benefits for people with chronic pain. Thus, our aim is to determine whether VR applications can result in significant pain reductions in people who experience persistent cancer pain.

Study Status: In Progress

Subcutaneous ketamine infusion in palliative care patients with advanced life limiting illnesses for major depressive disorder: A phase II pilot feasibility study | New in 2019



Researchers: Dr Wei Lee, University of Technology Sydney; Dr Amy Chow, Dr Mariclaire Francisco, HammondCare



Site: HammondCare Braeside Hospital



Duration: Feb 2019 to Feb 2024



Project Partners: University of Technology Sydney



Funding Source: Nil, in researcher's own time

Depression is very common in people with a terminal illness. Usual antidepressants used to treat depression can take up to a few weeks to work. They are not useful when life expectancy is very short, or when the depression is so severe that it requires rapid improvement of symptoms to prevent risk of harm. There is a need for treatment that helps alleviate depression sooner for these people.

There have been no similar trials done using ketamine to treat even de novo depression in the population with advanced life-limiting illness. There is a need to explore the activity of ketamine in palliative care patients, particularly those with very limited prognosis and/or severe depression that require immediate intervention where typical antidepressants are of limited utility for depression.

There is also a need to assess for ketamine's short-term (within a week) and medium-term responses (weeks to early months post ketamine administration) in these patients. Further evidence may potentially allow ketamine to be used to treat severe depression in patients with very limited but uncertain prognosis (e.g. in the range of weeks) and be considered as a bridging therapy for those who have a longer prognosis than average for the typical antidepressants to take effect.

Trials of antidepressants in this population are difficult to conduct due to several factors, including frailty, co-morbidities, co-concomitant medications and risks of adverse effects. These factors are compounded by the anhedonia from major depression, thus rendering recruitment challenging.

Prior to researchers committing to a larger double blinded, cross over, randomised controlled trial testing the activity of ketamine as an antidepressant in the palliative care population, a feasibility study will be conducted to investigate: the number of patients who participate in, and subsequently complete, the ketamine intervention; the safety and tolerability of ketamine in this population; and the potential effects of ketamine on depression.

Study Status: In Progress

Palliative care

Optimising end of life care for people living with dementia: A qualitative study of residential aged care staff perspectives



Researchers: Professor Josephine Clayton, Professor Chris Poulos, Dr Damian Harkin, Dr Jessica Borbasi, Dr Alison Ritchie, Dr Cindy Kok, HammondCare; Professor Allison Tong, University of Sydney



Sites: Various HammondCare sites



Duration: Nov 2018 to Dec 2020



Project Partners: University of Sydney



Funding Source: Internally funded and in researcher's own time

Dementia is a leading cause of death in Australia. Many people who are living with dementia live their last years and months of life in residential aged care settings. Despite being a progressive fatal condition, most people living with dementia do not receive the same level of palliative care support as people dying from cancer.

In this project, we will explore the perspectives and views of HammondCare's residential aged care staff, volunteers, general practitioners and family members of HammondCare's residents, regarding the key elements required to enable quality end of life care for people living with dementia in residential aged care, and the strengths and gaps in current care provision.

We will conduct focus groups and individual interviews with the different participant groups and use qualitative methods to analyse responses. This will inform development of strategies for optimising end of life care for people living with dementia in our model of residential care.

This project will provide a greater understanding of the key elements required to provide quality care at the end of life for people living with advanced dementia in residential aged care. A better understanding of these key elements will allow HammondCare to optimise the quality of end of life care for the people we serve in our residential aged care services.

This research is also in strong alignment with HammondCare's future directions and combines our key differentiators of dementia care and palliative care.

56 staff members have participated in an interview or focus group, analysis is in progress and an abstract has been accepted for presentation at the 2020 International Dementia Conference. Manuscripts and a report to inform care are in preparation.

Study Status: Ongoing

The experience of multidisciplinary specialist palliative care teams caring for people with intellectual disability (ID) who are dying



Researchers: Dr Michele Wiese, Dr Nathan Wilson, Bernadette Currye, Western Sydney University; Professor Roger Stancliffe, University of Sydney; Professor Josephine Clayton, HammondCare



Sites: New South Wales wide project



Duration: Jan 2017 to Dec 2019



Project Partners: University of Western Sydney; University of Sydney



Funding Source: Western Sydney University Fellowship and in researcher's own time

People with intellectual disability are living longer, and like the general community, are experiencing illnesses requiring extensive periods of palliative care.

This study, funded through a University of Western Sydney Women's Research Fellowship Grant, in collaboration with the University of Sydney and HammondCare, is being undertaken to understand the experience of multidisciplinary specialist palliative care teams in caring for people with intellectual disability who are dying.

Individual interviews will be conducted with physicians, nurses, social workers and pastoral care workers to explore the extent and nature of their role, the facilitators and barriers to care, and future needs of palliative care teams. It is expected that the findings of this study will impact strategic planning and health policy and practice for this group.

Study Status: Recruitment for the study has been completed, analysis is in progress and manuscripts are being prepared for publication.

Palliative care

Living after death: An exploration of the experiences of bereaved adults



Researchers: Nathan MacArthur, Emma Kirby, Jane Mowll, Alex Broom



Sites: All HammondCare sites



Duration: Sep 2017 to Mar 2023



Project Partners: University of New South Wales



Funding Source: In the researcher's own time; HammondCare in-kind support. The researcher received a scholarship from the HammondCare Centre for Learning and Research

Most people in Australia die in circumstances where death is anticipated and where family members are expected to have worked through some of the significant changes that accompany a loss before death occurs.

The assumption that grief is easier when death is expected stands in contrast to research which documents the profound impacts of bereavement, regardless of the circumstances of death.

This project will reveal the lived experiences of bereaved adults following an anticipated death, including experiences after deaths in hospital, at home and in residential aged care.

Data collection for Stage 1 of this study has been completed. In-depth interviews exploring bereavement experiences were conducted with 36 participants resulting in over 57 hours of recordings. In Stage 2, 23 of the participants from Stage 1 are responding to questions sent to them over a six-month period. To date, ten participants have completed this stage of the research.

Through analysis of this rich data, this project will:

1. Provide key insights into bereavement experiences in the context of anticipated death
2. Identify how experiences of formal and informal support are negotiated and managed
3. Identify unmet needs
4. Provide evidence to inform service developments and changes to policy and practice to improve the bereavement experience for family members and carers.

Study Status: Ongoing

A sustainable and supported clinical pathway for managing anxiety and depression in cancer patients: Developing and evaluating components and testing implementation strategies



Researchers: Professor Phyllis Butow (Lead), University of Sydney; Professor Josephine Clayton (one of the chief investigators), Professor Melanie Lovell (an advisor for the project), HammondCare



Sites: Off-site research



Duration: Jun 2015 to Jun 2020



Project Partners: PoCoG, Sydney Catalyst; Centre for Medical Psychology and Evidence Based Decision Making, University of Sydney



Funding Source: Cancer Institute New South Wales

This project will inform better and more streamlined psychosocial care of patients with cancer.

Patient and health professional educational materials have been developed with stakeholder input. Educational materials were piloted in a pre-post study. An online therapy program (iCanADAPT) for early and advanced cancer has been developed and evaluated in a randomised control trial (RCT) and pre-post study.

An online portal has been created to operationalise the pathway and has been piloted at a cancer service in Sydney. A large multicentre cluster RCT is in progress in 12 cancer services across New South Wales. Each service works with the ADAPT team to tailor the "Clinical Pathway for the screening, assessment and management of anxiety and depression in adult cancer patients: Australian guidelines" at their cancer service prior to introducing the recommendations over a 12-month implementation period. Nine of the 12 services have completed their 12 months of supported implementation of the Clinical Pathway using the developed resources, and three services will complete their study period for the cluster RCT in 2020.

Over 1200 patients have been registered within the ADAPT online portal and routine screening has been completed almost 1500 times. Survey and interview data from participating cancer services staff is providing valuable information on the success of the implementation planning and the practice reality. Study completion is planned for 2020.

Study Status: Ongoing

Palliative care

Cancer Pain Assessment Study



Researchers: Professor Jane Phillips, Professor Tim Shaw, University of Technology Sydney; Professor Melanie Lovell, HammondCare; Professor Patricia Davidson; Professor Fran Boyle; Professor Lawrence Lam, University of Technology Sydney; Dr Nikki McCaffrey, Deakin University



Sites: All HammondCare palliative care services



Duration: 2017 to 2019



Project Partners: University of Technology Sydney and Palliative Care Clinical Studies Collaborative



Funding Source: Cancer Australia

This study evaluated the use of Q stream education to improve health professionals' knowledge and skills in assessing cancer pain.

HammondCare cares for people with pain and cancer across its services. This study provided education for all our staff about assessing cancer pain. The education was tailored to each individual staff member's pre-existing knowledge and information needs.

Assessing cancer pain is crucial for determining the likely cause and mechanism of pain. Cancer pain impacts people in different ways and a thorough discussion and examination allows health professionals to determine how the pain is interfering with quality of life. Pain will also mean different things to different people so understanding what each person feels their pain means is also important. A thorough assessment allows a comprehensive pain management plan to be developed with each patient.

The education was delivered via email at regular intervals and retired when each learning outcome was achieved.

Recruitment was completed at all HammondCare sites. Analysis is under way.

Stop cancer PAIN



Researchers: Professor Melanie Lovell, Dr Najwa Reynolds, HammondCare; Professor Jane Phillips, Dr Tim Luckett, Professor Meera Agar, Professor David Currow, Professor Lawrence Lam, University of Technology Sydney; Professor Fran Boyle, Professor Tim Shaw, University of Sydney; Dr Nikki McCaffrey, Deakin University; Patricia Davidson, Johns Hopkins University



Sites: Off-site research



Duration: Nov 2014 to Oct 2019



Project Partners: University of Technology Sydney; University of Sydney



Funding Source: National Breast Cancer Foundation

The aim of this study is to facilitate improved pain outcomes for people living with cancer pain and their families, improved health service delivery for cancer pain and improved staff knowledge.

This study assessed the benefit of screening for pain alone versus screening plus health professional training, audit and feedback and patient self-management tools in 688 adults living with cancer pain from 8 cancer centres around Australia in a large randomised trial.

Over 8000 people gave their pain scores when they arrived at the cancer centre. Around 25% had pain at or greater than 5/10 in severity. The study looked at whether the interventions improved adherence to the National Cancer Pain guideline, pain scores, quality of life and people's ability to manage their own pain.

Recruitment and analysis are complete, and the study has been submitted for presentations. Publications are in preparation.

Palliative care

Rapid report of pharmacovigilance program



Researchers: Dr Amy Chow, Dr Mariclaire Francisco, Braeside Hospital HammondCare; Professor Melanie Lovell, Dr Bridget Johnson, Greenwich Hospital HammondCare; Professor Meera Agar, University of Technology Sydney



Sites: HammondCare Braeside Hospital and Greenwich Hospital



Duration: Jun 11 to Apr 2024 Braeside; May 11 to Dec 2020 Greenwich



Project Partners: Palliative Care Clinical Studies Collaborative



Funding Source: Nil

It is important that clinicians monitor patients when they begin taking a new medication, both for evidence that the medication is working and for any side effects.

This program provides clinicians at HammondCare a point of care approach to monitoring medications which is time efficient. It also adds the benefit that data is pooled internationally, giving more robust feedback on the actual effectiveness and side effects of the medications being used daily in our HammondCare facilities. This feedback improves prescribing to ensure patients are receiving medications with the maximum effect and minimal side effects.

The paper reporting on the series examining deprescribing Targin for pain was accepted for publication in 2019. Collection continued in 2019 for the medication series: Amitriptyline for neuropathic pain, non-steroidal anti-inflammatory drugs for pain, benzodiazepines for breathlessness, midazolam for terminal agitation, mirtazapine for anorexia, cyclizine for nausea and methadone for pain.

The program continues to grow in the number of interventions being studied; the number of contributing sites, the gathering of real-world data to inform clinical decision making; building of research capacity; and improvement of patient outcomes.

Study Status: Ongoing

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



Researchers: Professor Meera Agar, University of Technology Sydney; Dr Amy Chow, Dr Mariclaire Francisco, HammondCare



Sites: HammondCare Braeside Hospital



Duration: Oct 2017 to Dec 2020



Project Partners: University of Technology Sydney



Funding Source: Cancer Australia

Delirium is a highly prevalent, medical emergency in advanced cancer. Despite being preventable in many cases, two-thirds of people with advanced cancer will have a delirium episode at some point whilst hospitalised.

Delirium causes additional medical complications, excess mortality, high levels of patient and caregiver distress, and significant increases in health care costs. Delirium adversely affects cognition, awareness and communication ability at a critical time when being mentally aware and interacting with loved ones is crucial for quality of life. The aim of the investigator-initiated, cooperative group trial is to determine the effectiveness of melatonin in preventing delirium (number of delirium free days during hospital admission achieved by reducing overall delirium occurrence or reducing duration and severity of delirium if it occurs). Oral melatonin prolonged release (2mg) or placebo is taken at 2000 hours.

Intervention will be commenced within 48 hours of admission and continued until any of the following occurs: delirium occurrence, discharge, or for a maximum of 21 days if patient remains in hospital as, in most cases, any acute medical issues imparting a delirium risk have been resolved (e.g. while awaiting long-term care placement). Intention-to-treat analysis will be used for all statistical comparisons.

This is the first trial of its kind in cancer care, aiming to prevent delirium, or reduce its duration and severity to stall the cascade of functional and cognitive decline, morbidity, mortality and resultant health care costs. Melatonin use could be rapidly translated into practice, given the formulation already has Therapeutics Goods Administration registration for another indication.

Study Status: Ongoing

Dementia

ANAVEX2-73-AD-EP-004 | New in 2019



Researchers: Associate Professor Stephen Macfarlane, HammondCare; Dr Madeleine Healy, Dr Andrew Gleason, Monash University; Dr Ken Teo, Box Hill Hospital



Sites: HammondCare Malvern, Pallister House and Greenwich Hospital



Duration: Nov 2019 to Dec 2023



Project Partners: ANAVEX Life Sciences, Worldwide Clinical Trials, Signet Health, 360 Biolabs



Funding Source: ANAVEX Life Sciences

This study is an open label extension to the Anavex2-73-AD-004 randomised clinical trial. Participants who complete the 48-week placebo control study are eligible to receive the Anavex2-73 medication for an ongoing period of up to two years.

The Anavex2-73-AD-004 study is a phase 2b/3 clinical trial of This study is an extension phase of the Anavex2-73 clinical trial for early Alzheimer's disease. Upon completion of the 48-week placebo control clinical trial, eligible participants are offered the opportunity to receive an ongoing dose of Anavex2-73 for a period of two years. This extension phase reflects a commitment to participants who have contributed to essential investigation of the Anavex2-73 medication. The study will also provide supplemental data on the long-term use of Anavex2-73.

The Malvern clinical trial site enrolled their first patient into this phase of the study in October of 2019. Currently 12 participants are enrolled in this phase of the study and are receiving an ongoing dose of Anavex2-73. It is expected that most participants enrolled in the placebo-control arm of this study will continue onto the open label extension phase.

