

# Welcome

"Research allows us to seek the

best ways to provide for those

in need"

It is a wonderful privilege to introduce the 2017
Research Report for HammondCare. Research allows
us to seek the best ways to provide for those in need whether from pain, end of life circumstances, dementia,
disability or homelessness.

The projects reported here have focussed on ways to improve quality of life and provide best practice care across our clinical, residential and home-based services. These projects have involved:

Individuals - their requirements for investigations, medications, rehabilitation programs and their emotional and spiritual needs

Groups of people - whether at home, in residential care and in hospital

Government services – integrated evidence-based interventions such as CHOP (Confused Hospitalised Older Persons) into the Australian Health System.

There are projects focussing on care that enables people to remain in their own homes and live better lives. These include the rehabilitation research that has demonstrated that in-home rehabilitation for total knee replacement is as effective as hospital based rehabilitation for selected populations, the Arts on Prescription program being delivered at home for people with unmet health and wellness needs, and the outpatient pain self-management program.

These stories provide a look into the cutting edge of care within HammondCare that is linked with research. The teaching, publications and presentations that our staff are involved in is passing on knowledge and skills to others also involved in the care of those with similar needs to our clients.

We pray you will continue to support our clients, services and research.



**Dr Annette Britton**Chair, HammondCare Research Committee

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## **Foreword**

## Providing a bridge

One of the important categories of research that HammondCare conducts and supports is that which 'bridges the gap' between the academic world and what happens in the 'real world'.

This is often termed 'translational research'.

Don't get me wrong, I am not saying that academics don't consider how their research can be applied - in fact, this is often a major requirement for funding success. But research evidence that is generated under strict protocols, and with specifically trained staff, may not be readily transferable to situations outside of the research environment. The research will often have to be 'translated' to real world settings.

The problem is that the real world is complex. The research environment is often simplified – for example, research studies might only include people who speak English, who are under a certain age, and who have a limited number of associated health conditions. People in the real world may not be like the participants in studies. Another translation difficulty is that it is often not apparent from a published study exactly how an intervention was conducted.

HammondCare is currently leading a project which aims to develop a practical handbook of 'evidence-informed' reablement interventions to support function in people living with dementia. This project is described on page 8 and 49 of this report.

The first step in the project involved a synthesis of the key elements of reablement interventions reported in the scientific literature that help people living with dementia to maximise their functional ability. The second step was to design reablement programs, based on these proven interventions, which could be applied by providers in the aged care sector.

Included in the translation process was the requirement to make judgements, drawing on the research, about the recommended duration and intensity of the reablement programs to be implemented within the 'real world' setting.

Programs need to be of sufficient duration and intensity to achieve an outcome, but not prohibitively expensive to conduct.

Other translation elements included making recommendations on: who can conduct an intervention (for example, if the research study only used physiotherapists, would it also be appropriate to use exercise physiologists, if they were the only appropriately trained staff available to a provider?); and how can a program be delivered sustainably (for example, can treatment fidelity be maintained if specialist clinical staff train care workers or family members to assist in certain aspects of program delivery?).

The aim is for the outcomes of 'translated' research programs to be similar to those reported in the original research – but this of course needs to be determined, and so it is beholden upon us to evaluate the effectiveness of the translated programs as well. It was an Australian Prime Minister who once said, 'life wasn't meant to be easy", and this is true of the research world!



**Professor Christopher Poulos** 

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# Study examines new drug to treat early Alzheimer's Disease



### The opportunity

People living with Alzheimer's Disease have an abnormal build-up of a protein known as amyloid in their brain, which is thought to lead to memory loss and a decline in other mental processes. A new investigational study drug called elenbecestat (E2609) is being developed to potentially reduce the amount of amyloid accumulating in the brain. If studies show the drug is successful, it could potentially slow the progression of Alzheimer's and associated memory loss.

#### The research

While previous studies have looked at removing the amyloid protein to slow the progression of Alzheimer's Disease, elenbecestat is thought to prevent the formation of amyloid by inhibiting one of the enzymes required to produce it.

To test whether this has any benefit on the memory and thinking of a person with Alzheimer's, HammondCare is participating in the Australian arm of an international study on elenbecestat as a potential treatment for early Alzheimer's Disease.

The 'double-blind' study, sponsored by pharmaceutical company Eisai, involves 1,330 participants and 350 research centres around the world. Currently, the HammondCare East Malvern site is ranked eighth globally for numbers into the study.

Two treatment groups – each made up of a random selection of people aged between 50 and 85 years with Early Alzheimer's Disease – will receive either a 50mg dose of elenbecestat or a placebo over a 12-month period. During this time, the participants will undergo regular blood tests, urine tests, physical exams, and a series of specialised tests that assess memory, judgment, problem solving and the ability to independently perform daily tasks.

The research also aims to find out if elenbecestat is safe to take and well tolerated in people living with Early Alzheimer's Disease.

#### The outcome

Ten other studies have been performed on elenbecestat previously, including early stage studies in 375 healthy research volunteers.

This study is the first time the investigative study drug has been given to patients with Early Alzheimer's Disease on a large scale, and the final hurdle before the drug can potentially reach registration and approval.

Currently, researchers are in the process of recruiting participants for the study. Once the study is completed, the data will be checked for accuracy and analysed before findings are released.

It is hoped this study will show that elenbecestat is not only safe to take, but has a potential effect on modifying the course of people who have Early Alzheimer's Disease – slowing the disease's progression and improving prognosis.

## Case Study: Working together to treat Alzheimer's Disease

Don\* was a successful retired carpenter when he was diagnosed with Alzheimer's Disease. His wife Diane\* noticed he struggled to remember conversations prior to his diagnosis, and he had been making mistakes in his (usually meticulous) management of the household finances.

"Don was diagnosed promptly by a geriatrician and started on donepezil," Diane recalls. Although he seemed to remain stable for a while, he was having bad side effects and after a year, he went downhill. We looked around for something else that could help."

The now 71-year-old and his wife joined the elenbecestat study in January, and his care is being managed through the HammondCare site at East Malvern. "It's great to be one of the first patients in the world to try this new drug," says Don. "Knowing the drug is treating the cause of the disease, not just covering up the symptoms, is important to us."

Don has been taking one tablet a day of the study medication since early February. He and his wife attend the East Malvern site regularly to participate in reviews of the drug's safety and efficacy – a two-year process intended to prove the drug's benefits. "The study staff take great care of us," says Diane. "He's in good hands."



# Supporting reablement for people living with dementia



## The opportunity

Dementia is the greatest cause of disability in older Australians<sup>1</sup>. Despite this, most research on reablement interventions exclude people living with dementia. This means current dementia-specific reablement services may not be based on evidence, causing valuable funds to be spent on potentially ineffective services.

#### The research

The NHMRC Cognitive Decline Partnership Centre (CDPC) – of which HammondCare is an industry partner – released the Clinical Practice Guidelines and Principles of Care for People with Dementia in 2016, critically evaluating the evidence for interventions that can assist people living with dementia.

HammondCare, in collaboration with Brightwater Care Group, Helping Hand Aged Care, the University of New South Wales, Dementia Australia, and the Department of Health, with the support of the CDPC, is developing a practice handbook of reablement interventions based on the Guidelines.

The CDPC Practice Handbook for Reablement Interventions for People with Dementia will provide information on which evidence-informed programs may be useful to help someone in their daily functioning. This includes reablement strategies that health professionals and people working in the aged care sector may find effective in their own service.

The Handbook is supported by a Technical Report, which contains detailed information on the research and studies that inform the reablement programs in the Handbook.

A Consumer Companion Guide is also being developed to help people living with dementia and their carers understand the role of reablement, and guide them in selecting the right services. It will contain information about reablement programs, advice on how to liaise with healthcare professionals and links to resources.

#### The outcome

A team is now in the process of drafting the Handbook, based on feedback received from consumers, policy makers, academics, allied health professionals and aged care sector representatives.

After being launched at the HammondCare International Dementia Conference in June 2018, the Handbook, Technical Report and the Consumer Companion Guide will be made freely available online.

Although the outcomes of this project are yet to be finalised, the Handbook is intended to be an evidence-informed resource to help improve quality of life for people living with dementia. By upskilling professionals and carers, people living with dementia will be given the opportunity to participate in research-supported reablement programs.

This initiative will not only reduce the likelihood of funds being wasted on ineffective services; it will also provide opportunity for people with dementia to maintain their functional ability for longer or slow their decline, to stay at home for longer, and to experience improved quality of life.

... it will also provide opportunity for people with dementia to maintain their functional ability for longer or slow their decline



<sup>&</sup>lt;sup>1</sup> Australian Institue of Health and Welfare (2012)

# Helping GPs initiate palliative care and advance care planning



## The opportunity

In 2017, the Advance Project successfully trained general practice nurses to screen patients for palliative and supportive care needs, and initiate valuable conversations about advance care planning (ACP). The program's success opened the door for a new opportunity: to deliver similar training to GPs and other clinicians, and ensure a team approach to ACP in general practices around Australia.

#### The research

After evaluating the results of the initial Advance Project, a strong need to extend the program to GPs and clinicians was identified – so they, too, can be trained to have conversations about ACP and identify patients who might benefit from palliative and supportive care services.