Study Status: Currently Recruiting

7 Tiers | New in 2019



Researchers: Professor Henry Brodaty, Professor Brian Draper, University of New South Wales; Associate Professor Lee-Fay Low, University of Sydney; Dr Tom Morris, Hannah Baird, Sheridan Read, Marie Alford, Associate Professor Colm Cunningham, HammondCare



Site: NA



Duration: Aug 2018 to Sep 2019



Project Partners: University of New South Wales; University of Sydney



Funding Source: Australian Government Department of Health

This project reviewed and investigated policy, procedures and practice for entrance into Specialist Dementia Care Programs.

Following the commitment by the Australian Government to launch the Specialist Dementia Care Program (SDCP), HammondCare, in partnership with the original authors of Brodaty, Draper and Low's seven-tiered model of service delivery for people living with dementia, were commissioned by the Department of Health to revise the models of service delivery and help inform policy surrounding pathways and eligibility into SDCPs.

To achieve this, HammondCare conducted a range of independent activities, including a review of the literature, stakeholder engagement and consultation, a pathway and eligibility criteria to access SDCPs, and the pilot of an objective entry assessment tool.

Moving forward, and in collaboration with University of New South Wales and University of Sydney, HammondCare will use the extensive data collected through Dementia Support Australia to help refine and re-write the original and seminal seven-tiered model of service delivery publication.

Study Status: Completed

Dementia

Evaluation of the Life Changes Trust Funded Dementia-Friendly Communities Programme in Scotland | New in 2019



Researchers: Dr Julie Christie, Oonagh Thompson-Bradley, Associate Professor Colm Cunningham, HammondCare; Dr N Yates-Bolton



Sites: Scotland wide



Duration: Jul 2019 to Jun 2021



Project Partners: Nil



Funding Source: Life Changes Trust

The Life Changes Trust exists to support partnerships, organisations and projects which share a common goal of improving the lives of people living with dementia and their carers. To this end, the Trust has provided funding to a number of Dementia Friendly Communities (DFCs) in recognition of the impact DFCs can have on quality of life through increased engagement and support for the person living with dementia and their unpaid carer(s). Relationships are at the heart of these communities, which extend beyond geographical communities to include communities of interest. This evaluation will explore this work and includes a Social Return on Investment study of two sites.

Since April 2015, 40 DFCs have been funded across Scotland. Over this period, the individual communities have completed six-monthly self-evaluations, and these have formed the basis of the DFCs reports produced by the Life Changes Trust. These self-evaluations represent an extension of the grassroots approach of the communities, whose members have been active participants in the planning and implementation of each project.

While self-evaluations have offered the opportunity to gather ongoing feedback and identify potential new directions or opportunities, this independent evaluation of the DFCs will examine:

1. The extent to which they are creating better lives for people living with dementia
2. The extent to which they are creating better lives for unpaid carers of people living with dementia
3. What has not worked and why
4. The benefits and challenges of a community development approach
5. The extent to which dementia friendly communities can provide short, medium and long-term post-diagnostic support for people living with dementia and unpaid carers
6. Whether these communities are able to complement and, importantly, inform national and local dementia strategies and action plans
7. The extent to which the communities work in partnership and any significant benefits this partnership brings
8. Any barriers and challenges that the communities have faced and how they, where possible, overcame them
9. The likelihood that these communities will be sustained in the long-term.

The first report of this work is due in May 2020.

Study Status: In Progress

Dementia

ANAVEX2-73-PDD-001 | New in 2019



Researchers: Associate Professor Stephen Macfarlane, HammondCare; Dr Madeleine Healy, Monash University; Dr Ken Teo, Box Hill Hospital



Sites: HammondCare Malvern



Duration: Jul 2019 to Jun 2020



Project Partners: ANAVEX Life Sciences, Worldwide Clinical Trials, Signet Health, 360 Biolabs



Funding Source: ANAVEX Life Sciences

It is estimated that up to 80% of patients with Parkinson's disease will eventually develop dementia. There are currently no approved disease modifying therapies which improve the cognitive deficits associated with Parkinson's disease dementia. Anavex2-73 is a new therapy showing promising disease modifying effects.

The Anavex2-73-PDD-001 study is a phase 2 placebo-controlled clinical trial of Anavex2-73 for the treatment of cognitive impairment in patients with Parkinson's disease living with dementia. The experimental drug under investigation, Anavex2-73, is a sigma-1 receptor agonist which has shown promising results in the improvement of memory and thinking in people diagnosed with dementias.

In this 18-week study participants are randomised to one of three treatment arms; 30mg, 50mg or placebo. Participants take the dose once daily as oral capsules. The purpose of this study is to determine the effects of ANAVEX2-73 on participants with Parkinson's disease dementia, to find out how it impacts on their cognitive problems and how it is tolerated by the body.

The Malvern clinical trial site enrolled their first patient for this study in July 2019. A total of six participants have been screened for this study with five moving on to be randomised and receive medication.

Study Status: Recruitment for this study is expected to close by the end of January 2020

ANAVEX2-73-PDD-EP-001 | New in 2019



Researchers: Associate Professor Stephen Macfarlane, HammondCare; Dr Madeleine Healy, Monash University; Dr Ken Teo, Box Hill Hospital



Site: HammondCare Malvern



Duration: Nov 2019 to Jun 2021



Project Partners: ANAVEX Life Sciences, Worldwide Clinical Trials, Signet Health, 360 Biolabs



Funding Source: ANAVEX Life Sciences

This study is an open label extension to the Anavex2-73-PDD-001 randomised clinical trial. Participants who complete the 18-week placebo control study are eligible to receive the Anavex2-73 medication for an ongoing period of up to 12 months.

This study is an extension phase of the Anavex2-73 clinical trial for individuals with Parkinson's disease dementia. Upon completion of the 18-week placebo control clinical trial, eligible participants are offered the opportunity to receive an ongoing dose of Anavex2-73 for a period of 12 months. This extension phase reflects a commitment to the participants who have contributed to essential investigation of the Anavex2-73 medication. The study will also provide supplemental data on the long-term use of Anavex2-73.

The Malvern clinical trial site enrolled their first patient into this phase of the study in November of 2019. Currently three participants are enrolled in this phase of the study and are receiving an ongoing dose of Anavex2-73. It is expected that most participants enrolled in the placebo-control arm of this study will continue onto the open label extension phase.

Study Status: Recruitment closing May 2020

Dementia

What does it mean for carers to be present for people living with advanced dementia? Part 1-Model of care enhancement | New in 2019



Researchers: Professor John Swinton, Joy Robinson, Julia Patton, HammondCare



Site: HammondCare Miranda



Duration: Nov 2019 to Mar 2020



Project Partners: Nil



Funding Source: HammondCare

Most people in Australia die in circumstances where death is anticipated and where family members are expected to have worked through some of the significant changes that accompany a loss before death occurs.

The key question that this project seeks to respond to is: precisely what does it mean to be fully present with and towards people living with advanced dementia, and how best can carers be enabled to develop forms of relationship that will facilitate meaningful and constant presence.

The project falls into two parts, one focused on service enhancement and the other on empirical research. The object of the first aspect of the project is to explore the issues with a view to enhancing the efficacy of the model and developing positive changes in practice to address the issue of presence. The second part of the project comprises a formal research project that will look at the issues from a research perspective.

The issue of carer presence with people living with advanced dementia has been highlighted as a prominent issue that had not been as thoroughly considered as it could be in relation to the HammondCare model of care. The HammondCare model requires that people living with dementia are treated with respect, that they are seen as individuals, and that all care must be person-centred and fitting for the specific needs of the individual. It has been noted however, that some staff found it difficult to engage with people living with dementia in ways that ensured that the goals of the model were constantly kept in mind and in practice. This is particularly the case for those living with advanced dementia and communicational and behavioural challenges. The primary questions are as follows:

1. How can people remain "switched on" for extended lengths of time?
2. How do we ensure that our care staff who are working a full day, multiple days, can structure their workdays in order to improve their ability to be present in the right ways at the right time?
3. What are the structures that occur during a workday that one can tap into to recharge people in order to get the best out of them when they are in front of a resident?

The service development aspect of the project explores the issue in detail through conversations with staff and engagement with the broader literature with a view to implementing constructive changes to address the issue. The final report will be available in March 2020.

Study Status: In Progress

Dementia

Barriers and enablers for accessing the outdoors for people living with dementia living in aged care homes | New in 2019



Researchers: Dr Cindy Kok, Dr Meredith Gresham, Sabrina Chao, Dr Najwa Reynolds, Associate Professor Colm Cunningham, HammondCare



Sites: HammondCare Southwood, Wahroonga, Strathearn House, Waldegrave



Duration: Apr 2019 to Apr 2020



Project Partners: Nil



Funding Source: HammondCare in-kind support

This research project describes the perceptions of care home staff regarding the barriers that may hinder people living with dementia in care homes to access and utilise outdoor areas.

Humans have an inherent need to connect with life and the process of life in nature. Many studies have shown that the natural environment can have a positive impact on people living with dementia, including those living in care homes. However, access to the outdoors is often restricted for people living with dementia. The doors in care homes have been found to be kept locked and the residents are de facto detained.

This study used a qualitative descriptive design using in-depth interviews to explore the barriers of using outdoor areas by people living with dementia in aged care homes. We have completed 26 individual interviews with care home staff who met the following eligibility criteria: staff including clinical staff members (e.g. registered nurse) and front-line care staff (e.g. care worker). In addition, we conducted an environmental and building assessment at each site to compare the physical environment of each facility.

This study aims to show that it is important to effectively communicate the benefits to going outside. This is important for staff taking care of people living with dementia, who have additional barriers to going outside and are often unable to express clearly their wish to go outside.

Study Status: Data collection completed, undergoing analysis

Economic impact of Dementia Support Australia | New in 2019



Researchers: Dr Tom Morris, Sofia Rahman, HammondCare; Dr Chris Schilling, Dr Erick Hasnata, Klynveld Peat Marwick Goerdeler (KPMG)



Site: NA



Duration: Feb to Jun 2019



Project Partners: KPMG



Funding Source: Internally funded

This project investigated the economic impact of Dementia Support Australia to health service utilisation in Australia.

The benefits of non-pharmacological support of behaviours and psychological symptoms of dementia are well known. Despite this, limited research has investigated the cost benefits, if any, of operating such programs. As such, the Dementia Centre commissioned KPMG to undertake an economic evaluation of Dementia Support Australia (DSA).

The findings of this evaluation were notable. All programs operated by DSA were found to deliver clinically meaningful reductions to behaviour. Taking into account changes to behaviour in the context of operating the program, Dementia Behaviour Management Advisory Service (BMAS) was identified as likely being the dominant intervention for behaviour support in the world.

Importantly, DSA was found to save \$35million every year in downstream health utilisation. Taken together, the results of this evaluation support the many benefits of funding dementia support programs both in Australia and worldwide.

Study Status: Completed

Dementia

Evaluation of HammondCare Caulfield



Researchers: Dr Meredith Gresham, Dr Cindy Kok, Dr Tom Morris, Sabrina Chao, Associate Professor Colm Cunningham, HammondCare



Site: HammondCare Caulfield



Duration: Oct 2018 to Oct 2019



Project Partners: NIL



Funding Source: HammondCare in-kind support

This project aims to validate HammondCare's model of care by evaluating outcomes pertaining to residents, staff, and family.

Community standards and changes to regulatory requirements for the built environment has increased the number of older, frail and cognitively impaired residents being relocated to new buildings. Relocation is frequently associated with negative outcomes including increased confusion, falls and risk of death.

This project aims to validate HammondCare's model of care by evaluating the outcomes of residents, staff and family following the move of residents from a traditional facility to a newly built HammondCare facility. This study is a pre-post observational study of residents transferring from HammondCare Nursing Home Caulfield to dementia specific cottages. A key feature of this new facility is that it adopts a unique cottage design similar to that of a home-like environment.

Each participant will be observed at different times of the day and the resident then scored as either positively, negatively or not engaged. Data is summarised to reflect the percentage of observations whereby the resident was engaged, negatively engaged or not engaged. This study will contribute to and inform future improved care practices pertaining to this vulnerable group of people. It will also be instrumental in enhancing training and support for the people who care for people living with dementia.

Study Status: Completed

New Ways for Better Days: Tailoring activities for persons living with dementia and their caregivers – Tailored Activity Program-Australia (TAP-Australia)



Researchers: Associate Professor Sally Bennett, Professor Brenda Gannon, Professor Trevor Russell, University of Queensland; Professor Lindy Clemson, University of Sydney; Professor Laura Gitlin, Drexel University; Dr Maria O'Reilly, Central Queensland University



Sites: NA



Duration: Jul 2018 to Aug 2020



Project Partners: University of Queensland



Funding Source: NHMRC – Boosting Dementia Research Grant

This project seeks to investigate how the Tailored Activity Program (TAP) can be implemented in Australia.

The Tailored Activity Program (TAP) involves assessing the capabilities of the person living with dementia in order to tailor meaningful activities to the person's strengths. TAP involves working closely with family carers on effective communication techniques and strategies for modifying environments and activities to support engagement from the person living with dementia.

TAP has been shown to be effective in supporting both the person living with dementia and their family members. Despite this, it is not available to consumers in Australia.

This implementation project aims to investigate how TAP can be implemented within Australia and build capacity within the Australian healthcare workforce to deliver TAP beyond the life of the project.

Study Status: In Progress

Dementia

Intervene Phase 2 – Multi-disciplinary collaboration to support the implementation of best practice pain management for older people living with dementia: A participatory action research study in Australian Residential Aged Care Services



Researchers: Associate Professor Colm Cunningham, Professor Chris Poulos, Professor Philip Siddall, Dr Catriona Lorang, HammondCare; Professor Anneke Fitzgerald, Griffith University



Sites: HammondCare Woy Woy and Caulfield, and two non-HammondCare sites



Duration: Jan 2017 to Oct 2019



Project Partners: Griffith University



Funding Source: Cognitive Decline Partnership Centre (CDPC)

There has been a pressing need to address the evidence practice gap between what has been described as best practice in pain management for people living with dementia in Residential Aged Care (RAC) services and what has been happening 'on the ground'.

Over a decade of research has highlighted that pain is largely unrecognised and frequently undertreated in people living with dementia. Persistent problems with the identification, assessment and management of pain are associated with systemic and cultural barriers specific to the RAC setting. Issues of key concern that were addressed in this project are cultural barriers that:

1. Reduce the ability of Personal Care Assistants (PCAs), who provide the most direct and constant care to people with dementia, to effectively engage in pain management processes
2. Constrain development of a culture that supports evidence-based pain management.

These issues were addressed through a participatory action research approach. Researchers worked in partnership with Multi-Disciplinary Teams (MDTs) at four RAC sites to develop strategies which targeted individual, group and organisational behaviours to facilitate the development of a culture that prioritises evidence-based pain management. Integral to this objective is the empowerment of PCAs as central stakeholders in the pain identification, assessment and management. The project findings informed the development of a transferable MDT Pain Management Model that will support RAC services to translate best practice pain management evidence into practice, to improve the lives of people with dementia who experience pain.

Study Status: Completed

Functional and symptomatic outcomes of psychogeriatric patients in Riverglen inpatient unit



Researchers: Professor Janine Stevenson, HammondCare



Sites: HammondCare Greenwich Hospital



Duration: Apr 2014 to Jun 2019



Project Partners: Nil



Funding Source: Internally supported

Determination of contributions to better outcomes should result in more efficient and better care of psychogeriatric inpatients and reductions in their length of stay.

During 2016, slow participant uptake has meant only 30 assessments have been completed (we are aiming for 100).

However, preliminary results indicate that patients fall into two groups: rapid responders and treatment-resistant, the latter requiring much longer stays and skewing length of stay figures.

Study Status: Data collection completed, data analysis in progress

Dementia

Mission-AD



Researchers: Associate Professor Stephen Macfarlane, HammondCare; Dr Madeleine Healy, Dr Antony Sutherland, Monash University



Sites: HammondCare Malvern



Duration: Sep 2017 to Sep 2019



Project Partners: Eisai Co. Ltd, Syneos Health, Covance, Bioclinica Inc.



Funding Source: ANAVEX Life Sciences

Recent years have seen the exploration of BACE-1 inhibitors as potential disease modifying therapies for Alzheimer's disease. To date BACE-1 inhibitor treatments have been unsuccessful including the BACE-1 inhibitor treatment tested in the MISSION-AD study.

The MISSION-AD study was a phase 3 placebo-control clinical trial of Elenbecestat (E2609) in subjects with early Alzheimer's disease. In this two year study participants were randomised to receive either 50mg of Elenbecestat or placebo, given as a once daily oral tablet. The investigational product under study, Elenbecestat (E2609), is a small-molecule BACE-1 inhibitor which has been hypothesised to lower concentrations of toxic amyloid proteins associated with cognitive impairment in Alzheimer's disease.

In September of 2019 the pharmaceutical sponsor of this study, Eisai, announced the closure of the study. Eisai reported findings of the safety and efficacy of the drug which warranted the studies closure.

At the Malvern clinical trial site 12 subjects were screened for the study with 7 eventually enrolled and randomised to receive medication. At the time of the study's closure 6 subjects were still enrolled in the study. None of these subjects experienced adverse events related to the study medication.

Study Status: Completed

Guided by Excellence



Researchers: Professor Susan Kurrle, University of Sydney; Associate Professor Colm Cunningham, Dr Meredith Gresham, Dr Patricia Knight, Dr Tom Morris, HammondCare



Sites: NA



Duration: Jul 2018 to Sep 2019



Project Partners: University of Sydney



Funding Source: Australian Government Department of Health

This project aims to evaluate the value of Dementia Support Australia services and provide further dementia guidelines for future development.

This research comprises 2 complementary activities:

1. To determine the extent to which clinical intervention recommendations made by health professionals employed by the Dementia Support Australia (DSA) service reflect recently released, NHMRC approved Dementia Clinical Practice Guidelines using detailed audit processes
2. Interviews with DSA clinicians and service users will determine barriers and enablers to the implementation of DSA clinicians' intervention recommendations in nursing homes and the community.

We anticipate that the results of this research will inform better understanding of preparation of DSA reports and translation of evidence-informed, best practice intervention for people living with dementia and those that provide support.

The audit is 75% complete and interviews are commencing nationally to capture a spread of geographic locations and service user types.

Study Status: Completed

Dementia

ANAVEX2-73-AD-004



Researchers: Associate Professor Stephen Macfarlane, HammondCare; Dr Madeleine Healy, Dr Andrew Gleason, Monash University; Dr Ken Teo, Box Hill Hospital



Sites: HammondCare Malvern, Pallister House and Greenwich Hospital



Duration: Aug 2018 to Aug 2020



Project Partners: ANAVEX Life Sciences, Worldwide Clinical Trials, Signet Health, 360 Biolabs



Funding Source: ANAVEX Life Sciences

Currently there are no commercially available therapies which address the underlying cause of Alzheimer's disease. Anavex2-73 is a new treatment showing promising disease modifying results.

The Anavex2-73-AD-004 study is a phase 2b/3 clinical trial of the experimental drug Anavex2-73 for the treatment of early Alzheimer's disease. This is a 48-week randomised, double blind and placebo control study. The experimental drug under investigation, Anavex2-73, is a sigma-1 receptor agonist and is thought to slow the progression of Alzheimer's disease pathology. In this study participants are randomised to receive one of three doses of Anavex2-73: 30mg, 50mg or placebo where each dose is given in the form of once daily oral capsules. The aim of this study is to understand how Anavex2-73 is processed in the body as well as how it impacts the participant's memory and thinking abilities.

The Malvern clinical trial site enrolled their first patient for this study in September of 2018. Since then over 45 patients have been screened for this study, with over 40 of those moving on to be randomised and receive medication. It is expected that screening for this study will be open until late 2020. The Anavex2-73-AD-004 study will be opening at the Sydney clinical trial site in early 2020.

Study Status: Ongoing

Ageing, restorative care & reablement

Evaluation of HammondCare Darlinghurst: An aged care home for people experiencing, or at risk of, homelessness | New in 2019



Researchers: Professor Chris Poulos, Dr Claire O'Connor, Dr Allison Rowlands, Angela Raguz, HammondCare; Associate Professor Roslyn Poulos, Dr Anurag Sharma, Kyall Flakelar, University of New South Wales; Associate Professor Steven Faux, St Vincent's Hospital; Peter Valpiani, The Haymarket Foundation



Site: HammondCare Darlinghurst



Duration: Aug 2019 to Jun 2021



Project Partners: University of New South Wales; St Vincent's Hospital



Funding Source: Ian Potter Foundation

Older people currently experiencing homelessness face barriers in accessing health and aged care, risking rapid decline in health with subsequent premature ageing and mortality. HammondCare Darlinghurst Aged Care Home will be one of the first facilities of its type in New South Wales providing a permanent home for this population.

This study is a service evaluation of the Darlinghurst Aged Care Home. The purpose of this study is to evaluate the value of the service in a holistic way to inform policy and practice in the key areas of policy and service provision for older people currently experiencing, or at risk of, homelessness. Objectives of the study are to:

1. Evaluate the impact of the HammondCare Darlinghurst model of care on residents' health and wellbeing
2. Explore potential intervention points in the trajectory of older people at risk of homelessness
3. Explore the contribution of HammondCare Darlinghurst to improved collaboration across the sector to reduce individual and societal burden of homelessness in older people
4. Explore the cost benefit of residents living in HammondCare Darlinghurst compared to their prior living arrangements

The outcomes from this research will be fundamental to informing future service model improvements.

Study Status: In Progress

Ageing, restorative care & reablement

Developing an assessment guide for practitioners implementing reablement programs for people living with dementia | New in 2019



Researchers: Dr Claire O'Connor, HammondCare; Professor Chris Poulos, HammondCare and University of New South Wales



Sites: HammondCare Hammondville and North Turramurra



Duration: Aug 2019 to Dec 2020



Project Partners: University of New South Wales



Funding Source: Australian Association of Gerontology Research Trust

The recently completed Reablement in Dementia project developed an evidence-informed Handbook of Reablement programs to support function in people living with dementia. Appropriate assessment of the effectiveness of these newly synthesised programs is paramount. Yet, how the programs will be assessed in practice in such a diverse industry with a range of health practitioners has not been determined.

Assessments used across the aged care sector to monitor intervention efficacy for people with dementia are heterogeneous, and health practitioners may be unfamiliar with using Goal Attainment Scaling (GAS) in practice. The focus of this study is to develop a brief guide for health practitioners on using GAS as a standardised approach to assess the impact of engaging in reablement interventions for the person living with dementia.

Guide development will be achieved through a process of:

1. Exploring what goals consumers (ie people with lived experience of dementia) might prioritise when planning reablement programs
2. Exploring with health practitioners the following : current intervention assessment protocols, understanding and experience with using GAS to assess therapy outcomes, what realistic therapy goals would apply to identified reablement programs, and how a resource could best support the application of GAS in their reablement practice
3. Developing an item bank (based on consumer and practitioner identified goals) to support standardised application of GAS in practice.

Disseminating this assessment guide with the Reablement Handbook will contribute to a standardised, evidence-informed approach to the provision and assessment of reablement services for people living with dementia.

Study Status: Completed

Preparing the workforce for an ageing Australia: the development of multidisciplinary competencies for healthcare | New in 2019



Researchers: Associate Professor Roslyn Poulos, Christina Maurice, Dr Mei-Ying Boon, University of New South Wales; Professor Chris Poulos, University of New South Wales and HammondCare; Associate Professor Ajesh George, Associate Professor Karen Liu, University of Western Sydney; Dr Karen Watson, University of Technology Sydney; Sarah Ramsey, HammondCare



Duration: Sep 2019 to Nov 2019



Project Partners: University of New South Wales



Funding Source: SPHERE Age and Ageing Clinical Academic Group

Caring for older people has unique challenges and complex needs that often require multiple health care providers. This may result in difficulties in ensuring consistent and streamlined care as they move from provider to provider. The research project aims to develop shared competencies which can promote consistent and integrated care, facilitate teamwork and inter-disciplinary practice, and improve the quality of care delivered to older people.

The project primarily involves two phases – a literature review to look at workforce competencies, and a 2-stage Delphi (via de-identified online survey) with a group of identified experts.

Study Status: In Progress

Ageing, restorative care & reablement

Development of evidence-based dementia reablement guidelines and programs deliverable to people living with mild to moderate dementia



Researchers: Professor Chris Poulos, Dr Meredith Gresham, Dr Claire O'Connor, HammondCare; Associate Professor Roslyn Poulos, University of New South Wales; Associate Professor Kathy McGilton, University of Toronto; Helen Radoslovich, Helping Hand; Wendy Hudson, Brightwater Group; Professor Lindy Clemson, Professor Ian Cameron, University of Sydney; Joan Jackman, Dementia Australia



Site: NA



Duration: Jan 2017 to Aug 2019



Project Partners: University of New South Wales; University of Sydney; Helping Hand Aged Care; Brightwater Group; Dementia Australia



Funding Source: NHMRC Cognitive Decline Partnership Centre

The recently released CDPC Clinical Practice Guidelines and Principles of Care for People living with Dementia (Guideline Adaptation Committee, 2016) were a major step forward in critically evaluating the evidence for interventions that could delay the onset of functional decline, or improve functioning and quality of life for people living with dementia.

The next step was to operationalise these guidelines for the community and residential aged care sectors to enhance the use of evidence-informed reablement interventions for people with mild to moderate dementia.

This project sought to gain an understanding of current provider knowledge and practice with respect to the meaning and utility of reablement for the person living with dementia, as well as the perceived barriers to implementing reablement interventions.

We reviewed the reablement interventions contained within the Clinical Practice Guidelines and Principles of Care for People living with Dementia for suitability for implementation by aged care providers. We also reviewed the literature for additional interventions published since, or not included within, the Practice Guidelines. Together with Cognitive Decline Partnership Centre (CDPC) partners and other stakeholders, including a consumer advisory team, we produced an evidence-informed Handbook of Reablement Interventions for People living with Dementia, for use within the Australian aged care sector. The Handbook and supporting resources, a Consumer Information Book and a Technical Guide, were launched at the International Dementia Conference in 2018. Since then, a process of review in consultation with the consumer advisory team resulted in development of the second editions, released in August 2019.

Study Status: Ongoing

HammondCare Darlinghurst Research Project



Researchers: Professor Chris Poulos, Dr Allison Rowlands, Angela Raguz, HammondCare; Associate Professor Roslyn Poulos, Dr Maria Agaliotis, University of New South Wales; Associate Professor Steven Faux, St Vincent's Health Australia



Sites: HammondCare Darlinghurst, HammondCare Hammondville and various government and non-government health and social service agencies



Duration: Oct 2018 to Oct 2019



Project Partners: The University of New South Wales Sydney St Vincent's Health Australia



Funding Source: Perpetual IMPACT Philanthropy

This qualitative research project informed the development of models of care for the new 42 bed nursing home in Darlinghurst for older people currently experiencing, or at risk of, homelessness.

30 participants were recruited from all levels of government and non-government service providers, research and policy groups, and key roles within HammondCare. Representatives came from the homelessness, health and aged care sectors.

Individual and structural factors lead to and sustain the experience of homelessness and indicate the wide range of care needs and organisational resources required to deliver care.

The care needs of people with co-morbid health issues and a background of loss and trauma were detailed by participants; from this a preferred model of care for residents was derived.

The findings supported HammondCare's current model of residential care, with the integration of a trauma-informed approach, consistently applied by all staff to all processes throughout the care home. Such an approach will further strengthen the existing model of care and take into account both health needs (such as mental health, substance dependence and acquired brain injury) and significant losses through the life course of this vulnerable population.

Findings from the project have also fed into the methodology for the evaluation of care that will be provided in the Darlinghurst home, once operational in February 2020.

Study Status: Completed

Rehabilitation

Randomised, Double-blind, Placebo-controlled Phase II Multi-Centre Evaluation to Assess the Safety and Tolerability of DM199 Administered Intravenously and Subcutaneously in Subjects with Acute Ischemic Stroke (ReMEDy Trial) | New in 2019



Researchers: Associate Professor Dennis Cordato, Liverpool Hospital; Professor Friedbert Kohler, Caitlin Anderson, HammondCare



Site: HammondCare Braeside



Duration: Apr 2019 to Apr 2020



Project Partner: Liverpool Hospital



Funding Source: External

Test safety, tolerability and efficacy of DM199 in acute stroke.

The objective of this Phase II clinical trial is to test the safety, tolerability and efficacy of a new drug DM199 in treating patients presenting with acute stroke. These objectives will be assessed as follows:

Safety

- Incidence, severity and causality of adverse events (AE) and serious adverse events (SAEs)
- Physical examination changes from baseline (days 4, 22, 56, and 90)
- Vital sign changes from baseline (resting heart rate, systolic/diastolic blood pressure, respiratory rate, and temperature) (days 1, 4, 7, 10, 13, 16, 19, 22, 56, and 90)
- Haematology and chemistry parameter changes from baseline (days 4, 22, 56, and 90)
- 12 lead ECG changes from baseline (days 1, 4, and 22)

Tolerability

- Assessed by incidence and severity of injection site adverse events

Efficacy

- NIH Stroke Scale (days 22 and 90)
- Barthel Index (days 22 and 90)
- Modified Rankin Scale (days 22 and 90)
- Plasma concentration of DM199 (days 2, 22, and 90).

A positive outcome will lead to a larger Phase III clinical trial and eventually an approved new treatment available for stroke sufferers.

Study Status: In Progress

New Model of Interpreter-mediated Aphasia Assessment for People from Diverse Language Backgrounds | New in 2019



Researchers: Hui Tao, Associate Professor Peter Roger, Macquarie University



Site: HammondCare Braeside Hospital



Duration: Apr 2019 to Dec 2019



Project Partners: Nil



Funding Source: In researcher's own time

Patients who develop aphasia following a stroke require comprehensive assessment by a speech pathologist in order to plan appropriate therapy.

For patients from diverse language backgrounds, an interpreter generally assists with the assessment. However, previous research has identified shortcomings of the current model of interpreter-mediated aphasia assessment.

The proposed research aims to investigate the efficacy of a new model of interpreter-mediated assessment that has been described in the research literature. In brief, this entails two separate sessions: the first is a video-recorded language assessment, while the second involves the speech pathologist and interpreter in a collaborative analysis of the recording.

Study Status: In Progress

Rehabilitation

Work smarter and harder – Optimising the dosage of swallow rehabilitation exercises | New in 2019



Researchers: Jacinda Choy, University of Sydney; Hans Bogaardt, Fereshteh Pourkazemi, University of Sydney; Caitlin Anderson, HammondCare



Site: HammondCare Braeside Hospital



Duration: Nov 2019 to Dec 2022



Project Partners: Nil



Funding Source: In researcher's own time

This research aims to identify optimal dosages and exercise types of swallowing therapy for patients with stroke for better patient outcomes and more efficient and cost-effective therapy across all Speech Pathology practice.