This led to a new Advance Project, which tailors the same evidence-based toolkit and multi-component training program from the initial program to GPs, GP registrars, practice managers and other clinicians working in primary and chronic/complex care.

The new project – supported by a \$2m federal government grant and led by HammondCare in collaboration with various universities and health organisations – aims to increase the clinician's confidence in screening for supportive and palliative care needs, and initiating conversations with patients and their carers about ACP.

To support implementation of the program, several 'champion' sites around Australia will be selected to deliver face-to-face training and provide local support.

The new project will also provide ongoing support and mentoring for GP nurses to incorporate the Advance assessments in their clinical practice. This 'whole of general practice' approach aims to ensure ACP conversations and palliative/supportive care screenings occurs in a systematic way that involves the whole team in a general practice setting.

#### The outcome

To inform ongoing implementation, the Advance research team will collect data throughout the project for evaluation.

Findings from the initial Advance Project saw evidence of significant improvements in GP nurse confidence, comfort, knowledge and attitudes towards initiating ACP and palliative care assessments.

It is hoped that similar benefits will be found amongst clinicians who undertake the new Advance Project - as well as earlier uptake of ACP and more timely referrals to specialist palliative care services, if required.

Professor Josephine Clayton, Director of HammondCare Centre for Learning & Research in Palliative Care and the project's lead researcher, says extending the Advance Project to GPs and clinicians will encourage a "team approach" to ACP and palliative and supportive care needs, "Providing skills development through education and training for frontline health providers will significantly strengthen understanding around the importance of ACP, and confidence to initiate conversations about it to facilitate patient uptake."

## Case study: Asking the important questions at end of life

For Associate Professor Joel Rhee, the need to support palliative care conversations in primary care became clear when a patient was diagnosed with advanced bladder cancer after he was admitted into hospital with worsening kidney function.

John\*, who was in his eighties and lived alone, chose not to pursue curative treatment due to the extent of his cancer. Follow-up from the specialists was scheduled in four months' time.

"During that time, I felt I needed to ask him: 'Do you have any wishes or goals?" says Associate Professor issues were in my mind. It was challenging for me to

"Amongst other things, Advance training provides concrete strategies on how participants could identify people who may require supportive care assessment. and when and how to raise these issues," says Associate Professor Rhee.

"It's important for GPs to step back from the clinical problems that are affecting the patient and look at the whole person – to see if there are any symptoms or care needs not being met."

\*not his real name



# Fostering purpose in people living with pain



## The opportunity

For people who experience chronic pain, its impact can go beyond the physical to cause loss of purpose and decreased psychological wellbeing. The concept of post-traumatic growth – that adverse life circumstances can lead to positive psychological change – could be used to assist those living with pain, but has received little attention to date in the field of pain management.

#### The research

The Greenwich Hospital Pain Clinic runs a pain management program focussed on four key areas: physical, psychological, social and spiritual. The program addresses the spiritual dimension by helping people rebuild a sense of purpose when living with chronic pain. However, feedback indicated that many people were interested in exploring the spiritual dimension more deeply. To do this, the team wanted an evidence-based framework.

Post-traumatic growth provides that framework by proposing that people who endure challenging life circumstances can experience positive psychological change. Two key factors that have been shown to contribute to this are a strong sense of purpose, and a connection with something beyond ourselves.

To develop an evidence-based pain management program based on strategies associated with post-traumatic growth, Pain Clinic researchers performed a systematic literature review of the concept, with a major focus on fostering a stronger sense of purpose, and building connections with a spiritual dimension.

A pilot version of the program was run in 2017. Afterwards, researchers interviewed participants to gain their feedback, and amended the original program to incorporate their comments and suggestions.

A facilitator will now run three programs over a ninemonth period, with eight to ten people recruited to participate in each group.

#### The outcome

To further assess the usefulness of the program, a mixed methods approach will be used – including quantitative assessments with standardised and validated measures of pain, pain-related disability, mood, cognitive function, spiritual wellbeing, life purpose and quality of life; and qualitative evaluation through participant interviews.

Once revisions are made based on the assessment data, the program will be implemented for full clinical use in pain management. There has also been interest in using a modified version of the program in other settings, such as people with spinal cord injuries, and staff working in a healthcare setting.

While post-traumatic growth doesn't offer pain relief, studies show it promotes resilience and psychological strength for people who have experienced trauma or difficult challenges. The hope is that these benefits – along with an improved sense of wellbeing – can be similarly developed in people who live with chronic pain, enabling them to experience a better quality of life.

## Case Study: Finding purpose in pain

For the past few years, Astan Croft has been living with peripheral neuropathy: a condition which causes him to experience constant pain in his feet.

The father-of-two says pain not only took over his IT career, but also led him to shut himself away from family and friends. "I was in a bad place; I didn't have a way forward," he says.

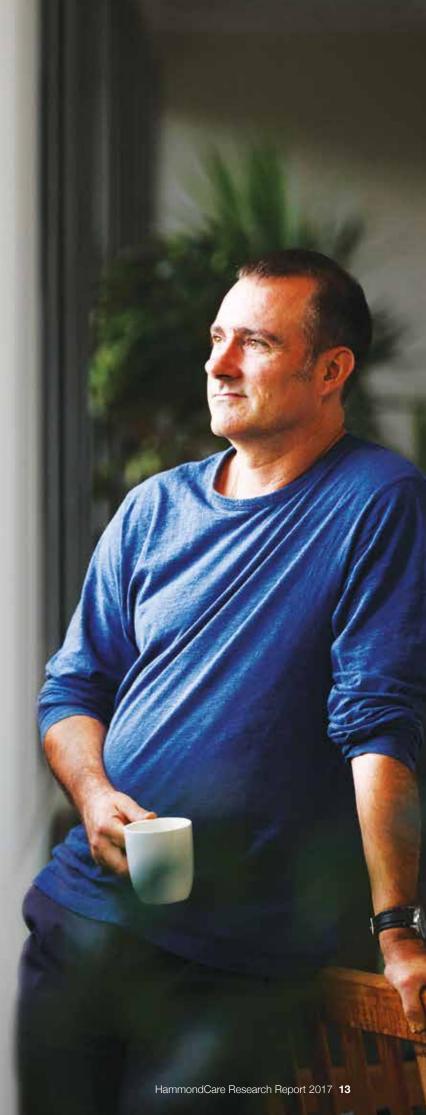
Things started to turn around when Astan attended a pain rehabilitation retreat and was put in touch with the Pain Clinic at Greenwich Hospital. He took part in the clinic's six-week core strength pain management program, which he describes as "an epiphany".

Amongst other concepts, the program introduced 'purpose' as a key part of managing pain. This not only changed Astan's perspective on pain, but also assisted him in exploring his own life goals, and to start volunteering with HammondCare.

"I went from just looking after myself and my family, to looking outside of myself and what I can do. If you have a purpose and build on that, it pushes your pain and your problems into the background," he says.

"My realistic goal is to minimise my pain and to be at peace with myself – to be strong in my mind and my body ... and to give as much as I can back."

Pictured: Astan Croft



# Establishing best practice in pain management for people with dementia



## The opportunity

In 2016, a HammondCare pilot study revealed problems with identifying, assessing and managing pain in people living with dementia in residential aged care. Specifically, systemic and cultural barriers were identified in residences. These barriers can impact on the way pain is managed, and hamper the work of Personal Care Assistants, reducing their ability to engage in evidence-based pain management.

#### The research

Intervene Phase 2, led by the Cognitive Decline Partnership Centre and HammondCare, draws on the findings of the pilot study to support the implementation of best practice pain management for people living with dementia.

The aim of this project is to enhance the practice of Personal Care Assistants and modify the cultural conditions that reduce their ability to identify, assess and manage pain. To achieve this, the Intervene team collaboratively engaged with multidisciplinary teams at four residential aged care sites to critique current practices and identify areas for improvement.

A tool called the Behaviour Change Wheel was used to help design the intervention strategy, with the aim of changing behaviour.

Several key components were also developed: educational videos on the total impact of pain and how to identify, assess, manage and monitor pain; a protocol to guide staff through the pain management pathway; a pocket reference card with a modified version of the Abbey Pain scale for staff; and social support through team leaders and registered nurses.

The Intervene team is currently implementing these components as part of the project's overall intervention strategy. Post implementation data collection will commence in June 2018.

#### The outcome

A significant aspect of the Intervene Phase 2 project is empowering care staff to be involved in all aspects of pain management, encapsulated by the slogan, 'Pain Management is Everyone's Business'. By achieving this, it is hoped that all aspects of pain management will improve, narrowing the gap between best practice and what is happening 'on the ground' for people living with dementia in residential aged care.

Intervene Phase 2's findings and outcomes will be made available in the latter half of 2018. Once completed, these findings will inform Phase 3: the development of a transferable multidisciplinary team Pain Management Model that can be rolled out in all residential aged care homes across Australia.

It is hoped this model will embed best practice pain management where it matters most, improving the lives of people with dementia who experience pain.

## Case Study: Giving those in pain a voice

Jo Sillick is very familiar with how hard it can be to recognise pain in people living with dementia.