Recommendations from other areas (such as physiotherapy and exercise physiology) will be applied to swallowing therapy exercises and implemented with patients with dysphagia as part of a clinical trial. We are hoping that outcomes demonstrate more efficient therapy, that is, patients' swallowing ability and diet/fluid progression improve more rapidly (with less sessions or over less time) using optimal dosages and recommended exercise types. These outcomes will be presented internally and externally.

The HammondCare Speech Pathology department will change therapy practice for patients with dysphagia, through roll out of a quality improvement project after completion of the research. These results will also be presented to other sites and speech pathology departments to facilitate change of practice.

Study Status: Completed

A qualitative evaluation of The Jacaranda Cancer Rehabilitation Unit, Greenwich Hospital



Researchers: Dr Najwa Reynolds, Associate Professor Andrew Cole, Dr Bruce Walmsley, Professor Chris Poulos, HammondCare



Site: HammondCare Greenwich Hospital



Duration: Aug 2017 to Dec 2019



Project Partners: Nil



Funding Source: Internally funded

The project was a qualitative study which involved focus-groups with staff, and pre-and post-inpatient stay interviews with patients. 14 health professionals providing cancer rehabilitation services, and 22 patients receiving cancer rehabilitation services participated.

Part 1 of this study, regarding staff experience has been published in The European Journal of Cancer Care. Results revealed that staff participants in the study expressed a deep commitment to quality care of cancer survivors and their families, despite the challenges of providing sustained and equitable therapy within existing available limited resources. The health professionals working within this cancer rehabilitation setting sought to reduce disability and optimise patient function, whilst providing multidisciplinary rehabilitation services across multiple domains, in response to individual need, as they journeyed towards strength and independence.

Part 2 of this research, regarding the patient experience, is currently being reviewed for publication. Results revealed an immense array of personal challenges, including coping with functional losses, whilst assimilating the reality that life would likely not be the same as before the cancer diagnosis. A specific issue raised by patients, was their need for autonomy around food choices.

Outcomes have been presented internationally at the International Society of Physical & Rehabilitation Medicine in Kobe, June 2019, and in Norway, October 2019.

Study Status: Completed

Rehabilitation

ACTiveARM: Australian Constraint Therapy Implementation study of the ARM



Researchers: Reem Rendell, Nicola Acworth, South Western Sydney Local Health District; Lauren Christie, South Western Sydney Local Health District and University of Sydney; Annie McCluskey, Meryl Lovarini, University of Sydney; Lionel Wong, HammondCare



Site: HammondCare Braeside Hospital



Duration: Mar 2017 to Dec 2019



Project Partners: South Western Sydney Local Health District; University of Sydney; The Ingham Institute of Applied Medical Research



Funding Source: New South Wales Health Translational Research Grant Scheme (TRGS)

Constraint Induced Movement Therapy (CIMT) is an effective intervention for upper limb recovery following stroke and traumatic brain injury (TBI).

We aimed to establish whether a two-week publicly funded CIMT program could be translated into practice and sustained over two years across multiple health services in South Western Sydney Local Health District (SWSLHD).

Preliminary outcomes have been presented as oral and poster presentations at the Australasian Society for the Study of Brain Impairment (ASSBI) in Wellington, New Zealand in May 2019, the National Occupational Therapy Conference, Sydney in June 2019 and the Smart Strokes Conference in the Hunter Valley in August 2019. Final data analysis is currently ongoing with four papers planned for submission for publication based on the findings from this study.

Results: Baseline file audits (T1-T3, n=420) found 30% of patients were eligible for CIMT but few were provided with CIMT (n=3, <1%). File audits after delivery of the CIMT implementation package (T4, n=149; T5, n=156; T6, n=158; T7, n=164; T8, n=158; T9, n=165) showed improvements in CIMT delivery. More eligible people were offered CIMT (52% -73%, T4-T9). More people received CIMT (27% - 46%, T4 -T9). File audits at follow up (T10, n=175) showed sustained practice change (56% of eligible people offered CIMT; 40% received CIMT).

Conclusion: Nine therapy teams overcame an evidence-practice gap and increased CIMT delivery.

Study Status: Completed

Pain management

The effects of virtual reality on pain intensity and brain activity in people with neuropathic pain following spinal cord injury | New in 2019



Researchers: Professor Philip Siddall, Dr Phil Austin, HammondCare; James Middleton, Ashley Craig, Paul Wrigley, Yvonne Tan, Kolling Institute, Royal North Shore Hospital



Site: HammondCare Greenwich Hospital



Duration: Mar 2019 to Mar 2020



Project Partners: Kolling Institute, Royal North Shore Hospital, University of Sydney



Funding Source: Australian and New Zealand College of Anaesthetists

The aim of this study is to determine the effectiveness of virtual reality (VR) in reducing pain in people with spinal cord injury. In addition, it will examine whether the use of VR is associated with changes in brain activity that we know are associated with pain.

Evidence now shows that distraction type VR is useful for people with persistent pain. Virtual reality is becoming increasingly affordable and available for use in both clinical and experimental settings. Despite growing evidence of benefit and increased accessibility and affordability, there are no studies that have examined the effectiveness of distraction type VR in people with pain following spinal cord injury. The ability for patients to individually reduce the intensity of their neuropathic pain using affordable VR software would be a major advance for people who currently face major challenges in obtaining satisfactory relief from their pain.

In this study, people with a spinal cord injury and a diagnosis of chronic neuropathic pain will undergo two 20-minute intervention sessions. One session will comprise the use of immersive VR exploring a scene using a VR headset attached to a laptop. The alternate session will comprise viewing the same scene but directly watching the laptop screen. During each VR session, EEG recordings will be obtained from several cortical sites allowing analysis of cortical regions associated with neuropathic pain.

Early results are extremely promising and show major reductions in pain during VR and a very high level of satisfaction from people using the technique.

Study Status: In Progress

Restoring hope: fostering connections, engagement and purpose following a spinal cord injury | New in 2019



Researchers: Professor Philip Siddall, Rebecca McCabe, Dr Skye Dong, Shane Clifton, Dr Cindy Kok, HammondCare



Sites: HammondCare Greenwich Hospital



Duration: Sep 2019 to Mar 2022



Project Partners: icare



Funding Source: icare Foundation

The aim of this project is to promote psychological well-being and quality of life for people living with spinal cord injury through the development of a program that fosters a stronger sense of purpose in life.

Post-traumatic growth is a concept that proposes that positive psychological change can be experienced when people are faced with highly challenging life circumstances. The evidence shows that most people who experience traumatic life events actually emerge from the experience with greater inner strength. There is also extensive evidence of factors that are associated with a positive trajectory. This research is clearly applicable to people who have faced major trauma and injuries.

Our team has had experience developing and delivering a program based on the principles of post-traumatic growth to people with chronic pain. Based on our experience with developing and delivering this program, we were awarded funding by icare to develop a similar program for people with spinal cord injuries. The program will be piloted and evaluated in groups of people with a spinal cord injury. Evaluation and feedback from those in the pilot programs will inform changes for further refinement before finalising the program prior to full implementation. In addition, we will develop a support structure to follow up on issues raised by the program. This will include peer and health professional support and the development of an on-line platform to support interaction.

Study Status: In Progress

Pain management

Evaluation of the core strength program



Researchers: Professor Philip Siddall, Rebecca McCabe, Dr Skye Dong, HammondCare



Site: HammondCare Greenwich Hospital



Duration: Apr 2018 to Dec 2019



Project Partners: Nil



Funding Source: Donor support and in-kind support

The aim of this study is to develop and assess an innovative new program that addresses the existential and spiritual dimension of living with chronic pain.

Chronic pain affects 1 in 5 people and is a major cause of suffering. For many people, the impact of pain goes beyond the physical to deeper issues such as loss of purpose that are critical to our wellbeing. This means that a large number of people have ongoing pain that is compounded by a loss of purpose in life which contributes to further suffering.

There is now a growing body of evidence around the concept of post-traumatic growth - that positive psychological change can be experienced when faced with highly challenging life circumstances. A key component of post-traumatic growth appears to be the presence of a strong sense of purpose. This process and the fostering of a strong sense of purpose appear to be highly relevant and potentially helpful for people living with pain.

The program was very successful with positive outcomes and a high level of satisfaction from participants. The positive outcomes of this innovative program have been instrumental in being awarded funding from icare to develop a similar program using the same principles for people with spinal cord injuries.

Study Status: Completed

Outpatient pain self-management program



Researchers: Professor Philip Siddall, Rebecca McCabe, Dr Skye Dong, HammondCare



Site: HammondCare Greenwich Hospital



Duration: May 2011 to Dec 2019



Project Partners: Nil



Funding Source: Internally supported

This project aims to collect data from people attending HammondCare's group pain program and determine the effectiveness of our program in reducing pain and improving quality of life.

This project evaluates the pain program at Greenwich Hospital which has distinctive features in line with the HammondCare mission of addressing the whole person. This evaluation is essential in disseminating the results of our program and establishing the value of the program, particularly as it takes a new approach. This project has enabled us to identify factors within the program which are contributing to positive outcomes. This has led to further improvements that have meant that our chronic pain program consistently achieves outcomes that place us as one of the most effective pain programs in Australia.

The researchers evaluated outcomes from over 100 people who completed the pain program. The results either match or exceed results from other pain clinics including an average reduction in pain of over 30% which places us in the top three clinics across Australia and New Zealand. An unexpected but interesting finding was that one of the best predictors of a reduction in pain during the program was the person's level of spiritual wellbeing.

Study Status: Completed

Pain management

A clinically relevant tool for assessing pain modulatory pathways



Researchers: Professor Philip Siddall, Dr Phil Austin, HammondCare; Dan Costa, Ali Asghari, University of Sydney



Site: HammondCare Greenwich Hospital



Duration: Feb 2014 to Jun 2019



Project Partners: University of Sydney



Funding Source: Australian and New Zealand College of Anaesthetists

This project aims to develop a new questionnaire that can assess the level of pain modulation in the central nervous system of people living with pain.

Pain modulation describes the pathways and chemicals within the brain and spinal cord system that act to enhance or reduce the intensity of pain. As such, it is a major determinant of the severity of pain. However, there is still no simple, non-invasive tool that can quickly assess pain modulation in the clinical setting.

The aim of the project was to develop and validate a new, inexpensive and easy-to-use measure consisting of a short patient questionnaire that evaluates symptoms and signs associated with changes to internal pain modulation. This was done by using a questionnaire that has been developed in preliminary studies and administering it to a sample of people with various chronic pain conditions and a group of people without pain.

From this pilot study, an initial "pain modulation index" was developed. The Pain Modulation Index with its supporting results was submitted as a research article and was published by the *Scandinavian Journal of Pain* in late 2019. This study has already garnered a high level of interest from researchers and clinicians around the world.

Study Status: Completed

Advance care planning

National prevalence study of advance care planning documentation and self-reported uptake in Australia



Researchers: Led by Dr Karen Detering and Linda Nolte from Advance Care Planning Australia; Professor Josephine Clayton from HammondCare is an investigator on the study



Sites: National



Duration: Jan 2017 to Jun 2020



Project Partners: Advance Care Planning Australia



Funding Source: Australian Government National Palliative Care Project (as part of funding for Advance Care Planning Australia)

This is the first national multicentre cross-sectional prevalence study consisting of records audit and surveys of persons aged 65 years or more.

This project aims to determine the prevalence of advance care planning (ACP) documentation in Australian hospitals, residential aged care facilities and general practices.

A paper reporting the outcomes of the first phase of the project was published in 2019 including data from 2285 people. The results of this study suggest that greater efforts are required to promote and standardise advance care directives across jurisdictions to assist older people to navigate and complete advance care directives and to receive care consistent with their preferences. The findings also informed future steps towards improved ACP data collection methodology, ACP implementation strategies and evaluation processes.

Phase 2 of the study included 101 sites and data from over 4,000 people. Analysis of Phase 2 is in progress.

Study Status: Ongoing

Advance care planning

The Advance Project: Initiating palliative care and advance care planning through training and resources for primary care clinicians



Researchers: Professor Josephine Clayton, Associate Professor Joel Rhee, Srivalli Nagarajan, Kelly Arthurs, HammondCare (lead organisation)



Sites: National Project led by HammondCare's Centre for Learning and Research in Palliative Care, Greenwich Hospital



Duration: Aug 2017 to Jun 2020



Project Partners: Professor Jennifer Tieman, Caresearch; Professor Geoffrey Mitchell, University of Queensland; Professor Elizabeth Halcomb, University of Wollongong; Professor Jane Phillips, University of Technology Sydney; Dr Karen Detering, Advance Care Planning Australia; Associate Professor Rachael Morton, Associate Professor Virginia Lewis, La Trobe University



Funding Source: Australian Government Department of Health

This national program is enabling GPs, nurses and practice managers across Australia to implement a team-based approach to initiating advance care planning and palliative care to improve care for older and chronically ill Australians.

Primary care has been advocated as an ideal setting to initiate early Advance Care Planning (ACP) and palliative care so that more Australians can benefit. Evidence from evaluation of the initial phase of the Advance Project suggests that nurses in general practice are well placed to initiate conversations about ACP and assess patients' and carers' palliative/supportive care needs. Further funding from the Australian Government has enabled expansion of the Advance Project to support GPs, nurses and practice managers using a systematic and team-based approach to initiating ACP and assessing and addressing palliative care needs in everyday general practice.

Feedback from nurses participating in Phase 1 of the project, an updated literature review and extensive stakeholder engagement with GPs, general practice nurses, practice managers and consumers informed development of new clinician, patient and carer resources, and new online learning activities and training videos, specifically designed to meet the learning needs of Australian GPs and practice managers. The online training for general practice nurses has been revised and updated to incorporate feedback from Phase 1 and the new resources. One-on-one mentoring is available to support individual primary care clinicians and general practices to implement the resources in clinical practice.

Four champion primary health networks/alliances across three states of Australia are being supported with grants and train-the-trainer support to deliver face-to-face training and support implementation locally. Data is being collected from a subset of clinical sites to inform ongoing implementation. The online training and resources are freely available from www.theadvanceproject.com.au

Study Status: Ongoing

Prevalence of Advance Care Directives in Australian health and residential aged care services



Researchers: Dr Karen Detering and Linda Nolte, Austin Health; Veronica Mera, Rodney Berg, HammondCare



Sites: HammondCare Braeside, Greenwich and Neringah Hospitals



Duration: Oct 2018 to Jun 2019



Project Partners: Austin Health



Funding Source: In-kind support

The specific aims of this study are to:

1. Assess the prevalence of Advanced Care Directives (ACDs) and other Advanced Care Planning (ACP) documentation in health records of people aged 65 years or more in general practices, hospitals, and Residential Aged Care Facilities (RACFs)
2. Assess the content and quality of ACDs
3. Explore whether medical orders developed for the person are consistent with their documented preferences for care
4. Explore the characteristics of individuals who have an ACD in their medical record
5. Promote awareness of advance care planning and provide data to assist organisations, including HammondCare, to monitor and improve advance care planning processes and practices.

69 health records were audited from HammondCare hospitals. The results have informed ongoing improvements in advance care planning processes at these sites.