A Specialist Dementia Carer with close to ten years' experience, she says carers in her position often face barriers when managing pain in those they care for; recognising signs of pain in someone who doesn't communicate verbally; keeping track of information; and ensuring things are escalated to the right health professional.

To help improve the situation, Jo is one of eight 'champions' at HammondCare's Woy Woy site. Champions are part of a multi-disciplinary team that will help roll out the Intervene project: a program designed to implement best practice pain management for people living with dementia at residences.

She believes Intervene will make it easier for carers like herself to manage and alleviate pain that would otherwise go unrecognised.

"Intervene will help staff be more aware to look for pain first. Most importantly it's going to benefit the residents; and it's going to benefit the carers and make their role easier."

**Pictured:** Annabelle Lewin is an Occupational Therapist at Greenwich Hospital who has utilised the Intervene program for support in her clinical practice.



<sup>&</sup>lt;sup>1</sup> Michie et al. 2011; Michie et al. 2014

# Promoting mental wellbeing and positive ageing through the arts



## The opportunity

Arts on Prescription is a unique program which 'prescribes' the creative arts to help older people living in the Australian community with unmet health and wellness needs. To determine the program's effectiveness, a project evaluation was undertaken.

#### The research

The Arts on Prescription program was delivered by HammondCare between August 2015 and April 2017 through a federal government funding grant. 61 arts programs were delivered by professional artists across two regions in Sydney. Participants engaged in a range of creative disciplines – including drama, visual art, music, poetry and clay work – with the aim of improving their health and wellbeing.

For the duration of the project, HammondCare conducted an evaluation in association with the School of Public Health and Community Medicine at the University of New South Wales.

Quantitative data was collected, including pre-and post-program measures of self-reported creativity, frequency of creative activities, mental wellbeing using the Warwick-Edinburgh Mental Well-Being Scale (WEMWBS) and recognised criteria for frailty.

Qualitative data was also collected from questionnaires, interviews and focus groups. Participants were asked about their experience of the program, how the program might benefit older people with health and wellness needs, and suggestions for improvement.

#### The outcome

The evaluation found that Arts on Prescription had a positive impact on participants.

Data from the WEMWBS scores found, on average, an increase in mental wellbeing amongst those who took part in the program. For many participants, the increase was large enough to likely be recognisable to the individual as an important change.

Analysis of the qualitative findings suggests that program participants also experienced benefits in four main domains: sense of purpose; personal growth and achievement; empowerment through self-confidence and self-determination; and relationships with others through meaningful interactions.

This result not only supports the WEMWBS data; it also suggests the type of wellbeing experienced by the program's participants may be a deeper sense of purpose and fulfilment than 'happiness', which can be transient.

Overall, our results suggest that Arts on Prescription has a positive impact on mental wellbeing for participants – potentially due to the program's ability to foster wellbeing through activities which challenge, create new interests and offer a sense of achievement in an environment that promotes meaningful relationships with others.

Evidence in support of the role of arts in health and wellbeing is growing internationally. As the number of older Australians continues to increase, programs like Arts on Prescription, that promote healthy ageing in ways that are complementary to traditional health care, are needed.



# Improving cancer pain outcomes in clinical practice



## The opportunity

Managing pain is an important part of cancer care – to improve quality of life and enable people to more fully engage in the community. However, barriers to identification, management and coordination of care often prevents optimal pain management from happening 'on the ground'. The Stop Cancer PAIN trial aims to address this problem by giving people living with advanced cancer access to evidence-based best practice pain management.

#### The research

Led by Professor Melanie Lovell from HammondCare, the Stop Cancer PAIN trial is currently supporting and evaluating the implementation of the *Australian Cancer Pain Guidelines* across nine outpatient oncology and palliative care sites around Australia.

The guideline – which offers step-by-step recommendations on pain screening, assessment and management for carers and clinicians – has been developed by the Stop Cancer PAIN team and is available on the Cancer Council Australia wiki-page.

The guideline's implementation is supported by a suite of resources: a patient handbook on self-management, communication and coordination between different healthcare providers; quality improvement resources including audit tools to record adherence to cancer pain indicators; and an online training program called 'QStream' to help health professionals increase long-term knowledge retention.

Currently, three out of the eight sites have completed the trial, and the project is on track for completion by the end of 2018. The evaluation will include statistical analysis and reporting, and interviews with patients and carers about their experiences of pain management at the participating sites.

#### The outcome

Qualitative data to date has found the project's resources, such as the Qstream education, has been well received. Staff at implementation sites report being made more aware of pain assessment and management in their day-to-day work.

A principal investigator at one of the sites reported that the resources have prompted discussions amongst staff about the best way to screen for pain symptoms in an outpatient setting.

"There has been a raised awareness of appropriate assessment and management of cancer pain. Although we know that this is part of core business, it's more at the top of our minds to remember to screen for pain at every visit now – to manage it appropriately and document what we are doing," they said.

This awareness has translated into documented improvements in adherence to the *Australian Cancer Pain Management Guidelines* at some participating sites.

Ultimately the Stop Cancer PAIN trial is aiming to embed the guidelines into routine clinical practice at Oncology and Palliative Care outpatient departments. This has the potential to greatly improve pain outcomes for people in these settings, and promote quality of life.



# Virtual reality makes a difference in person-centered care

In the UK, HammondCare's Dementia Centre is delving into the world of cutting edge technology, using Virtual Reality (VR) to make a difference in the field of dementia care and education.

"One application HammondCare is actively exploring is the use of VR in dementia-specific interior design."

VR's potential to help people living with dementia has been in development for over a decade. In 2003, a small UK study examined the experience of six people with dementia as they navigated a virtual outdoor park. The study found the participants felt 'in control' of the interaction, and moved freely about the virtual environment.

This lends weight to the potential use of VR in person-centered care, with possible applications such as gathering knowledge about how the brain navigates and solves problems; a resource for memory rehabilitation and reminiscence; for anxiety management; as an education tool; as a fun activity, and as a tool for assessment and diagnosis.

One application HammondCare is actively exploring is the use of VR in dementia-specific interior design. The Dementia Centre, in partnership with Aitken Turnbull Architects and Wireframe Immersive, has helped develop the Virtual Reality Empathy Platform (VR-EP): a VR program that offers insight into the sensory challenges dementia can bring.

Consisting of a laptop with high-performance graphics, a VR headset, games controller, camera and bespoke software, the platform allows you to 'walk' around a building and experience some of the symptoms of dementia, such as how a toilet might disappear if you are in an all-white bathroom, how lights appear dimmer, or how background noise can be overwhelming.

While these environmental experiences can be explained to architects and designers, it is another thing to experience them personally. By immersing people in the challenges that a person living with dementia can face, the VR-EP could be used to help test dementia-inclusive elements, improving the design of aged care residences, hospitals, sheltered housing and other public buildings.

Another potential use for VR technology is in the treatment of chronic pain. Evidence shows chronic pain, especially in scenarios involving amputation or spinal cord injury, is linked to changes in the brain, as it no longer receives normal sensory or visual cues from the missing limb or below the injury, and tries to reorganise itself to accommodate.

When this occurs, VR could potentially be used to create an environment where people are given a strong impression that they can move their missing limb, thereby reversing the brain changes that cause pain.

Although this research is still in the early stages, there are some promising signs that it may be effective in helping manage some instances of chronic pain. It also opens the possibility of providing another non-medication option for pain management in older people, and potentially people with dementia.

By harnessing the benefits of VR, new technology can be used to make a real difference in the context of person-centered care.



# **Shedding light on aged homelessness** in Australia

Across Australia, increasing numbers of older members of our community are experiencing homelessness for the first time. The root causes are varied, including housing stress leading to financial difficulties, marriage breakdown, and domestic violence.

"This is why HammondCare is building a 42-bed residential aged care home for older people who are homeless or at risk of homelessness."

Many of the elderly who are homeless also have complex healthcare needs that require specialised care, and the unfortunate situation is that in NSW there are currently not enough facilities to care for them. Recent Census data indicates that as many as 800 older people in Sydney may be homeless or vulnerable to homelessness.

This is why HammondCare is building a 42-bed residential aged care home for older people who are homeless or at risk of homelessness. HammondCare Darlinghurst will provide a permanent home for older men and women who are vulnerable to homelessness, and require specialised nursing care. Construction is underway and the multi-storey home will be built over 4 levels, providing a home-like environment with domestic kitchens, shared living spaces, and individual en-suite bedrooms for each resident.

Professor Chris Poulos, in collaboration with The University of New South Wales and St Vincent's Hospital, will be leading an evaluation of the project over the next 24-36 months. The research seeks to demonstrate the impact of HammondCare Darlinghurst on the overall wellbeing of its residents, along with addressing their physical health, mental health needs, oral health, and issues around

addressing any cognitive impairment. There will also be a component addressing issues arising from brain injuries and drug/alcohol addiction.

This critical evaluation will provide much-needed insight into the overall needs of this cohort of older Australians, with the objective being to identify opportunities for early intervention.

Qualitative, ethical research into aged homelessness is rare. This research will bring a significant contribution to community knowledge of the needs of older people who are vulnerable to homelessness. Importantly, it will also share results widely about how to reduce the demand for expensive hospital, emergency and other care services. Longer-term, HammondCare is considering how we can quantify this benefit to local and state government.

HammondCare has received some financial support towards this research as part of a grant from The lan Potter Foundation, and we continue to seek further philanthropic partners to support us. If you would like to become a partner in this crucial research project, please contact Louise Burton or Victoria Grimes at the HammondCare Foundation on 1300 426 666.



# **Research Projects**

## **Key Research Areas**

An overview

### **Grants + Statistics**

Successful grant applications
+ grants with continuing funding in 2017

### Palliative Care

Seven new projects in 2017 + continuing projects

#### Dementia

Six new projects + continuing projects

## Ageing, Restorative Care+Reablement

Five new projects + continuing projects

## Rehabilitation

Two new projects + continuing projects

## Pain Management

Continuing projects

## Advance Care Planning

Four new projects + continuing projects

## **Spiritual Aspects of Care**

Two new projects + one continuing project



## **Key Research Areas**

#### Overview



#### **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 wellbeing for people living with life-threatening illness and their families, and the quality of end of life care. 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, a recent study to investigate barriers to provision of palliative care for people with intellectual disability.

We do translational research projects to embed evidence in practice, including pain guidelines, an anxiety and depression pathway, and a toolkit and multicomponent training program for initiating palliative care in general practice. In addition, we are supervising PhD students' research in a number of areas, including pain management and investigating what helps make a 'good' rural death. We are also active partners in the Palliative Care Clinical Studies Collaborative (PaCCSC): a national 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 a number of 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.

#1



#### Dementia

The Dementia Centre exists to improve the lives of people with dementia, their families and staff by providing training, consultancy and evidence-based interventions. They conduct research with a significant focus on understanding and addressing the causes of dementia behaviours, drawing on the expertise of the national Dementia Support Australia program. Other areas of research focus include environmental design, technology use, and other evidence-based interventions. Drawing on a wealth of national and international partnerships, including the NHMRC's Cognitive Decline Partnership Centre, the Dementia Centre delivers 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. A key adjunct to their existing research suite is the conduct of a range of sponsored pharmaceutical trials of new, potentially disease-modifying Alzheimer's Disease medications, which may provide hope for people living with dementia.

#2



## Ageing, Restorative Care+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 wellbeing 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 is 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 with dementia.

#3

## **Key Research Areas**

#### Overview



#### Rehabilitation

As the number of persons with disabilities increases rapidly, particularly, but not solely due to population ageing around the globe, there is an increased focus on rehabilitation and rehabilitation research – and HammondCare is playing a role. A recently published paper in the prestigious Journal of the American Medical Association (JAMA) reported findings from a study at HammondCare's Braeside hospital comparing community and inpatient rehabilitation for patients who had had total knee replacement. This paper has received international and local media attention and has contributed to the development of the evidence-base supporting the development of best practice models of community-based rehabilitation for this patient group. HammondCare researchers are also working on using the International Classification of Functioning, Disability and Health in various ways, and are playing a leading role in understanding the benefits of rehabilitation in people with a diagnosis of cancer.

#4



## Pain Management

By nature, the problem of pain is multidimensional 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 different 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.

#5



## **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 a number of research projects aimed at improving ACP for people with a range of different life limiting illnesses. 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.

#6



### 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 disabling or a 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.

#7

26 Key research areas

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## **Grants**

## Successful Grants and continuing funding

## Successful Grant Applications in 2017

- 1. Bush I, Woodward M, Macfarlane S, Ellis D, Ayton S, Desmond P, Salvado O. National Health and Medical Research Council. Deferiprone to Delay Dementia (The 3D study). Awarded \$1,855,000 over five years from 2017.
- 2. Christie J, Marshall M, in collaboration with researchers in the Edinburgh Centre for Research on the Experience of Dementia at the University of Edinburgh, the Health and Wellbeing in the Built Environment Group, Heriot Watt University and Innovations in Dementia. Scottish Universities Insight Institute Knowledge Exchange Programme. Widening Choices for people with dementia: What can Scotland learn from Australia and Japan about alternative housingwith-care models? Group Awarded 12,800 GBP, April 2017, six months.
- 3. Christie J, Bradley-Thompson O. Life Changes Trust. Evaluating the Impact of Assistance Dogs in the Lives of People with Dementia. Alzheimer Scotland Project Tender. Awarded 18,000 GBP, August 2017 over three years.
- 4. Clayton J, Rhee J (HammondCare), Tieman J (Caresearch), Detering K (Austin Hospital Advance Care Planning Department), Mitchell G (University of Queensland), Phillips J (University of Technology Sydney), Halcomb E (University of Wollongong), Morton R (University of Sydney), Lewis V (La Trobe University). 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 and chronic/complex care clinicians. Awarded \$2 million from August 2017 until end of June 2020.
- 5, Clayton J. Cunningham C. Palliative Care Australia. Development of a resource to support people living with dementia to participate in decision-making about their end of life care. Awarded \$110,000 from Nov 2017 to end June 2018.
- 6. Lovell M, Keall R. New South Wales Agency for Clinical Innovation (ACI) 2016/2017 Palliative Care Rapid Response Team: a hospital avoidance and enhanced care approach. Awarded \$45,000.
- 7. Phillips J, Shaw T, Lovell M, Davidson PM, Boyle FM, Lam L, McCaffrey N. Cancer Australia Grant ID: PdCCRS 1127011 2017-2019 Improving Patient Reported pain Outcomes through mHealth Practitioner Training (I-PROMPT): A phase III wait-listed randomised control trial.
- Poulos C, Gresham M, Poulos R, Radoslovich H, Hudson W, Clemson L. NHMRC Cognitive Decline Partnership Centre. Development of evidence-based dementia reablement guidelines and programs deliverable to people with mild to moderate dementia. Awarded \$219,000 2017-2018.
- 9. Stancliffe R, Wiese M, Clayton J, Jeltes G, Tieman J. Australian Government, Department of Health National Palliative Care Project. An online toolkit for carers and practitioners helping people with intellectual disability understand dying and death. Awarded \$70,643 from April 2017 to end April 2018.

#### Grants with continuing funding in 2017

- 1. 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 (Y1 \$730,264; Yr2 \$717,465; Yr3 \$724,127; Yr4 \$745,737; Yr5 \$726,398).
- 2. Clayton J (Project Director) and Rhee J (from HammondCare lead organisation), Tierman J (Caresearch), Detering K (Austin Hospital Advance Care Planning Department), Halcomb E (University of Wollongong), Mitchell G (University of Queensland), Phillips J (University of Technology, Sydney); Shaw T and Morton R (from University of Sydney). Australian Government, Department of Health National Palliative Care Project. The Advance Project. Initiating palliative care and advance care planning: training and resources for General Practice Nurses. Awarded \$1,400,000 from February 2016 until end of December 2017.
- 3. Smith A, Karlawish J, Lee S, Moran P, Clayton J (Consultant), Sudore R (Consultant). Enhancing Prognosis Communication with Disabled Elders. USA National Palliative Care Research Center Grant (This project is based within the Department of Geriatrics, Palliative, and Extended Care, University of California, San Fransisco (UCSF) Division of Geriatrics, Department of Medicine). Awarded \$140,000 from July 2015 for two years.



#### Music in Palliative Care | New in 2017



Researchers: Dr Kirsty Beilharz & Professor Chris Poulos, HammondCare



Site: Greenwich Hospital



Duration: Jan 17 to Apr 18



**Project Partners: None** 



Funding Source: HammondCare Foundation

**Single-Site Research Project** 

The majority of people receive palliative care in a hospice or in their home. Especially for those who have few visitors or little family support, therapeutic use of music can provide emotional and diversional support.

The availability of palliative care at home is becoming an increasingly important part of HammondCare's work. This research will gather evidence of music's impact for people coming to terms with terminal illness and end of life. Potential benefits include improved serenity, adding quality, opportunity for reflection and meaningful experiences, for emotional and spiritual support, and to shift focus away from illness and care routines. The objective of supporting emotional as well as physical needs, especially pain amelioration, is to improve the quality of death and dying for family and friends, as well as for patients. Especially for those with little speech, e.g. people receiving palliative care who have dementia, music may provide connection, comfort, and reduction in stress for people who cannot receive conventional pain management pharmacological medications, or who cannot engage in cognitive pain management such as cognitive therapies, meditation, relaxation therapies, due to the effects of dementia. Music has been shown to assist with relaxation, rest, calming delirium or 'agitation', and to facilitate emotional expression, such as processing grief, anger, and loss at the end of life. If proven effective, music is a cost-effective noninvasive way to improve the quality of the experience of terminal illness and support spiritual needs.

**Study Status: In Progress** 

# Randomised, double-blind, placebo-controlled phase III trial of oral melatonin for the prevention of delirium in hospital in patients with advanced cancer | New in 2017



Researchers: Professor Meera Agar University of Technology Sydney; Dr Fiona Stafford-Bell & Dr Amy Chow, HammondCare



Site: Braeside Hospital



Duration: Oct 17 to Dec 20



Project Partners: University of Technology Sydney



Funding Source: NHMRC

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: delirium occurrence, discharge, or for a maximum of 21 days if

Delirium is a highly prevalent, medical emergency in

two thirds of people with advanced cancer will have a

delirium episode at some point whilst hospitalised.

advanced cancer. Despite being preventable in many cases,

Delirium causes additional medical complications, excess mortality,

high levels of patient and caregiver distress, and significant increases

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.