Study Status: Completed

Spiritual aspects of care

Spiritual care for people living with dementia | New in 2019



Researchers: Dr Robyn Wrigley-Carr, Senior Lecturer in Theology and Spirituality, Alphacrucis College



Site: HammondCare Wahroonga



Duration: Aug 2019 to Dec 2019



Project Partners: Alphacrucis College



Funding Source: ARTfinc Grant

People living with dementia in nursing homes have spiritual needs that need to be recognised and nurtured. Corporate worship through weekly chapel services is an important means for spiritual care for people living with dementia. These weekly chapel services can be made more accessible and meaningful for people living with dementia through emphasising sensory stimulation and rituals to 'awaken' people through bodily engagement. Small group worship involving communal and bodily rituals such as partaking in the Eucharist, hand washing to accompany confession, and 'Ignatian meditation' provide effective ways to deepen the spiritual care for people living with dementia.

This research funded through an ARTfinc Grant examined spiritual care for people living with dementia through corporate worship - both chapel services and small group sessions. The researcher was a participant-observer of weekly chapel services led by the Pastoral Care Coordinator at a HammondCare dementia care home over a 6-month period. People living with dementia participating in the chapel services were interviewed after chapel services to hear their expressed experiences, plus their suggestions for creative ways forward for enriching future chapel services. Some of these ideas were incorporated into subsequent chapel services. For example, the 'passing the peace,' where people clasp each other's hands, greeting each other with a smile. The role of volunteers in sensory stimulation during chapel services was significant.

The theoretical undergirding for this research was Baron Friedrich von Hügel's philosophy concerning the 'Three Elements of Religion' – the 'Mystical Element' (people's experiences of God), the 'Intellectual Element' (people's thoughts about God), and the 'Institutional Element' (the corporate, bodily, and sacramental). Given the diminution of the 'Intellectual Element' of religion for people living with dementia, this research sought to compensate by attending to the 'Institutional Element' of religion and von Hügel's argument that the human spirit is 'awakened' through the stimulation of the senses and through corporate experiences of religious rituals.

Observation revealed that sensory stimulation and engagement in simple rituals appeared to make chapel services more accessible for many participants, enriching both their attentiveness and enjoyment of corporate worship.

This research also involved engaging people living with dementia in small group sessions where they received the Eucharist, partook in hand washing (symbolic of cleansing during corporate confession) and 'Ignatian meditation' on a short biblical gospel narrative.

This research formed the basis for a keynote lecture given at the '8th International Conference on Ageing and Spirituality' held in Canberra at Old Parliament House in October 2019, being published in the *Journal for Religion, Spirituality and Aging* in 2020. The specific aspect of 'Ignatian meditation' for people living with dementia is the basis for a conference talk being given at the 'Sixth International Conference for the British Association for the Study of Spirituality' in York, UK in June, 2020 and will be submitted for publication in the *Journal for the Study of Spirituality*.

Study Status: Completed

Spiritual aspects of care

Palliative caregivers' spirituality, views about spiritual care, and associations with well-being



Researchers: Associate Professor Clare O'Callaghan, Natasha Michael, Cabrini Health; Professor Josephine Clayton, Steve Calder, Dr Sarah Thompson, HammondCare; Davinia Seah, St Vincent's Hospital Sydney; David Kissane, University of Notre Dame Australia (Sydney)



Sites: Various palliative care sites at HammondCare, Cabrini Health and St Vincent's Hospital



Duration: Aug 2017 to Jun 2019



Project Partners: Cabrini Health; St Vincent's Hospital Sydney



Funding Source: Cabrini Health Foundation

Spiritual care is integral to palliative care. It engenders a sense of purpose, meaning, and connectedness to the sacred or important and may support caregiver well-being.

Scant information exists on how caregivers of people living with advanced illnesses conceptualise spirituality and their need for support in this area. Finding meaning and religiosity can support coping with adversity. This is a mixed methods study utilising an anonymous semi-structured questionnaire to examine caregivers' spirituality, religiosity, spiritual well-being, and views on spiritual/religious support.

109 caregivers of patients with a life expectancy of under 12 months participated across four Australian sites including HammondCare. In 2019 the analysis was completed and a manuscript was accepted for publication.

Participating caregivers prayed and meditated more following patients' diagnoses, gaining comfort, guidance and strength. Caregivers whose spiritual/religious needs were met to moderate/full extent by external religious/faith communities reported significantly greater spiritual well-being. Pastoral care visits comforted 84% of those who received them. Caregivers also emphasised the importance of humane staff and organisational tone in supporting spiritual care.

The results also suggested that spiritual care providers should seek to identify those who seek pastoral or religiously orientated care. Genuine hospitality of showing concern for other perspectives ensures the varied yet frequently humanist requirements of the caregiver community are met.

These findings will inform ongoing enhancements to spiritual support provided to caregivers of patients being cared for in HammondCare's palliative care services.

Study Status: Completed

Spiritual aspects of care

Understanding spiritual encounters and requirements of patients living with serious illnesses



Researchers: Associate Professor Clare O'Callaghan, Associate Professor Natasha Michael, Cabrini Health; Daviniah Seah, St Vincent's Hospital Sydney; David Kissane, University of Notre Dame Australia (Sydney); Professor Josephine Clayton, Steve Calder, Dr Sarah Thompson, HammondCare



Sites: Various palliative care sites at HammondCare, Cabrini Health and St Vincent's Hospital



Duration: Aug 2017 to Jun 2020



Project Partners: Cabrini Health Foundation



Funding Source: Cabrini Health Foundation

Spirituality refers to how people experience meaning, purpose and connectedness to that which they consider significant (possibly religion). Finding meaning and religiosity can support coping with adversity.

Scant information on how Australian patients conceptualise spirituality and their requirements exist. The study aims to understand spiritual needs, views, encounters and requirements of palliative care patients to inform future development of palliative spiritual care.

Specific objectives are to:

1. Examine quantitative associations between spiritual well-being, level of spirituality/religiosity, spiritual concerns and spiritual/religious support given
2. Understand qualitatively how patients conceptualise their spirituality and religiosity
3. Explore qualitatively patients' views about advancing spiritual care.

The mixed methods design includes: semi-structured, anonymous surveys which will include a validated spiritual well-being measure (FACT-Sp12), researcher devised spiritual concerns lists, selected questions from another study (Balboni, JAMA, 2013) to examine pre-post diagnosis religious behaviours and spiritual support received, and other study specific questions, including about how to connect participants with what is valued. Australia's Palliative Care Strategy asserts that healthcare needs to address 'spiritual requirements' of those affected by serious illnesses.

Findings are anticipated to:

1. Provide insight into spiritual concerns amongst patients living with serious illnesses
2. Inform evidence-based development of spiritual care strategies, e.g. prompt lists identifying those needing additional spiritual support; generalist staff; spiritual care guidelines/training; and spiritual care resources/interventions.

Recruitment has been completed involving 261 patients from four sites.

Study Status: Analysis is in Progress

**We seek to research,
develop and improve
care and services. We
encourage creativity
and innovation.**



Teaching & professional activities

Professor Josephine Clayton

Director of Centre for Learning and Research in Palliative Care Medicine, HammondCare

Josephine is Director of Centre for Learning and Research in Palliative Care, Senior Staff Specialist Physician in Palliative Medicine for HammondCare and Professor of Palliative Care at the University of Sydney.

She is Director and Chair of the National and International Advisory Groups for the Advance Project for initiating palliative care and Advance Care Planning (ACP) in primary care www.theadvanceproject.com.au. This project is funded by the Australian Government and led by HammondCare in collaboration with various health organisations and universities across Australia.

In 2019, Josephine served on several national committees in the field of palliative care and ACP, was Scientific Committee Member for the ACP International Conference and invited opening plenary speaker at the Asia Pacific Hospice Conference.

Josephine contributes to teaching various health professionals about palliative care and ACP locally, nationally and internationally. She is also leading the revision of palliative care teaching for medical students across the University of Sydney for the new Medical Curriculum from 2020.

Professor Melanie Lovell

Senior Staff Specialist, Palliative Care, HammondCare

Melanie is Senior Staff Specialist in Palliative Care with HammondCare, Clinical Associate Professor at University of Sydney and Adjunct Professor at University of Technology Sydney.

During 2019, she continued her active participation in the Palliative Care Clinical Studies Collaborative and Cancer Symptom Trials Group in the Scientific and Trials Management Committees.

Melanie was on the Management Committee of Sydney Vital, the Northern Sydney Translational Cancer Research Centre, and leads the Translational Centre of Excellence in Palliative Care and Pain. She is also reviewer for several palliative care journals and grant programs.

Melanie continues to teach students at University of Sydney. She has one current PhD student with University of Technology Sydney, one who completed this year, and another with the University of Sydney. She is on the Working Party of the National Cancer Pain Assessment and Management Guideline and the Royal Australasian College of Physicians Working Party to develop a Spirituality Workshop for physicians.

Professor Roderick MacLeod

Senior Consultant, HammondCare and Honorary Professor at the University of Sydney School of Medicine

Rod is a Senior Consultant at HammondCare and Honorary Professor at the Sydney School of Medicine. He spends much of the year in Auckland, New Zealand where he is Clinical Advisor to Hospice New Zealand and Honorary Professor in the University of Auckland's Department of General Practice and Primary Health Care.

Rod has given talks to the public and professionals on several aspects of end of life care in both Australia and New Zealand. He is also a reviewer for several international journals and grant giving bodies.

He is one of two Editors in Chief for a major reference work Textbook in Palliative Care published this year by Springer. Rod has also been involved in several research projects in aspects of palliative care and end of life care.

Teaching & professional activities

Professor Christopher Poulos

Head of Research and Aged
Care Clinical Services for
HammondCare

Chris is Head of Research and Aged Care Clinical Services for HammondCare. He is also a Conjoint Professor in the School of Public Health and Community Medicine, Faculty of Medicine, University of New South Wales, and a Visiting Professorial Fellow with the Australian Health Services Research Institute (AHSRI), University of Wollongong.

Chris has an active teaching role in the areas of rehabilitation, reablement and restorative care, and the role of arts in health and aged care. He contributes to the University of New South Wales postgraduate and undergraduate teaching programs, and has presented widely at national and international aged care and rehabilitation conferences.

He is the co-convenor for the postgraduate course, Contemporary Issues in Ageing, within the Master of Public Health degree at the University of New South Wales and is actively involved in Rehabilitation Medicine registrar training.

Chris has presented widely at national and international aged care and rehabilitation conferences.

During 2019, Chris delivered the annual Burniston Oration at the Royal Australasian College of Physicians Conference in Auckland, New Zealand.

Professor Philip Siddall

Senior Staff Specialist,
Pain Management Service,
HammondCare

As well as his role as Director of the Pain Management Service at Greenwich Hospital, HammondCare, Phil is Conjoint Professor in Pain Medicine at University of Sydney. He teaches within the Graduate Medical Program at the university and the Postgraduate Program in Pain Management in addition to teaching trainees in anaesthesia, pain medicine and rehabilitation.

During 2019, he presented lectures to doctors, nurse and allied health practitioners in general practice, rehabilitation, anaesthesia and pain medicine.

In 2019, Phil also served as a member of state and national professional committees in the areas of state-wide policy development and service implementation including co-chair of the NSW Agency for Clinical Innovation Pain Management Network.

Professor Janine Stevenson

Director,
Aged Care Psychiatry,
HammondCare

Janine is involved in curriculum development, lecturing and supervising in the Master of Medicine (in Psychotherapy) Program for Sydney University.

She also leads tutorials and lectures for medical students, and post-graduate students at the BMRI and HETI, as well as involvement in examining both medical students and registrars. She is on the RANZCP committee for examinations and CSIMGE and lectures internationally as well as supervising psychiatrists in China via Skype.

Associate Professor Colm Cunningham

Director of
The Dementia Centre,
HammondCare

Colm is the Director of HammondCare's Dementia Centre. He holds dual tertiary posts: as a Visiting Fellow in Dementia Design and Practice at the University of Edinburgh, School of Health in Social Science, and he is a Conjoint Associate Professor at the University of New South Wales in the School of Public Health and Community Medicine. He is also a member of the Wicking Strategic Review Panel.

Colm is widely published in the areas of pain management in dementia, environmental design that supports people with dementia, dementia and delirium, behavioural and psychological symptoms of dementia, dementia and intellectual disabilities and night care.

Teaching & professional activities

Associate Professor Andrew Cole

Chief Medical Officer;
Senior Staff Specialist,
Rehabilitation Medicine,
HammondCare

Andrew continues in his substantive roles within HammondCare as Senior Staff Specialist (Rehabilitation) at Greenwich Hospital and as Chief Medical Officer. He is a Conjoint Associate Professor at University of New South Wales in the School of Public Health and Community Medicine. In 2019, Andrew was appointed to the Faculty of Medicine and Health Science at Macquarie University, as Chair of that Faculty's Admission and Selection Development Committee (ASDC).

During 2019 he also continued regular teaching of medical students at University of New South Wales in Med 4 at Kensington and St George campuses, and presented lectures and seminars to doctors, nurses and allied health professionals in continuing education and training programs in rehabilitation, general practice, community health and aged care settings in Australia, China, Thailand, Norway and the United States of America.

Andrew continued to serve as a member of several national and international Rehabilitation Medicine peak bodies throughout 2019. He is currently AFRM Past-President and AFRM representative on the Fellowship Committee of the Royal Australasian College of Physicians. He continues as a member of the Education, Statutes and UN Liaison Committees of the ISPRM.

Associate Professor Friedbert Kohler

Director of Medical Services,
HammondCare Health

In addition to his role as Director of Medical Services, HammondCare Health, Friedbert was also the President of the International Society for Prosthetics and Orthotics until October 2019. He is the Chair of Age and Ageing Clinical Academic Group of the Sydney Partnership for Health, Education, Research and Enterprise.

Friedbert is actively involved in promoting better awareness of elder abuse and in the development of a more coordinated approach.

Friedbert's work includes a continued emphasis on models of care and he has been invited to join the Ministry of Health Steering Committee on Value Based Health Care. He continues to focus on translational change in the clinical practice arena with a focus on enhancing specialty services in acute wards and increasing community-based services.

His work has sought to better understand the journey of an elderly patient requiring hospital admission and in developing community services to minimise the requirement of admission into hospitals.

Associate Professor Stephen Macfarlane

Head of Clinical Services,
The Dementia Centre,
HammondCare
Binational Chair, Faculty
of Psychiatry of Old Age,
RANZCP

Steve is Head of Clinical Services at The Dementia Centre and a Clinical Associate Professor of Aged Psychiatry at Monash University. He is active in medical student teaching at Monash and is co-convenor of the Advanced Training Program in Aged Psychiatry for Victoria.

Steve sits on several committees for the Royal Australian and New Zealand College of Psychiatrists (RANZCP), including the Committee for Research and the Members' Advisory Council. An RANZCP Examiner, he is also Chair of the Faculty of Old Age Psychiatry (FPOA) within the College.

He has been actively involved in Alzheimer's disease clinical trials since 1999 as a Principal Investigator at site, national and global levels, and has authored over 30 publications in the areas of dementia, senile squalor, and BPSD management.

Teaching & professional activities

Dr Julie Christie

International Service
Manager, HammondCare

Julie is the International Service Manager for HammondCare based in the United Kingdom, a visiting Research Fellow at University of Edinburgh and Adjunct Lecturer at University of New South Wales. Julie's teaching contributions have focused on resilience in the context of dementia and at the end of life, and community development approaches for dementia support.

Julie has delivered two books this year - Talking Sense: Living with Sensory Changes and Dementia, co-authored with Agnes Houston, a Scottish dementia activist, and her forthcoming book Promoting Resilience in Dementia Care: A person-centred framework for assessment and support planning is available in February 2020.

Her research has included the impact of different types of support for people with dementia including the Dementia Assistance Dog Programme in Scotland, a Social Return on Investment Study of a Community Navigator Service in Northern Ireland and most recently, an evaluation of funded dementia-friendly communities across Scotland.

Dr Meredith Gresham

Formerly Head of Research
and Design, HammondCare

Meredith is an Occupational Therapist and Head of Research and Design for HammondCare's Dementia Centre. She is a Designated Systems Based Investigator for the NHMRC Cognitive Decline Partnership Centre.

Meredith has worked in many areas of dementia care over the last 30 years including clinical care, family carer support, advocacy, service development and research.

Meredith's research interests span family carer education, policy and service development for people with severe behavioural and psychosocial symptoms of dementia, environmental design, the use of novel technologies in aged care and the use of clinical care guidelines.

The overarching theme of her research has been embedding research outputs into practice that make tangible, positive differences in the lives of people living with dementia and their supporters.

Dr Stephen Judd

Chief Executive,
HammondCare

As Chief Executive of HammondCare Stephen is an active contributor to sustainable aged care policy development and best practice.

Stephen is currently a member of the Aged Care Sector Committee, and the Advisory Council to the Aged Care Quality and Safety Commission. In 2019 Stephen was also a member of the Dementia, Ageing and Aged Care Research Mission Expert Advisory Panel.

Having written and contributed to the publication of numerous books on dementia care, aged care design and the role of charities, Stephen continues to be actively involved with Government councils, consultative committees, peak industry bodies and research partnerships.

He attends and presents at national and international aged care, health and dementia care conferences. In 2019, this included being a panel member at the Global Ageing Conference on Promoting a Human Rights Based Approach to Dementia and speaking about the future of aged care, at a CEDA event.





2019 RESEARCH UPDATE

Education Publications & Presentations

Education

Higher research degrees
Academic degree supervision
Awards

Publications

Books and chapters
Journal articles
Industry and magazine articles
Technical and other reports

Presentations

Academic conference and
industry seminars

Education

Higher research degrees



Student name: Juliet Kelly
Degree: MSc Dementia – International Policy and Practice
University: The University of Edinburgh
Graduated: December 2019

Academic degree supervision



Student name: Jessica Lee
Degree: PhD
University: The University of Sydney
Thesis title: Improving outcomes for people living with neuropathic cancer pain: a mixed methods doctoral research project
Supervisors: Agar M, Phillips J, Lovell M.

Student name: Graham Grove
Degree: PhD
University: The University of Sydney
Thesis title: Euthanasia: predictors of opinions
Supervisors: Best M, Lovell M.

Student name: Marcus Sellars
Degree: PhD
University: The University of Sydney
Thesis title: Towards person-centred advance care planning in chronic kidney disease
Supervisors: Clayton J, Tong A, Morton R.

Student name: Jim Xu
Degree: PhD
University: The University of New South Wales
Thesis title: A Core Set for people following lower limb amputation based on the International Classification of Functioning, Disability and Health
Supervisors: Dickson H, Kohler F.

Student name: Seema Radhakrishnan
Degree: PhD
University: The University of New South Wales
Thesis title: The Development of an Internationally valid ICF based mobility outcome measure in lower-limb limb amputation rehabilitation
Supervisors: Kohler F, Dickson H.

Student name: Salina Iupati
Degree: PhD
University: University of Otago
Thesis title: Models of Effective Community Based Specialist Palliative Care Services: delivery, international experience and the current landscape in New Zealand. Proposed model(s) to meet future demand
Supervisors: MacLeod R.

Student name: Lis Latta
Degree: PhD
University: University of Otago
Thesis title: Experiences of palliative care education in NZ undergraduate medical and nursing education. (University of Otago)
Supervisors: MacLeod R.

Education and Publications

Academic degree supervision



Student name: Xiangfeng Xu (Renee)

Degree: PhD

University: The University of Sydney

Thesis title: Developing a cultural specific education program for Chinese background cancer patients on pain management: a mixed methods study

Supervisors: Philips J, Luckett T, Wang A, **Lovell M.**

Student name: Jane Wu

Degree: PhD

University: The University of NSW

Thesis title: Early Rehabilitation in Trauma and Critical Illness

Supervisors: **Poulos C**, Faux S and Harris I.

Awards



O'Connor C. DCRC: *Capacity Building in Care Research Program (CBCR) – Fellowship*, 2019-2021.

Siddall P. The effects of virtual reality on pain intensity and brain activity in people with neuropathic pain following spinal cord injury, *Russell Cole Memorial ANZCA Research Award*, May 2019

Books and chapters



Beilharz K, **Poulos C**, Poulos R, **Fodera J**, **Cole A**, **MacLeod R**. 2019. Creative art making in palliative care. In: **MacLeod R**, Van den Block L. (eds) *Textbook of Palliative Care*. Springer, Cham. https://doi.org/10.1007/978-3-319-31738-0_3-1

Christie J, **Marshall M**. 2019. Technology for Organisations Supporting People with Dementia. In: Astell A, Smith S, Joddrell P. (eds) *Using Technology in Dementia Care. A Guide to Technology Solutions for Everyday Living*, JKP, London.

Houston A, **Christie J**. *Talking Sense: Living with Sensory Changes and Dementia*. HammondCare Media, Australia.

MacLeod R, **Macfarlane S**. 2019. *The Palliative Care Handbook*. (9th Edition) Hospice New Zealand, Wellington, New Zealand.

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MacLeod R, Latta E. 2019. Education and Palliative Care, Overview. In: **MacLeod R**, Van den Block L. (eds) *Textbook of Palliative Care*. Springer, Cham. https://doi.org/10.1007/978-3-319-31738-0_95-1

MacLeod R, Van den Block L. (editors), 2019. *Textbook of Palliative Care*. Springer, Cham. <https://doi.org/10.1007/978-3-319-31738-0> ISBN 978-3-319-31738-0

Marshall M. 2019. *Talking Murals. The Use of Murals in Places where People with Dementia Live*. HammondCare Media, Australia.

Siddall P, **MacLeod R**. 2019. Physical, Psychological/Psychiatric, Social, and Spiritual Problems and Symptoms. In: **MacLeod R**, Van den Block L. (eds) *Textbook of Palliative Care*. Springer, Cham https://doi.org/10.1007/978-3-319-31738-0_3-1

Sinclair C, Bucks R, Blake M, Williams K, **Clayton J**, Auret K, Radoslovich H, Callaghan S, Field S, Kurrle S. 2019. We've always thought of one another": Relational perspectives on autonomy and decision-making among people with dementia and their family carers. In Macdonald G, Mears J (eds) *Dementia as Social Experience: Valuing Life and Care*. Routledge, Taylor & Francis, Oxon UK. ISBN: 978-0-9153-7457-2

Swinton J, Kelly E. 2019. Chaplaincy and the Soul of Health and Social Care: *Fostering Spiritual Wellbeing in Emerging Paradigms of Care*. Jessica Kingsley Publishers, London.

Publications

Journal articles



Andrews S, Dipnall J, Tichawangana R, Hayes K, Fitzgerald J, Siddall P, Poulos C, Cunningham C. 2019. An exploration of pain documentation for people living with dementia in aged care services. *Pain Management Nursing*. doi: 10.1016/j.pmn.2019.01.004.

Austin P, Lovell M, Siddall P. 2019. The efficacy of virtual reality for persistent cancer pain: A call for research. *Journal of Pain and Symptom Management*. 58:e11-e14, doi:10.1016/j.jpainsymman.2019.07.009

Austin P, Siddall P. 2019. Virtual reality for the treatment of neuropathic pain in people with spinal cord injuries: a scoping review. *Journal of Spinal Cord Medicine*. doi: 10.1080/10790268.2019.1575554

Austin P, Asghari A, Costa D, Siddall P. 2019. The development of a novel questionnaire assessing alterations in central pain processing in people with and without chronic pain. *Scandinavian Journal of Pain*. doi: 10.1515/sjpain-2019-0087.

Best M, McArdle M, Huang Y, **Clayton J**, Butow P. 2019. How and how much is spirituality discussed in palliative care consultations for advanced cancer patients with and without a question prompt sheet? IN PRESS *Patient Education & Counseling*. 102 (12): 2208-2213 doi: 10.1016/j.pec.2019.06.016. Epub 2019 June 19. PMID:31235394

Bourne E, McAllister L, **Nagarajan S**, Short K. 2019. The effect of speech-language pathology students on clinician time use and activity. *International Journal of Speech-Language Pathology*. 21(2), 163-174.

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Butow P, **Clayton J**, and Epstein RM. 2019. Prognostic awareness in adult oncology and palliative care. IN PRESS *Journal of Clinical Oncology*, accepted April 2019.

Chow J, Gonzalez-Arce V, Knight A, Maurya N, & **Kohler F.** 2019. Learnings from implementing telemonitoring – the LITE study. *Journal of Integrated Care*. 27(4), 346–356. doi:10.1108/jica-05-2019-0022

Clark K, Byrne P, Rowett D, Brown L, Hunt J, **Lovell M**, Currow D. Pharmacovigilance in Hospice/ Palliative care: De-prescribing Combination Controlled Release Oxycodone-Naloxone. Accepted *Journal of Palliative Medicine*, October 29, 2019.

Clayton J, Ritchie A, Butow P. 2019. Enabling better end of life communication in residential aged care. *Patient Education & Counseling*, Dec;102(12):2131-2133. doi: 10.1016/j.pec.2019.10.014. PMID: 31711603

Detering K, Buck K, Ruseckaite R, Kelly H, Sellars M, Sinclair C, **Clayton J**, Nolte L. 2019. Prevalence and correlates of advance care directives among older Australians accessing health and residential aged care services: Multi-centre audit study. *BMJ Open*, January 15;9(1):e025255. doi: 10.1136/bmjopen-2018-025255. PMID: 30647047

Gresham M, Heffernan M, Brodaty H. 2018 The Going to Stay at Home program: combining dementia caregiver training and residential respite care. *International Psychogeriatrics*. 30 (11) 1697-1706.

Gresham M, Taylor L, Keyes S, Wilkinson H, McIntosh D, **Cunningham C.** 2019. Developing evaluation of signage for people with dementia. *Housing, Care and Support*, Vol. 22 No. 3, pp. 153-161. <https://doi.org/10.1108/HCS-12-2018-0035>

Harkin D, O'Connor C, Birch M, **Poulos C.** 2019. Perspectives of Australian family carers of people with dementia on the 'cottage' model of respite: compared to traditional models of residential respite provided in aged care facilities. IN PRESS. *Health and Social Care in the Community*, DOI: 10.1111/hsc.12916.

Hosie A, Phillips J, Kochovska S, Brassil M, Noble B, Kurrle S, Cumming A, Caplan G, Chye R, Le B, Ely E, Lawlor P, Bush S, Davis J, **Lovell M**, Brown L, Fazekas B, Cheah S, Edwards L, Agar M. 2019. Multicomponent non-pharmacological intervention to prevent delirium for hospitalised people with advanced cancer: study protocol for a phase II cluster randomised controlled trial. *BMJ Open*. 9 (1).

Houston A, Christie J. 2019. Seeing Dementia through the Senses. *Australian Journal of Dementia Care*, October / November 2019.

Publications

Journal articles



Kelly A, Luckett T, **Clayton J**, Gabb L, Kochovska S, Agar M. 2019. Advance Care Planning in different settings for people with dementia: A systematic review and narrative synthesis. *Palliative & Supportive Care*, June 10:1-13. doi: 10.1017/S1478951519000257. [Epub ahead of print] PMID:31177997

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O'Callaghan C, Seah D, **Clayton J**, Welz M, Kissane D, Georgousopoulou E, Michael N. 2019. Palliative caregivers' spirituality, views about spiritual care, and associations with spiritual well-being: a mixed methods study. IN PRESS *American Journal of Hospice and Palliative Medicine*, accepted 2019 September 24:1049909119877351. doi: 10.1177/1049909119877351. [Epub ahead of print] PMID:31550902

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Phillips J, Heneka N, **Lovell M**, Lam L, Davidson P, Boyle F, McCaffrey N, Fielding S, Shaw T. 2019. A phase 3 wait-listed randomised controlled trial of a novel targeted interprofessional clinical education intervention to improve cancer patients' reported pain outcomes. *Trials*. 20 (1) 62.

Poulos R, Marwood S, **Harkin D**, Opher S, Clift S, **Cole A**, Rhee J, Beilharz K, **Poulos C**. 2019. Arts on prescription for community-dwelling older people with a range of health and wellness needs. *Health and Social Care in the Community*. vol. 27, pp. 483 - 492, <http://dx.doi.org/10.1111/hsc.12669>

Poulos C, Poulos R. 2019. A function-focused approach in primary care for older people with functional decline: Making the most of reablement and restorative care. *Australian Journal of General Practice*, 48(7): 434-439

Rainsford S, Phillips C, **MacLeod R**, Wilson D. 2019. Funeral and interment practices of rural residents: A mixed methods study. *Death Studies*. DOI:10.1080/07481187.2019.1616853

Raymond B, Luckett T, Johnson M, Hutchinson A, **Lovell M**, Phillips J. 2019. Low-intensity educational interventions supporting self-management to improve outcomes related to chronic breathlessness: a systematic review. *NPJ primary care respiratory medicine*. 29 (1) p 41. PMID 31784524.

Reynolds N, Cole A, Walmsley B, Poulos C. 2019. Multidisciplinary healthcare providers' experience of working in an inpatient cancer rehabilitation unit in Sydney, Australia. *European Journal of Cancer Care*. First published November 2019. Vol. 28(6). doi.org/10.1111/ecc.13162

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Publications

Journal articles



Sellars M, **Clayton J**, Detering K, Tong A, Power D, Morton R. 2019. Costs and outcomes of advance care planning and end-of-life care for older adults with end-stage kidney disease: A person-centred decision analysis. *PLOS ONE*. May 31;14(5):e0217787. doi: 10.1371/journal.pone.0217787. eCollection 2019. PMID: 31150504

Sellars M, Detering K, Sinclair C, White B, Buck K, Ruseckaite R, **Clayton J**, Nolte L. 2019. Personal and interpersonal factors and their associations with advance care planning documentation: a cross-sectional survey of older adults in Australia. IN PRESS *Journal of Pain and Symptom Management*, accepted December 2019

Sellars M, Morton R, **Clayton J**, Tong A, Mawren D, Silvester W, Power D, Ma R, Detering K. A case-control study of end-of-life treatment preferences and costs following advance care planning for adults with end stage kidney disease. *Nephrology*. February;24(2):148-154. doi: 10.1111/nep.13230. PMID: 29389053

Shepherd H, Geerligs L, Butow P, Masya L, Shaw J, Price M, Dhillon H, Hack T, Girgis A, Luckett T, **Lovell M**, Kelly B, Beale P, Grimison P, Shaw T, Viney R and Rankin N. 2019. The Elusive Search for Success: Defining and Measuring Implementation Outcomes in a Real-World Hospital Trial. *Frontiers in Public Health*. 7:293. doi: 10.3389/fpubh.2019.00293.