Multi-Site Clinical Trial Study Status: In Progress

# **Palliative Care**

The VOICE Study valuing opinions, individual communication and experience: building the evidence base for undertaking patient-centred family meetings in Palliative Care: A mixed methods study | New in 2017



Researchers: Philippa Cahill, University of Notre Dame Australia (Sydney); Professor Jane Phillips, University of Technology Sydney; Professor Liz Lobb & Associate Professor Christine Sanderson, Calvary Health Care Kogarah and University of Notre Dame Australia (Sydney); Professor Melanie Lovell, HammondCare



Sites: Greenwich Hospital



**Duration: Aug 17 to Mar 18** 



Project Parners: University of Notre Dame Australia (Sydney); University of Technology Sydney; Calvary Health Care Kogarah and University of Notre Dame Australia (Sydney)



Funding Source: Department of Industry, Innovation, Climate Change, Science, Research and Tertiary Education (DIICCSRTE)

**Multi-Site Thesis Project** 

The aims are to determine: (i) if a planned Patient-Centred Family Meeting held soon after an inpatient admission to an palliative care unit, is feasible and acceptable to the patient, family and clinicians; (ii) if the selected outcome measures are suitable and feasible from the patient and family perspective.

Patient-Centred Family Meetings will be provided as an intervention in one of the two specialist palliative care facilities with the other facility acting as a control site where standard care will be provided and observed. Validated outcome measures will be collected at both sites to assess satisfaction with quality of life at end of life, and distress for both patient and families. Semi-structured interviews with patients and families and focus groups with multidisciplinary staff will be undertaken to gain insights about the participants' experiences of the meetings. The Family Meeting Observation Sheet will be used to capture key elements of both types of family meetings to enable comparison of family meetings practices. Proposed outcomes: (i) determine whether planned Patient-Centred Family Meetings are feasible and acceptable to participating patients, families and clinicians; (ii) determine if the selected outcome measures are suitable and feasible to patients and families; (iii) better understand the benefits and burden of participating in a Patient-Centred Family Meetings from the patient, family and clinician perspective; (iv) inform the need for the development of a future phase III Randomised Control Trial (RCT).

**Study Status: In Progress** 

### The experience of refractory breathlessness on everyday life | New in 2017



Researchers: Associate Professor Lynette Mackenzie & Ms Kezia Tieck, University of Sydney; Professor Melanie Lovell, HammondCare



Site: Greenwich Hospital



Duration: May 17 to Nov 17



Project Partners: University of Sydney



Funding Source: In the researcher's own time

Single-Site Research Project

## This research project focuses on patients with refractory breathlessness. Exploring how it affects their everyday lives.

Refractory breathlessness is reported to be an under-researched area. but the symptoms cause these patients significant distress. Therefore research to better understand their experience on a day to day basis could bring valuable insight in assisting planning and interventions for this group. The research question is - What is the experience of refractory breathlessness for patients at a breathlessness clinic and how does it affect their daily lives? Patients will be recruited by the medical team in the Breathlessness Clinic at Greenwich Hospital, who will select eligible patients who are medically fit to participate in an interview, and will invite them to participate by giving them an information sheet about the study and consent form for them to complete and return if they wish to participate. Consenting participants will be scheduled for a semi-structured one-on-one interview during one of their attendances at the Clinic at Greenwich Hospital. Patients will be asked verbally at the beginning of the interview if they consent to the interview being recorded. Interviews will be recorded and transcribed verbatim. No follow-up interviews are planned unless patients need to split up the interview time to manage their breathlessness symptoms. This qualitative study aims for ten participants. We anticipate we will achieve data saturation with this size sample of key informants.

Study Status: In Progress

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# The experience of multidisciplinary specialist palliative care teams caring for people with intellectual disability (ID) who are dying | New in 2017



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



Sites: NSW wide project



Duration: Jan 17 to Jun 18



Project Parners: University of Notre Dame Australia (Sydney); University of Technology Sydney; Calvary Health Care Kogarah and University of Notre Dame Australia (Sydney)



Funding Source: Western Sydney University Fellowship

**Multi-Site Research Project** 

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 UWS Women's Research Fellowship Grant (2017), in collaboration with the University of Sydney and Hammond Care 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: Data collection complete, analysis in progress.

# Palliative Care rapid response team: a hospital avoidance and enhanced care approach | New in 2017



Researchers: Dr Robyn Keall & Professor Melanie Lovell, HammondCare



Sites: Greenwich Hospital



Duration: Jun 17 to Jul 18



**Project Parners: Nil** 



Funding Source: ACI NSW Agency for Clinical Innovation

This project aims to evaluate the feasibility of a Rapid Response Team (RRT) embedded within a palliative care service, and patient and health economic outcomes in the intervention site (Greenwich Community Palliative Care Service) and a control site (Northern Beaches Community Palliative Care Service) within the same Local Health District.

The Palliative Care Rapid Response Team (RRT) would cover seven days a week and utilise the current, but enhanced, After Hours' telephone support line to provide 24/7 coverage. The RRT would enable: (i) urgent admission to the service for patients who wish to be discharged from an acute hospital for end-of-life care, thereby reducing bed block, (ii) assessment of patients who are reaching the terminal phase of their life from a predicted cause who wish to die at home, providing increased support to carers and (iii) those who require out of business hours admission to a Palliative Care Unit but have deteriorated suddenly and wish to avoid acute hospital admission. The expected outcomes are (i) avoidable hospital presentations will be reduced, (ii) increased number of patients enabled to have end-of-life care in their preferred place of death and (iii) the service will be positively evaluated by patients, carers and providers alike.

**Multi-Site Research Project** 

Study Status: In Progress

## **Palliative Care**

#### The PRESERVE pilot study | New in 2017



Researchers: Professor Meera Agar, Dr Annmarie Hosie & Professor Jane Phillips, University of Technology Sydney; Professor Melanie Lovell & Dr Cynthia Parr, HammondCare



Site: Greenwich Hospital



Duration: Jul 17 to Jun 19



Project Partners: University of Technology Sydney



Funding Source: National Breast Cancer Foundation

**Multi-Site Clinical Trial** 

This study aims to determine if a multicomponent nonpharmacological delirium prevention intervention is feasible and acceptable for people with advanced cancer in hospital.

Patients and family caregivers receiving care at Greenwich Palliative Care Inpatient Unit may benefit from the interventions because, in particular, the provision of information about delirium and what can be done to prevent it is highly valued by them. HammondCare clinicians and volunteers at the participating site will be supported with education and training to implement routine delirium screening, diagnostic assessment and the prevention intervention.

The overall intent of the trial is to inform whether a phase III (efficacy) trial of the intervention is feasible for testing in advanced cancer patients in palliative care inpatient unit settings, rather than to immediately inform clinical practice. A negative trial will inform a re-design of the processes and measures of the phase III trial. However, by participating in this trial, Greenwich Palliative Care Inpatient Unit will be better positioned to meet the ACSQHC Delirium Clinical Care Standard (to be instituted for all Australian hospitals in January 2019), because the screening, diagnostic assessment and prevention strategies align with the Delirium Standard.

Study Status: In Progress

# An observational study to document inter-observation in the reporting of plain radiographs of constipated palliative care patients



Researchers: Professor Katherine Clark, Calvary Mater Newcastle; Professor Melanie Lovell & Dr Bridget Johnson, HammondCare



Sites: Greenwich Hospital



Duration: May 16 to Apr 17



Project Parners: Calvary Mater Newcastle



Funding Source: Internally supported

Constipation symptoms are commonly experienced by people with palliative and supportive care needs with laxatives being the most commonly prescribed of all medications for this cohort in Australia. Despite the fact that as many as 60% of palliative inpatients require treatment for constipation, there remains a lack of robust evidence in this population as to how the severity of this problem is best assessed.

Plain radiographs are commonly used in palliative care to assess constipation with the appearance of faecal loading used as a surrogate indicator of the severity of the issue. However, this has not been objectively confirmed as an effective practice and further investigations are required to ensure that this is not a low value intervention that should be discontinued.

The aims of this low risk study are to investigate whether:

- 1. Palliative care staff are reliably able to assign a faecal loading score to a plain radiograph;
- 2. Palliative care staff are able to predict patient's symptoms based on the appearance of a radiograph; and
- 3. If patient's self-reported symptoms correlate with the assigned faecal loading score.

#### **Translational Outcomes:**

This study is complete and has been published. The clinical implications are that plain radiographs are not useful for assessing constipation and clinical assessment is most valuable.

Multi-Site Research Project

Study Status: Completed

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BEAMS: A pragmatic, phase III, multi-site, double-blind, placebo controlled, parallel arm, dose-increment randomised trial of regular low dose extended release morphine for chronic refractory breathlessness



**Researchers: Professor David Currow. Flinders University: Professor Melanie Lovell &** Dr Bridget Johnson, HammondCare



Sites: Northern Sydney HammondAtHome



Duration: Jul 16 to Dec 21



**Project Parners: Flinders University; Palliative Care Clinical Studies Collaborative** 



**Funding Source:** In researchers' own time

**Multi-Site Clinical Trial** 

Three hundred thousand Australians are breathless at rest or on minimal exertion despite optimal treatment of underlying cause. The aim of this study is to enhance the evidence base for the pharmacological treatment of chronic refractory breathlessness using potential therapies compared to placebo.

The primary objective is to compare the difference of the net effect on chronic breathlessness in people with chronic obstructive pulmonary disease (COPD) and baseline breathlessness of 3-4 on a breathlessness scale for people taking once a day extended release morphine at two different doses when compared to placebo. The co-primary objective is to compare difference in steps per day measured using Fitbit between people taking once daily extended release oral morphine by dosing level.

This study will recruit people with optimally treated chronic breathlessness of 3-4 and COPD. Those recruited will use a diary to record the change of breathlessness over a 24-hour period each morning using an 11 point numerical rating scale.

The study will answer several practical questions including whether regular, low dose extended release oral morphine delivers a net benefit in people with COPD in reducing breathlessness on exertion in steady state.

This study aims to assess the clinical benefit of PAX-1

medication on pain intensity, and also ensure it is not

associated with adverse effects that outweigh its potential

A phase III trial would then be undertaken to confirm these results,

to allow the agent to be available more widely in clinical practice.

cancer pain. The management of cancer pain is core business for

our palliative care services, and this project ensures the evaluation of new treatments which might allow us to better manage more

This project provides our clients' access to a novel agent for

**Study Status: In Progress** 

#### A randomised double-blind parallel-group placebo-controlled phase III study to assess the clinical benefit of three doses of PAX - 1 as adjunctive treatment for persistent cancer pain

benefit.



Researchers: Professor Meera Agar, University of Technology Sydney; Ms Julie Wilcock, Ms Natalie Ohrynowsky & Dr Fiona Stafford-Bell, HammondCare



Site: Braeside Hospital



Duration: Jun 15 to Apr 18



**Project Parners: Bio and Gene** 



**Funding Source: Flinders** University

**Multi-Site Study** 

Study Status: In Progress

complex cancer pain.

## **Palliative Care**

#### The impact of constipation on health-related quality of life for advanced cancer patients



Researchers: Professor Meera Agar, University of Technology Sydney; Ms Julie Wilcock, Ms Natalie Ohrynowsky & Dr Fiona Stafford-Bell, HammondCare



Site: Braeside Hospital



Duration: Jun 11 to Jun 17



**Project Partners: PaCCSC** 



**Funding Source: DoHA & Paccsc** 

**Multi-Site Clinical Trial** 

This study will help us understand the impact of constipation and more broadly will assist clinicians in a more holistic approach to management of this distressing symptom.

During 2016 a total of 60 respondents returned the survey and all but 11 participants came from the lead site. 29 respondents reported dissatisfaction with their bowel habits despite receiving laxatives, whereas only 15 respondents are satisfied without laxative intervention. The remaining 16 respondents were satisfied with laxative intervention.

Some preliminary data analysis has been undertaken and shows that the gender distribution is even and the most common age group is 70+. The youngest respondent is 28 and the eldest 89 years of age.

#### **Translational Outcomes:**

Currently a full data analysis is underway for the impact of constipation on health-related quality of life for advanced cancer patients. Results when available will be written up for publication.

**Study Status: Completed** 

symptoms our patients face.

#### A randomised double-blind multi-site parallel arm controlled trial to assess relief of refractory breathlessness comparing oral sertraline and placebo



Researchers: Professor Meera Agar, University of Technology Sydney; Ms Julie Wilcock, Ms Natalie Ohrynowsky & Dr Fiona Stafford-Bell, HammondCare



Site: Braeside Hospital



Duration: Nov 10 to Jun 17



**Project Partners: PaCCSC** 



Funding Source: DOHA/ PaCCSC/

**Multi-Site Clinical Trial** 

### Nausea Study 3



Researchers: Ms Janet R Hardy, Queensland University of Technology; Professor Melanie Lovell & Dr Bridget Johnson, HammondCare



Site: Greenwich Hospital





**Project Partners: Flinders University** of South Australia (sponsor), The Institute for Breathing and Sleep, University of Hull, Monash University, The University of Adelaide and University of Melbourne.



**Funding Source: National Health** and Medical Research Council

**Multi-Site Clinical Trial** 

It is immensely frightening for caregivers, when faced with a loved

Refractory breathlessness is one of the most distressing

one who cannot breathe. It affects the ability to sleep and function independently and is strongly correlated with sensations of panic and anxiety. Sertraline shows some promise as an agent to manage this symptom, where very few treatments are available.

#### **Translational Outcomes:**

Study Status: Completed

Currently a full data analysis is underway for the Sertraline for Refractory Breathlessness study.

This study follows on from the previous two nausea studies, which HammondCare did not participate in. Patients with cancer and suffering from nausea will be invited to participate.

The project is looking at two cohorts - one will receive oral Methotrimeprazine and the other oral Haloperidol to manage their nausea. Assessments are over three days and there is a four-week follow up period. The outcome is for improvement of nausea by 2 points on the nausea rating scale over the baseline reading.

#### **Translational Outcomes:**

Study closed and preliminary results presented at the palliative care clinical studies collaborative meeting in February 2018. The results will inform nausea management in palliative care settings.

**Study Status: Completed** 

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#### Let's talk about it



Researchers: Ms Brigitte Karle, Professor Roderick Macleod, Ms Joo Ling Tan, Dr Sarah Thompson & Ms Michelle Griffiths; HammondCare



Site: Neringah Hospital



Duration: Aug 16 to Jul 17



**Project Partners: Nil** 



Funding Source: Internally supported

Single-Site Research Project

Sexuality in palliative care is a very difficult topic for patients and health care workers to discuss, and yet there is a huge unmet need for these discussions to occur in this population.

A survey of staff will be conducted prior to intervention to discover the challenges in an inpatient palliative care ward. The participants will be asked to provide suggestions for interventions they think will be beneficial to enable staff to feel more comfortable to 'start the conversation' with their patients, and also to suggest ways of providing patients with privacy.

The researchers will then evaluate the findings. From this an educational program will be implemented as well as initiatives suggested by the staff survey to facilitate staff comfort and provide patients opportunities for privacy. After these interventions, a post intervention survey will be conducted to evaluate their success.

#### **Translational Outcomes:**

This study highlighted that there are unmet intimacy needs in our palliative care population, and that staff need training to increase their comfort levels in recognising this. An education program was delivered and strategies developed to assist staff in increasing their comfort in this area. A practical tool called the "Private Time" sign was designed, and staff educated on recognising the cues of who would be suitable for offering this sign, and who needed referral for specialised follow-up. Feedback from staff and patients about the use of the tool was highly positive. This project has changed clinical practice in this area for our patients.

**Study Status: Completed** 

# Randomised control trial of oral risperidone versus oral haloperidol versus oral placebo with rescue subcutaneous midazolam in the management of delirium in palliative care inpatients



Researchers: Professor Meera Agar, University of Techology Sydney; Ms Julie Wilcock, Ms Natalie Ohrynowsky & Dr Fiona Stafford Bell; HammondCare



Site: Braeside Hospital & Greenwich Hospital



Duration: Jun 11 to Jun 17



**Project Partners: PaCCSC** 



Funding Source: DoHA & PaCCSC

Delirium occurs in over one third of patients admitted to palliative care, increasing to 80% in the days before death.

Delirium causes highly distressing symptoms including loss of cognition, behavioural disturbance and perceptual disturbances. Delirium is also predictive of risk of anxiety disorders in the caregiver who witnesses it in a loved one. There is currently no medication registered for delirium treatment.

This study puts HammondCare on the cutting edge of delirium research internationally. The desired-for outcome is a potential treatment for delirium which has implications not only for palliative care but also in aged care where delirium is also highly prevalent.

#### **Translational Outcomes:**

This landmark study has shown that for patients receiving palliative care, individualised management of delirium precipitants and supportive strategies result in lower scores and shorter duration of distressing symptoms than when respiridone or haloperidol are added. The findings of this study have significant implications for management of delirium in palliative care settings worldwide. Further research, including at HammondCare's Greenwich Hospital, is planned to understand how to tailor, implement and embed screening for delirium and multi-component supportive interventions for delirium into palliative care settings.

Multi-Site Clinical Trial Study Status: Completed

## **Palliative Care**

#### Rapid report of pharmacovigilance program



Researchers - Braeside: Professor Meera Agar, University of Techonolgy Sydney; Ms Julie Wilcock, Ms Natalie Ohrynowsky & Dr Fiona Stafford-Bell, HammondCare - Greenwich: Professor Melanie Lovell, Dr Bridget Johnson, & Ms Bronwyn Raymond, HammondCare



Sites: Braeside and Greenwich Hospital



Duration: Jun 11 to Feb 19 Braeside May 11 to Jun 19 Greenwich



Project Partners: PaCCSC



**Funding Source: PaCCSC** 

#### Multi-Site Study

It is important clinicians monitor patients when they are started on a new medication, both for evidence that the medication is working and for 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. During 2017, the intervention series: Hypodermoclysis was completed. We continue to collect for the medication series: Amitriptyline for neuropathic pain, Targin for pain and Macrogol for constipation. 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: In Progress** 

# 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 (Chief Investigator), HammondCare



Site: Off-site research



Duration: Jun 15 to Jun 20



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



**Multi-Site Study** 

Funding Source: Cancer Institute NSW & funds administered by USyd

## psychosocial care of our patients.Patient and health professional educational materials h

This project will inform better and more streamlined

Patient and health professional educational materials have been developed with stakeholder input. Educational materials were piloted in a pre-post study. Online therapies (iCanAdapt) for early and advanced cancer have been developed and evaluated in an randomised control trial (RCT) and pre-post study. An online portal has been created to operationalise the pathway, and is currently being implemented. The study protocol for the multicentre cluster randomised controlled trial has been finalised and approved by ethics. Recruitment for the cluster randomised controlled trial has commenced.