Sinclair C, **Bajic-Smith J**, **Gresham M**, Blake M, Bucks R, Field S, **Clayton J**, Radoslovich H, Agar M, Kurrle S. 2019. Professionals' views and experiences in supporting involvement in decision-making among people living with dementia". IN PRESS *Dementia*. July 26:1471301219864849. doi: 10.1177/1471301219864849. [Epub ahead of print] PMID: 31349752

Sinclair C, Gersbach K, Hogan M, Blake M, Bucks R, Auret K, **Clayton J**, Stewart C, Field S, Radoslovich H, Agar M, Callaghan S, Martini A, **Gresham M**, Williams K, Kurrle S. 2019. "A real bucket of worms": Views of people living with dementia and family members on supported decision-making. IN PRESS *Journal of Bioethical Inquiry*, accepted October 2019.

Smith-Uffen M, Johnson S, Martin A, Tattersall M, Stockler M, Bell M, Detering K, **Clayton J**, Silvester W, Clarke S, Vaccaro L, Beale P, Kiely B. 2019. Estimating survival in advanced cancer: a comparison of estimates made by oncologists and patients. IN PRESS *Supportive Care in Cancer*. November 28. doi: 10.1007/s00520-019-05158-5. [Epub ahead of print] PMID:31781946

Stiel H, **Nagarajan S**, **Forster B**, **Clayton J**. 2019. Palliative care physicians' perspectives on transferring patients to nursing homes and communication strategies to facilitate this transition: a qualitative study. *Palliative Medicine*. 33(3): 323-331. doi: 10.1177/0269216319827803 PMID: 30758275

Tan H, Lai E, Kunasekaran M, Chughtai A, Trent M, **Poulos C**, MacIntyre C. 2019. Prevalence and predictors of influenza vaccination among residents of long-term care facilities. *Vaccine*. 37(43):6329-6335 08

Vaccaro L, Butow P, Lee D, Johnson S, Bell M, **Clayton J**, Detering K, Tattersall M. 2019. Fidelity is fundamental: intervention predictors in advance care plans in terminal cancer. *BMJ Supportive & Palliative Care*. December; 9(4):397-403. doi: 10.1136/bmjspcare-2019-001917. Epub 2019 September 19. PMID:31537578

Van den Berg M, Winsall M, Dyer S, Breen F, **Gresham M**, Crotty M. 2019. Understanding barriers and enablers to the use of outdoor spaces in nursing homes: a systematic review. *Gerontologist*. May 24. pii: gnz055. doi: 10.1093/geront/gnz055. [Epub ahead of print]

Wu J, Vratisstas-Curto A, Shiner C, Faux S, Ian Harris, **Poulos C**. 2019. Can in-reach multidisciplinary rehabilitation in the acute ward improve outcomes for critical care survivors? A pilot randomized controlled trial. *Journal of Rehabilitation Medicine*. 51(8):598-606 01

Wilson D, Cohen, J, Deliens L, **MacLeod R**, Hewitt J, Houttekier D. 2019. Is the bereavement grief intensity of survivors linked with their perception of death quality? A pilot study. *International Journal of Palliative Nursing*.

Wilson D, Truscott J, Cohen J, **MacLeod R**. 2019. Educational Needs of Healthcare Professionals and Members of the General Public Two Years After the Implementation of Medical Assistance in Dying. *Health & Social Care in the Community*.

Stiel H, **Nagarajan S**, **Forster B**, **Clayton J**. 2019. Palliative care physicians' perspectives on transferring patients to nursing homes and communication strategies to facilitate this transition: A qualitative study. *Palliative Medicine*. 33(3), 323-331.

Publications

Industry and magazine articles



Alford M, Rahman S. *Talking sense.* Australian Ageing Agenda, May - June 2019, p54

Arthurs K. *Better conversations for better end-of-life care.* Australian Primary Health Care Nurses Association. Primary Times, 2019 Vol 6/Issue 3/Spring 2019, p 13.

Christie J. *More than a picture.* Australian Ageing Agenda, September - October 2019, p56

Christie J. *The Use of Murals in Places where People with Dementia Live.* Australian Ageing Agenda, November 2019

Clayton J, Rhee J. *The Advance Project – supporting a team approach to advance care planning and palliative care in everyday general practice.* CareSearch blog: Palliative Perspectives, 28th March 2019

Cunningham C. *The barber challenging our thinking.* Australian Ageing Agenda, July - August 2019, p54

Gresham M. *The story of Linden,* Australian Ageing Agenda, January - February 2019, p48

Hamer B, Hutchison A, Zahedi S, Moser D, Hahn A, Soderberg B, **Kohler F.** *The role of the Industry Advisory Group of the International Society for Prosthetics and Orthotics as a vehicle for enabling appropriate innovation. Global perspectives on assistive technology: proceedings of the GReAT Consultation.* 2019, Vol B, p377-387. Geneva: World Health Organization; 2019. Licence: CC BY-NC-SA 3.0 IGO.

Kohler F, Hanspal R, Soderberg B. *Global survey of the World Health Organization's Standards for Prosthetic and Orthotic Services. Global perspectives on assistive technology: proceedings of the GReAT Consultation.* 2019, Vol B, p139-154. Geneva: World Health Organization; 2019. Licence: CC BY-NC-SA 3.0 IGO

MacLeod R. *Dementia palliative care; time for a rethink.* 2019. <https://www.thesenior.com.au/story/5880154/palliative-dementia-insight/?cs=6773>

MacLeod R. *Palliative care and dementia: rethinking how we do it.* 2019. <https://www.eqt.com.au/about-us/media-centre/news-items/whats-new/palliative-care-and-dementia-rethinking-how-we-do-it>

Pryor W, Harte C, Ishii Y, **Kohler F,** Smith F *Integrating a new prosthetics and orthotics workforce: Lessons from an evaluation of the Nippon Foundation's investments in South East Asia. Global perspectives on assistive technology: proceedings of the GReAT Consultation.* 2019, Vol A, p366-383. Geneva: World Health Organization; 2019. Licence: CC BY-NC-SA 3.0 IGO.

Rowlands A. *Care for Life and Care for the End of Life: The HammondCare Story,* Parity. August 2019, p27-29.

Swinton J, Martin D. *'Love in the time of dementia: is care without love enough?'* Beyond the Bucket List: Aging Grace-fully. Equip 35 November 2019, 17-19.

Thompson-Bradley O, Christie J. *My Life, My Way: A Social Return on Investment Analysis of Age NI's 'My Life My Way' Programme.* September 2019.

Xu J, **Kohler F,** Dickson H *A Core Set For People Following Lower Limb Amputation Based on the International Classification of Functioning, Disability and Health.* ISPO 17th World Congress, Kobe, Japan 5th-8th October 2019.

Publications

Technical and other reports



Clayton J, Arthurs K, Nagarajan S, Stoecker S, Tieman J, **Rhee J**, and the Advance Project National Advisory Group. *The Advance Project eLearning module for General Practice Nurses: Initiating Advance Care Planning and Palliative Care*. 2019. www.theadvanceproject.com.au

Clayton J, Nagarajan S, Rhee J, Stoecker S, Tieman J, **Arthurs K** and the Advance Project National Advisory Group. *The Advance Project eLearning module for General Practice Managers – Module 3: Successful integration of the Advance Project resources into your general practice*. 2019. www.theadvanceproject.com.au

Fisher A, **O'Connor C**, Piguett O. *Positive behaviour support for individuals with dementia: a family education workbook*. 2019. Adelaide, Flinders University.

Gresham M, Poulos C, Poulos R, **Maurice C, O'Connor C**. *Supporting independence and function in people living with dementia: an information booklet of reablement programs for people impacted by dementia* (2nd edition). Sydney: HammondCare. 2019. ISBN: 978-0-6483387-5-8.

O'Connor C, Poulos C, Gresham M, Poulos R. *Supporting independence and function in people living with dementia: a technical guide to the evidence supporting reablement interventions* (2nd edition). Sydney: HammondCare. 2019. ISBN: 978-0-6483387-4-1.

Poulos C, Gresham M, Poulos R, **Maurice C, O'Connor C**. *Supporting independence and function in people living with dementia: a handbook of reablement programs for service providers and others with an interest in improving function* (2nd edition). Sydney: HammondCare. 2019. ISBN: 978-0-6483387-3-4.

Sinclair C, Kurrle S, Field S, Agar M, Williams K, Bucks R, **Clayton J**, Stewart C, Blake M, Auret K, **Gresham M**, Martini A, Radoslovich H, and the NHMRC Cognitive Decline Partnership Centre (CDPC). *Supported Decision-Making in Dementia Care: Final Project Report*. 2019. Sydney: NHMRC Cognitive Decline Partnership Centre. <https://cdpc.sydney.edu.au>

Thompson-Bradley O, Christie J. *My Life, My Way: A Social Return on Investment Analysis of Age NI's 'My Life My Way' Programme*. September 2019.

Presentations

Academic conference and industry seminars



Alford M. Invited Panellist. *Panel: Oceans of Opportunities: Living, ageing and dying with Dementia*. Perth, September 2019.

Anand R. *The impact of educational videos on pain assessment in people with dementia and behavioural changes using the Abbey Pain Scale*. Australian and New Zealand College of Anaesthetists Annual Scientific Meeting, Kuala Lumpur, May 2019.

Antill G. *Palliative Care in the Home – building a sustainable workforce*. Oceanic Palliative Care Conference (19OPCC), Perth, Australia, 11th September 2019.

Arthurs K. *Building Capability and Confidence in Residential Aged Care (RAC) Registered Nurses (RN) and Care Workers (CW) to Provide Quality End of Life Care for Residents*. International Conference on Palliative Dementia Care, Belfast, UK, 9th May 2019.

Arthurs K. *Advance Care Planning Lunch and Learn Webinar about the Advance Project*. Healius, 16th October 2019.

Arthurs K. *Advance Project and Palliative Care Workshop*. 7th November 2019 Gladstone, and 8th November Rockhampton, Wide Bay Hospital and Health Service & Central Queensland, Wide Bay, Sunshine Coast Primary Health Network

Arthurs K, Clayton J. *The Advance Project: Team based initiation of advance care planning and palliative care*. Workshop for Southern Adelaide Postgraduate Medical Education Association (SAPMEA) and Adelaide Primary Health Network, 23rd October 2019.

Presentations

Academic conference and industry seminars



Arthurs K, Roach P, Clayton J. Multiple workshops in Sydney North Primary Health Network on *The Advance Project: Team based initiation of advance care planning and palliative care* including 30th April 2019, 11th June 2019, 25th July 2019, 3rd September 2019, 24th September 2019, 31st October 2019.

Austin P, Lovell M, Siddall P. *Virtual reality for the treatment of people with cancer-related pain: A scoping review.* Oceanic Palliative Care Conference, Perth, Australia. October 2019.

Baksa S. *The breathlessness program: designed to empower palliative patients to manage and live well with breathlessness.* Oceanic Palliative Care Conference (19OPCC), Perth, Australia, 11th September 2019.

Barton R, Wiese M, Stancliffe R, Read S, Jeltos G, **Clayton J.** *Factors that influence discussions about end of life between people with intellectual disability and disability support staff.* The World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Glasgow, Scotland, August 2019.

Bennett S, Clemson L, Gitlin L, Gannon B, Russell T, O'Reilly M, Laver K, Beattie E, Byrne G, **O'Connor C,** Pighills A, Low L, Liddle J, Khan A, Travers C & Smith S. *Occupational therapists' perspectives of implementing the Tailored Activity Program for people with dementia and their carers living at home.* Oral presentation. Occupational Therapy Australia 28th National Conference and Exhibition, Sydney, Australia, 2019.

Best M, McArdle M, Huang Y, **Clayton J,** Butow P. *How is spirituality discussed in palliative care consultations – do question prompt lists help?* Oceanic Palliative Care Conference (19OPCC), Perth, Australia, 11th September 2019.

Christie J. *Palliative Care and Dementia: Is there a place for resilience?* International Conference on Palliative Dementia Care, Belfast, UK, 10th May 2019.

Christie J. *Developments in Specialist Dementia Care in Australia.* Alzheimer Scotland Annual Conference, Edinburgh, UK, 3rd June 2019.

Christie J. *Re-imagining Resilience in the Context of Life with Dementia: New Concepts and Connections.* British Society of Gerontology 48th Annual Conference, Liverpool, UK, 11th July 2019.

Christie J. *My Life, My Way: A Social Return on Investment Perspective. My Life My Way: A Leadership Exchange on Innovation in Dementia Community Support.* Belfast, UK, 26th September 2019.

Clark K, Quinn S, Doogue M, Sanderson C, **Lovell M,** Currow D. *Routine prescribing of gabapentin or pregabalin in supportive and palliative care.* Palliative Care Clinical Studies Collaborative and Cancer Symptom Trials Joint Annual Forum, Sydney, Australia, 14th March 2019.

Clayton J. Invited Chair for session *Advance Care Planning in Patients with Chronic Diseases* at ACP-i - Advance Care Planning International Conference, Rotterdam, the Netherlands, March 2019.

Clayton J. Invited opening plenary lecture on *How to Bring Hope to Those in Despair: Communication in Advance Care Planning.* 13th Asia Pacific Hospice Conference (APHC 2019), Surabaya, Indonesia, 2nd August 2019.

Clayton J. Invited speaker, meet the expert seminar on *Advance Care Planning communication.* 13th Asia Pacific Hospice Conference (APHC 2019), Surabaya, Indonesia, 3rd August 2019.

Clayton J. Invited speaker on *Advance Care Planning in Australia.* 13th Asia Pacific Hospice Conference (APHC 2019), Surabaya, Indonesia, 4th August 2019.

Clayton J. Invited Chair for session *End of life discussion and Advance Care Planning in Asia and Pacific: Scope, challenges and opportunities.* 13th Asia Pacific Hospice Conference (APHC 2019), Surabaya, Indonesia, 4th August 2019.

Clayton J. Invited speaker on *The Advance Project* and panel member, Advance Care Planning Forum, Northern Beaches Hospital, 8th August 2019.

Clayton J. Invited speaker on *The Advance Project, National Palliative Care Projects,* Oceanic Palliative Care Conference (19OPCC), Perth, Australia, 11th September 2019.

Presentations

Academic conference and industry seminars



Clayton J. Invited speaker on *Online toolkit for carers and practitioners: helping people with intellectual disability understand dying and death*. Oceanic Palliative Care Conference (19OPCC), Perth, Australia, 11th September 2019

Clayton J, Arthurs K, Nagarajan S, Lewis V, Halcomb E, Tieman J, Detering K, Mitchell G, Phillips J, Morton R, **Rhee J.** *The Advance Project: New resources and revised training for general practice nurses to initiate advance care planning and palliative care*. Australian Primary Nurses Association National Conference, Adelaide, Australia, 6th April 2019.

Clayton J, Nagarajan S, Rhee J, Lewis V, Tieman J, Mitchell H, Halcomb E, Detering K, Morton R, Phillips J. *Evaluation of Phase 1 of the Advance Project – an Australian national program to support nurses to initiate advance care planning and palliative care in general practice*. Oceanic Palliative Care Conference, Perth, Australia, September 2019.

Clayton J, Arthurs K, Nagarajan S, Rhee J, Tieman J, Mitchell G, Halcomb E, Detering K, Lewis V, Advance Project Advisory Group. *What's new in the Advance Project? Training and resources to enable systematic and team-based initiation of advance care planning and palliative care in Australian general practices*. Oceanic Palliative Care Conference, Perth, Australia, September 2019.