Study Status: In Progress

### **End Of Life in Northern Sydney Local Health District**



Researchers: Professor Roderick MacLeod, HammondCare



Site: Greenwich Hospital



Duration: Mar 13 to Feb 18



**Project Partners: None** 



Funding Source: Funded by NSW Health

**Multi-Site Study** 

Study Status: This project has been completed and papers are being prepared for publication. The findings highlight strengths and weaknesses of aspects of care in North Sydney hospitals compared with similar facilities in New Zealand. Overall there are many encouraging trends. The results have been fed back to relevant personnel in the hospitals.

This study will assist in understanding the provision of end-

of-life care in acute settings and any deficiencies.

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#### Management of nausea in cancer patients - study 1



Researchers: Professor Meera Agar, University of Technology Sydney; Ms Julie Wilcock, Ms Natalie Ohrynowsky & Dr Fiona Stafford-Bell, HammondCare

Site: Braeside Hospital





**Project Partners: Queensland University of Technology** 



**Multi-Site Clinical Trial** 

Nausea is a highly prevalent symptom in palliative care which causes poor quality of life and impacts caregivers because the patient does not feel like eating.

This study is aiming to find the most effective way to control nausea symptoms, in particular with medications that are accessible via Pharmaceutical Benefits Scheme (PBS), for community patients. It also acknowledges the importance of food beyond "nutrition" as an important aspect of life even when illness is advanced.

#### **Translational Outcomes:**

Recruitment and analysis of this study is complete. Publication is pending. The results will inform nausea management in palliative

Study Status: Completed

#### Understanding Care: The volunteering experience in the space of **Palliative Care**



Researchers: Ms Holi Birman, **University of New South Wales** 



Sites: Greenwich. Braeside & **Neringah Hospitals** 



Duration: Jun 14 to Nov 17



**Project Partners: Nil** 



**Funding Source: Administered** by UNSW

This project aimed to increase our understanding of the role of volunteers in enhancing patient quality of care in the palliative care setting.

#### **Translational Outcomes:**

This project sought to identify and understand the key motivations of volunteers who offer their time and service to patients and their family/ loved ones in the palliative sphere. Drawing on narrative accounts through the undertaking of semi-structured in-depth interviews and thematic analysis, the project found that volunteers provide support to those in need by drawing on their own experiences of loss and grief, as well as their desire to 'give back', a concept which meant different things to different people. Crucially, the project identified that volunteer needs and vulnerabilities rarely inhibit their capacity to provide different forms of care. The researcher, Birman, recommends that discussions around the complexity of grief and vulnerability be integrated into future volunteer training. Articles based on the findings of this project are currently underway, which will be forwarded on to HammondCare upon publication over the coming 12-18 months. The researcher extends her sincere gratitude to the HammondCare community, in particular to all those who participated in, facilitated, and supported the project.

**Single-Site Study Study Status: Completed** 

#### Communication strategies when discussing transfer of palliative care patients to nursing homes



Researchers: Dr Hilary Stiel; **Professor Josephine Clayton** & Dr Ben Foster, HammondCare



Site: Off-site research



**Duration: Aug 15 to Jun 18** 



**Project Partners: Nil** 



**Funding Source: Internally** 

Multi-Site Study

This project will inform palliative care clinicians regarding optimal ways to discuss nursing home placement with palliative care patients and families as well as strategies to ease this transition

A set of recommendations for discussing transition to a nursing home from a palliative care unit will be developed based on this research. This will inform guidelines for communication strategies and highlight areas for future research.

This is a qualitative study, involving interviews with palliative care health professionals. Recruitment and analysis has been completed. A manuscript is being prepared for submission to peer reviewed journals.

Study Status: In Progress

## **Palliative Care**

#### The experiences of care, grief and adjustment for family members bereaved after a coronial or palliative care death: a mixed method longitudinal study



Researchers: Professor Roderick MacLeod, HammondCare; Dr Matra Robertson, University of Sydney; Ms Jane Mowll, University of Notre Dame Australia (Sydney); Professor Liz Lobb & Ms Christine Sanderson, Calvary Health Care Kogarah; Johan Duflou, **Department of Forensic Medicine** 



Neringah Hospital

Duration: Dec 15 to Aug 18



**Project Partners: Calvary Health** Care Kogarah; Department of Forensic Medicine, Sydney



**Funding Source: University Of** Notre Dame, Australia

**Multi-Site Study** 

#### **Stop Cancer PAIN**



Researchers: Professor Melanie Lovell, HammondCare, Ms Bronwyn Raymond, Ms Jane Phillips & Mr Tim Luckett, University of Technology Sydney; Professor Fran Boyle, University of Sydney



Duration: Nov 14 to Nov 18

Site: Off-site research



**Project Partners: University of Technology Sydney and Sydney** University



**Funding Source: National Breast Cancer Foundation** 

**Multi-Site Study** 

This research will contribute to understanding the experiences and needs of relatives and family care givers of the care and death of their relative whilst in the care of a HammondCare facility. Such understanding will contribute towards service development and service delivery in the palliative and post death period.

Data collection is almost completed from the participants. Data analysis is ongoing and presentations are being prepared for international conferences and publication.

Study Status: Data collection complete, data analysis in progress

The aim of this study is for improved pain outcomes for patients and improved staff knowledge.

During 2017, the study completed at one site, commenced the control arm at two sites and the intervention arm at one site.

**Study Status: In Progress** 

#### The role of Speech Pathologists in Palliative Care: Exploring the issues and reaching consensus



Researchers: Ms Katherine Kelly; Ms Kerry Gilsenan, HammondCare



Site: Braeside Hospital



Duration: Jul 15 to Jun 18



**Project Partners: Nil** 



**Funding Source: Internally** Supported

Single-Site Study

Development of a clear scope of practice and potential benchmarks for speech pathology service provision in palliative care will give HammondCare the opportunity to review its speech pathology palliative care service and ensure that it is optimally evidence based.

The data collection has been completed for both stages of the process. There is a set of agreed consensus statements for the role of speechlanguage pathologists in palliative care that have been endorsed. There are three separate manuscripts being drafted at present to report on all stages of the data collection. The plan is to submit them to the International Journal of Speech-Language Pathology for publication. The research team has been accepted to present on the consensus statements (the last piece of data collection) at the Speech Pathology Australia Annual Conference in Adelaide in May 2018.

Study Status: Data collection complete, data analysis in progress

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# MISSIONAD - A placebo-controlled, double-blind, parallel-group, 24-month study to evaluate the efficacy and safety of E2609 in subjects with early Alzheimer's Disease | New in 2017



Researchers: Dr. Peter Panegyres, Neurodegenerative Disorders Research Pty Ltd; Associate Professor Stephen Macfarlane, HammondCare



Site: Malvern HammondCare Offices



**Duration: Aug 17 to Aug 20** 



Project Partners: Neurodegenerative Disorders Research Pty Ltd



Funding Source: Eisai Inc

This study is a 24-month treatment, multicentre, doubleblind, placebo-controlled, parallel-group study in EAD including mild cognitive impairment (MCI) due to AD/ Prodromal AD and the early stages of mild AD.

In addition, the MCI due to AD population will also be consistent with the research criterion for 'Prodromal AD' in that episodic memory will be impaired on a list learning task (ISLT). An open-label Extension Phase will be available for subjects who complete the full 24-months of treatment in the Core study. The Extension Phase will continue until commercial availability of elenbecestat (E2609), or until a positive risk-benefit assessment in this indication is not demonstrated. Full details of the Extension Phase will be available in a future protocol amendment. A total of 1330 subjects will be randomised, in a double-blind manner, to receive either placebo or elenbecestat (E2609) 50mg per day (approximately 1:1 randomisation ratio) for 24 months. Randomisation will be stratified according to region, clinical dementia staging with no more than approximately 25% of the randomised subjects diagnosed with the early stages of mild dementia due to AD, and concurrent AD medication use. The study is designed to have more frequent visits focused on safety assessments during the first three months of treatment. Two longitudinal biomarker substudies will evaluate the effects of study treatment on the underlying pathophysiology of AD using amyloidPET and/or CSF biomarkers. Participation in the sub-study is optional and will require specific consent that will not affect enrolment or treatment in the main study.