Clayton J, Arthurs K, Nagarajan S, Rhee J, Tieman J, Mitchell G, Detering K, Lewis V, Halcomb E, Phillips J, Morton R. *What's new in the Advance Project?* GP19 Conference, Adelaide, Australia, 26th October 2019.

Clayton J, Nagarajan S, Lewis V, Detering K, Halcomb E, Tieman J, Mitchell G, Phillips J, Morton R, Costa D, Gavin J, Stokes J, Livingstone A, Shaw T, **Rhee J.** *The Advance Project: an Australian national program to support nurses to initiate advance care planning in General Practice*. 7th Advance Care Planning International (ACP-i) Conference, Rotterdam, Netherlands, 13th-16th March 2019.

Clayton J, Tieman J, Wiese MY, Stancliffe RJ, Jeltse G. *Helping people with intellectual disability to understand and plan for end of life: An online resource for caregivers*. Oceanic Palliative Care Conference, Perth, Australia, 12th September 2019.

Cole A. *Update in Diagnosing Dying and avoiding Futile Medical Treatments*. Presentation. Commission for Medical & Dental Education (CMDE) of the CMDA, 39th International Congress; Chiangmai, Thailand, 19th-24th February 2019.

Cole A. *New Challenges in managing people with Multiple Chronic Non-Infectious Disease in Resource-limited Settings*. Presentation. Commission for Medical & Dental Education (CMDE) of the CMDA, 39th International Congress; Chiangmai, Thailand, 19th-24th February 2019.

Cole A. *All About Strokes; Frailty & Reablement in Home Care*. Home Instead. Two presentations. Wuhan regional training seminar; Wuhan, Hubei Province, China, 23rd March 2019.

Cole A. *Feedback and the Rehabilitation Clinician-Educator*. Presentation. International Society of Physical & Rehabilitation Medicine, 13th World Congress; Kobe, 9th-12th June 2019.

Cole A. *Northern Rivers LHD Aged Care & Rehab Annual Seminar*. Rehabilitation and Restorative Strategies in Cancer Survivors, Ballina, Australia, 11th-12th July 2019.

Cole A. *Geriatric Frailty and its Management*. Presentation. 4th International Forum of the Wuhan Geriatrics Society; Wuhan, Hubei Province, China, 21st September 2019.

Cole A. *Models for Rehabilitation Services in Australasia*. 6th Baltic & North Sea Conference on Physical and Rehabilitation Medicine; Oslo, Norway, 8th-10th October 2019 (Presentation)

Cunningham C. *It started with a cottage: When the paradigm of dementia and palliative care shifted*. International Conference on Palliative Dementia Care, Belfast, UK, 9th May 2019.

Cunningham C, Tichawangana R, Hills D, Andrews S, **Siddal P,** Fitzgerald A, Hayes K, **Anand R, Lorang C, Poulos C, Gresham M.** *Intervene Phase 2: Best practice pain management in residential aged care. From participatory action to change of practice*. NHMRC National Dementia Research Institute Australian Dementia Forum, Hobart, 13th-14th June 2019.

Gresham M, Chao S, Truong T, Plant N, Lorang C, Nadjarian J, Bennett A, Cunningham C. *Special Dementia Care Programs: 10-years' experience*. NHMRC National Dementia Research Institute Australian Dementia Forum, Hobart, 13th-14th June 2019.

Presentations

Academic conference and industry seminars



Gresham M, Cunningham C. *Developing and Implementing a multidisciplinary Team pain management model for residential care.* Australian Association of Gerontology 52nd National Conference, Sydney, Australia, 5th-8th November 2019.

Gresham M. *DeMentia Design Schools: Tools for creating enabling and inclusive communities.* Invited keynote presentation. Eden Social Welfare Foundation Dementia Conference, Taipei, Taiwan, 13th May 2019.

Gresham M, McFarlane, S, Cunningham C. *Ruminations in an Era of Outrage.* Panel Discussion, Wicking Trust Symposium, Melbourne, Australia, 12th November 2019.

Houston A. *The Experience of Choice in Healthcare: A Personal Story.* International Conference on Palliative Dementia Care, Belfast, UK, 10th May 2019.

Houston A, Christie J. Book launch: *Talking Sense.* International Conference on Palliative Dementia Care, Belfast, UK, 10th May 2019.

Knight P, Gresham M, Alford M. *Implementing Evidence-informed recommendations for managing BPSD in residential care: Challenges and Solutions.* Australian Association of Gerontology 52nd National Conference, Sydney, Australia, 5th-8th November 2019.

Knight P, Gresham M, Morris T, Cunningham, C, Kurrle, S. *Evidence Based Care recommendations: What does this mean?* Australian Association of Gerontology 52nd National Conference, Sydney, Australia, 5th-8th November 2019.

Kok C, Gresham S, Chao T, Morris C, Poulos C, Cunningham C. *Evaluation of the behaviour impacts on residents pre and post relocation from a traditional style nursing home to purposively build cottages.* NNIDR, Hobart, Australia, June 2019.

Lovell M, Siddall P, Dong S, Corbett M. *Existential and spiritual wellbeing in people living with chronic and cancer pain.* Oceanic Palliative Care Conference, Perth, Australia, September 2019.

Lockett T, Phillips J, Newton-John T, Heneka N, Powell-Davies G, Holliday S, **Lovell M**, Liauw W, Rowett D, Pearson S. *Opioid-related problems in the cancer pain contest: a qualitative study of the experiences, beliefs and attitudes of Australian general practitioners.* Oceanic Palliative Care Conference, Perth, Australia, September 2019.

MacLeod R. *Dying, death and wisdom in an age of denial – a medical practitioner's workshop with Dr Kathryn Mannix.* Oral presentation. AUT University, Auckland, New Zealand, February 2019.

MacLeod R. *Dying, death and wisdom in an age of denial – Public Panel Discussion with Dr Kathryn Mannix.* Oral presentation. Public presentations and discussion. AUT University, Auckland, New Zealand, March 2019.

MacLeod R. *Who should receive palliative care?* Oral presentation. Harbour Hospice, Auckland, New Zealand, April 2019.

MacLeod R. *Demystifying palliative care.* Sweet Louise Members Day, Auckland, New Zealand, May 2019.

MacLeod R. *Pacific call to action on assisted dying.* Oral presentation. Mangere Arts Centre, Auckland, New Zealand, May 2019.

Marshall M. *Designing for complexity: Older people and people with dementia.* International Conference on Palliative Dementia Care, Belfast, UK, 10th May 2019.

Marshall M. *Accessible toilets for people with dementia: A human rights issue.* Poster presentation. British Society of Gerontology 48th Annual Conference, Liverpool, UK, 12th July 2019.

Marshall M. *Getting it right for people with dementia: Reflections on a dementia journey.* My Life My Way: A Leadership Exchange on Innovation in Dementia Community Support, Belfast, UK, 26th September 2019.

Matsuoka H, Lee J, **Lovell M**, Le B, Phillips J, Agar M, Kochovska S, Currow D, Satomi E, Ishiki H, Hasuo H, Matsudo Y. *A phase III, international, multicentre, double-blind, dose increment, parallel-arm, randomised controlled trial of duloxetine versus pregabalin over 14 days for opioid unresponsive cancer-related neuropathic pain.* Palliative Care Clinical Studies Collaborative and Cancer Symptom Trials Joint Annual Forum, Sydney, Australia, 14th March, 2019.

Presentations

Academic conference and industry seminars



Morris T, Alford M. *Other than Alzheimer's: Behaviour in people with less common forms of dementia.* AAG Conference, November 2019.

Morris T, Anand R, Cunningham C. *Prevalence of pain and behavioural correlates in people living with dementia.* NNIDR Dementia Forum, June 2019.

Nagarajan S, Rhee J, Mitchell G, Lewis V, Tieman J, Halcomb E, Detering K, Morton R, Phillips J, Costa D, **Clayton J.** *Evaluation of the Advance Project (Phase 1).* GP19 conference, Adelaide, Australia, 26th October 2019.

Nestor S, Lockett T, Phillips J, Agar M, Boyle F, Stubbs J, Hucker T, Lakhanpal R, **Lovell M.** *Cancer pain management in Australia: Update on the evolving evidence base/Where are we now?* Oceanic Palliative Care Conference, Perth, Australia, September 2019.

O'Callaghan C, Seah D, **Clayton J,** Martina W, Kissane D, Georgousopoulou E, Michael N. *Palliative Caregivers' Spirituality, Views about Spiritual Care and Associations with Spiritual Well-being: A Mixed Methods Study.* 16th Congress of the European Association for Palliative Care, Berlin, Germany, 23rd - 25th May 2019.

O'Callaghan C, Seah D, **Clayton J,** Welz M, Kissane D, Georgousopoulou E, Maleki S, Michael N. *Palliative caregivers' spirituality, views about spiritual care, and associations with spiritual well-being: A mixed methods study.* Oceanic Palliative Care Conference, Perth, Australia, September 2019.

O'Connor C. *Behaviour, function and reablement in dementia.* Dementia Centre Professional Development Session, Sydney, Australia, 2019.

O'Connor C, Gresham M, Poulos R, **Poulos C.** *Supporting function in people living with dementia: A Reablement Handbook.* Oral presentation. 52nd Australian Association of Gerontology Conference, Sydney, Australia, 2019.

O'Connor C, Heldon M. *Reablement and wellness for people living with dementia: a Handbook of reablement and Arts on Prescription.* Northern Sydney Community Care Regional Forum: Reablement and Wellness, Sydney, Australia, 2019.

Pollock A. *The Room Outside: Design Choices.* The Healthcare Buildings Forum Scotland, Edinburgh, UK, 2nd May 2019.

Poulos C. *Function.* Burniston Oration. RACP Congress 2019, Auckland, New Zealand, 6th-8th May 2019.

Poulos R, Beatty E, **Cunningham C, Poulos C.** *Home delivery of participatory art to support wellbeing in dementia carer and care recipient dyads – the Arts on Prescription model.* The RED Conference, Port Macquarie, NSW. 28th-29th March 2019.

Poulos C, O'Connor C, Gresham M, Poulos RG. *Evidence-informed reablement guidelines to support function in people living with mild to moderate dementia.* The RED Conference, Port Macquarie, NSW, 28th-29th March 2019.

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Poulos RG, **Poulos C.** *Use and evaluation of Participatory art for older people with health and wellness needs.* IAGG-ER Conference, Gothenburg, Sweden, 22nd-25th May 2019.

Roach P, Lovell M, Macfarlane S. *Predictors of death in people with behavioural and psychological symptoms of dementia.* Oceanic Palliative Care Conference, Perth, Australia, September 2019.

Sanderson C, Quinn S, Agar M, Chye R, Clark K, Doogue M, Fazekas B, Lee J, **Lovell M,** Rowett D, Spruyt O, Currow DC. *Pharmacovigilance of in hospice/palliative care: net effect of gabapentin for neuropathic pain.* Palliative Care Clinical Studies Collaborative and Cancer Symptom trials Joint Annual Forum, Sydney, Australia, 14th March 2019.

Sellars M, **Clayton J,** Detering K, Tong A, Power D, Morton R. *Hospital costs and outcomes of advance care planning and end-of-life care for older adults with end-stage kidney disease in hospital: A person-centred decision analysis.* 3rd International Conference on End of Life Law, Ethics, Policy, and Practice, Ghent, Belgium, 7th-9th March 2019.

Presentations

Academic conference and industry seminars



Sellars M, **Clayton J**, Detering K, Tong A, Power D, Morton R. *Hospital costs and outcomes of advance care planning and end-of-life care for older adults with end-stage kidney disease in hospital: A person-centred decision analysis*. 7th Advance Care Planning International (ACP-i) Conference, Rotterdam, Netherlands, 13th-16th March 2019.

Siddall P. *What is the role of spirituality in people living with pain?* Royal Ryde Rehabilitation Forum, Sydney, Australia, June 2019.

Stancliffe R, Wiese M, Read S, Jeltos G, **Clayton J**, Barton R. *Discussing end-of-life with people with intellectual disability: Anxiety, depression and fear of death*. The World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Glasgow, Scotland, August 2019.

Wiese M, Curryer C, Stancliffe R, Wilson N, **Clayton J**. *Multidisciplinary palliative care team experiences when caring for people with intellectual disability who are dying*. The World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Glasgow, Scotland, August 2019.

Wiese M, Stancliffe R, **Clayton J**, Jeltos J, Tieman J. *Supporting people with intellectual disability to understand the end of life: The "TEL" website practice example*. Public Health Palliative Care International Conference, Leura, NSW, Australia, 14th October 2019.

Xu X, **Lovell M**, Lockett T, Phillips J. *Exploring cancer and palliative care nurses' experiences of caring for Chinese migrants*. Cancer Nurses Society of Australia Congress, Melbourne, Australia, June 2019.

Xu X, Phillips J, Lockett T, **Lovell M**. *Exploring cancer and palliative care nurses' experiences of caring for Chinese migrants with cancer pain: a cross-sectional survey*. Oceanic Palliative Care Conference, Perth, Australia, September 2019.

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Service Locations

Where and how we care

HammondCare At Home

Canberra **ACT**
Batemans Bay **NSW**
Bathurst **NSW**
Broken Hill **NSW**
Cardiff **NSW**
Coffs Harbour **NSW**
Horsley **NSW**
Kyogle **NSW**
Merimbula **NSW**
Mudgee **NSW**
Narara **NSW**
North Gosford **NSW**
Nowra **NSW**
Picton **NSW**
Port Macquarie **NSW**
Scone **NSW**
Sydney **NSW**
 Hammondville
 Inner West
 Miranda
 St Leonards
 St Marys
 North Turrumurra
 Manly
 Wahroonga
Wentworth Falls **NSW**
Brisbane **QLD**
 Chermside
Melbourne **VIC**
 Northern Melbourne

Residential Care

Erina **NSW**
Cardiff **NSW**
Horsley **NSW**
Scone **NSW**
Sydney **NSW**
 Darlinghurst
 Hammondville
 Miranda
 North Turrumurra
 Wahroonga
Waratah **NSW**
Woy Woy **NSW**
Melbourne **VIC**
 Caulfield

HammondCare Health

Sydney **NSW**
 Prairiewood
 Greenwich
 Mona Vale
 Wahroonga

The Dementia Centre

Canberra **ACT**
Broken Hill **NSW**
Coffs Harbour **NSW**
Dubbo **NSW**
Sydney **NSW**
 Greenwich
 Hammondville
 North Turrumurra
 Miranda
 St Leonards
 St Marys
Horsley **NSW**
Newcastle **NSW**
North Gosford **NSW**
Nowra **NSW**
Tamworth **NSW**
Tweed Heads **NSW**
Alice Springs **NT**
Darwin **NT**
Brisbane **QLD**
Cairns **QLD**
Gold Coast **QLD**
Sunshine Coast **QLD**
Townsville **QLD**
Adelaide **SA**
 Daw Park - coming soon
 Dulwich
Devonport **TAS**
Hobart **TAS**
Ballarat **VIC**
Bendigo **VIC**
Geelong **VIC**
Gippsland **VIC**
Melbourne **VIC**
 Malvern
 Yarra Valley - coming soon
Mildura **VIC**
Wadonga **VIC**
Perth **WA**
 Wembley

Research

Sydney **NSW**
 Prairiewood
 Greenwich
 Hammondville
Melbourne **VIC**
 Malvern

Palliative Care Home Support Packages

358 rural and remote towns within NSW



● PERTH





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