Single-Site Research Project

Study Status: In Progress

# Validating and evaluating a quality of life (QOL) instrument for people with dementia | New in 2017



Researchers: Associate Professor Tracey Comans, Cognitive Decline Partnership Centre - Griffith University; Dr Bruce Walmsley & Dr Najwa Reynolds, HammondCare



Sites: Various HammondAtHome offices and HammondGrove Independent Living Units



**Duration: Sept 17 to Jun 18** 



Project Partners: Cognitive Decline
Partnership Centre - Griffith University



**Research Project** 

Funding Source: NHMRC Cognitive Decline Partnership Centre

This study will develop a preference based measure (QOL-AD) to value quality of life for people with a diagnosis of dementia or cognitive decline, using the expertise of consumers.

The preference-based QOL-AD can be used in economic evaluations of interventions for people with a diagnosis of dementia or cognitive decline. Data will be gathered as follows: (1) individual interviews with up to 80 people living with cognitive decline, mild or moderate dementia, who are receiving home care package assistance or living in a care home, across NSW; (2) individual interviews with up to 80 caregivers of people living with cognitive decline, mild or moderate dementia, across NSW; and (3) national online survey of 1000 people from the general population, stratified by age, gender, experience with dementia. Participants will be sourced through volunteer research forums and internally through HammondCare At Home.

Study Status: In Progress

## **Dementia**

# End of life symptoms and care in people with dementia, in an Australian context | New in 2017



Researchers: Peter Roach & Professor Melanie Lovell, HammondCare



Site: Pallister House



**Duration: Jul 17 to Mar 18** 



**Project Partners: Nil** 



**Funding Source: Internally Funded** 

**Single-Site Research Project** 

**Study Status: In Progress** 

to be 50 over a 12-month period).

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 | New in 2017



Researchers: Associate Professor Colm Cunningham, Professor Chris Poulos, Professor Phillip Siddall & Dr Catorina Lorang, HammondCare; Professor Anneke, Fitzgerald Griffith University



Sites: Woy Woy Residential Aged Care Home; Caulfield Residential Aged Care Home, Melbourne



Duration: Jan 17 to Oct 18



**Project Partners: Griffith University** 



Funding Source: Cognitive Decline Partnership Centre

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

Records from patients who died during their episode of care

with Dementia Support Australia will be identified. (expected

similar cases who did not die, in order to determine whether the

behavioural symptoms with which the two groups presented

differed. Cases will be examined to identify those for whom

palliative care services were engaged at the end of life.

The characteristics of those who died will be compared to

Over a decade of research has highlighted that pain is largely unrecognised and frequently undertreated in people 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 will be 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, and 2) constrain development of a culture that supports evidence-based pain management. These issues will be addressed through a participatory action research approach. Researchers will work in partnership with Multi-Disciplinary Teams (MDTs) at four RAC sites, to develop strategies which will target 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 will inform 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.

Multi-Site Research Project Study Status: In Progress

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# Understanding the factors influencing health professionals' use of supported decision-making in the context of Dementia care | New in 2017

with dementia.



Researchers: Dr Craig Sinclair, University of Western Australia; Ms Meredith Gresham, Dr Julie Bajic Smith & Professor Josephine Clayton, HammondCare



Sites: Various HammondCare sites



Duration: Apr 17 to Jun 18



Project Partners: University of Western Australia



Funding Source: Cognitive Decline Partnership Centre

**Multi-Site Research Project** 

**Study Status: In Progress** 

#### Dementia in the public domain | New in 2017



Researchers: Professor Simon Biggs & Professor Shelley Mallett, The University of Melbourne (Brotherhood of St Laurence); Ms Meredith Gresham, HammondCare; Dr Irja Haapala-Biggs, The University of Melbourne; Ashley Carr, The University of Melbourne



**Sites: Various HammondCare sites** 

We aim to conduct one-to-one interviews of persons with early stage dementia, individuals who provide support for people living with dementia, health and social care professionals and individuals working in service, trade, clerical, administrative or sales professions.

This study will explore the experiences and perceptions of

In-depth qualitative interviews will be undertaken with healthcare

nurses, social workers, occupational therapists, professional

professionals and workers (e.g. general practitioners, geriatricians,

carers) and legal professionals (e.g. lawyers, client advocates and

will be asked about their experiences in facilitating decision-making among people living with dementia, as well as the facilitators and

barriers to practice in this area. The findings will inform development

of educational resources to assist health care providers to support

decision-making among people with cognitive impairment.

members of Guardianship/Administrative tribunals). Participants

service providers in legal and healthcare sectors, with respect

to decision-making and advance care planning among people

The 30-60 minute interviews are conducted via phone or face-to-face, as required. The project is part of our three-year study which aims to examine current public perceptions of dementia from a range of perspectives, critically assess key components used in public campaigning, and further identify appropriate forms of public intervention to promote positive understanding of dementia as a social phenomenon.



Duration: Feb 17 to Jun 17



Project Partners: The University of Melbourne; Brotherhood of St Laurence



Funding Source: Cognitive Decline Partnership Centre

**Multi-Site Research Project** 

**Study Status: In Progress** 

## **Dementia**

# COGRX - clinical trial of CT1812 in mild to moderate Alzheimer's Disease | New in 2017



Researchers: Professor Michael Woodward, Austin Health; Associate Professor Stephen MacFarlane, HammondCare



Site: Malvern HammondCare Offices



Duration: Apr 17 to Jul 17



**Project Partners: Austin Health** 



Funding Source: Cognition Therapeutics Inc

**Multi-Site Clinical Trial** 

This clinical trial is a randomised, double-blind, placebo controlled trial of a new drug CT1812 in patients with mild to moderate Alzheimer's disease.

The study aims are to test the safety of 3 doses of CT1812 compared to a placebo (sugar pill). The study will also investigate how CT1812 is processed in the body. The drug, CT1812, aims to stop toxic protein binding to brain cells, which essentially causes them to malfunction. It also helps to remove toxic protein which is already present in Alzheimer's brains. This means the drug may not only slow the progression of Alzheimer's disease but it may also return impaired brain function to normal. The drug is taken orally in the form of a tablet, once a day for a period of 28 days. Patients will visit our clinic once a week where blood tests, tests of their memory and medical conditions will be performed. Patients will also undergo 2 lumbar punctures (spinal taps) throughout the study so that their CSF can be analysed. There will be up to 32 patients participating in this trial across Australia, HammondCare hopes to contribute 2-3 patients to this pool. Previous studies with CT1812 in patients who were healthy volunteers raised no significant safety concerns.

**Study Status: In Progress** 

# Optimising advance care planning in dementia through supported decision-making: An exploratory mixed methods study of community perceptions and law reform challenges in Australia



Researchers: Dr Craig Sinclair, University of Western Australia; Professor Josephine Clayton, HammondCare; Professor Sue Kurrle, University of Sydney; Professor Meera Agar, University of Technology, Sydney; Ms Sue Field, Western Sydney University; Ms Kathy Williams, Alzheimer's Australia Consumer Dementia Research Network Representative



Site: Pallister House and Greenwich Hospital



Duration: Jan 16 to Dec 18



Project Partners: Cognitive Decline Partnership Centre



Funding Source: Cognitive Decline Partnership Centre

Multi-Site Research Project

This project brings together a multi-disciplinary team of clinicians, consumer representatives and researchers (psychology, medicine and law), to examine supported decision-making as a means of promoting participation in healthcare decisions among people with dementia. Supported decision-making aims to assist people with cognitive impairment to maintain involvement in decision-making, typically through provision of a 'support person' (or persons).

The Australian Law Reform Commission recommends that legislation should encourage supported decision-making, however little is known about community perceptions towards this approach, or practical factors associated with implementation.

This project investigates community perceptions towards supported decision-making in the context of cognitive impairment. People with dementia, family caregivers of people with dementia and key health provider groups will be interviewed and surveyed, to assess community perceptions and identify barriers to implementation. Working groups of clinicians, consumers and policy-makers in each state will meet to discuss the research data, identify areas of current best practice, and establish strategies for broader implementation in each state. The researchers will also study existing laws, court cases and tribunal hearings across three Australian states (New South Wales, Western Australia and South Australia), to identify areas for future law reform. Based on study findings, the investigators will develop educational materials and practical resources to assist community members and healthcare providers to support decision-making among people with cognitive impairment.

Study Status: In Progress

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# Evidence-based programs to improve the wellbeing of people with dementia and their carers: Implementing COPE in the Australian health context



Researchers: Professor Lindy Clemson, University of Sydney; Dr Kate Laver, Flinders University



Sites: HammondCare At Home Western Sydney, South West Sydney, South East Sydney



**Duration: Mar 16 to Dec 18** 



Project Partners: University of Sydney, Flinders University, Cognitive Decline Partnership Centre



Funding Source: Internally supported

**Multi-Site Research Project** 

We will conduct implementation research to integrate an evidence-based intervention, Care of Older Persons with Dementia in their Environments (COPE), within existing health systems in Australia and determine strategies for implementation and sustainability to enable wider dissemination. COPE is a bio-behavioural program designed to improve function and has proven effective in reducing dependency and increasing engagement of the person with dementia and in improving carer wellbeing in a randomised trial in the US.

The program works at a very practical level using occupational therapy skills (e.g. problem solving issues such as poor toilet habits that result in stress and limited outings, environmental adaptations to facilitate safe behaviours and activity engagement, and joint problem solving with the carer to identify solutions and strategies) and complimentary nursing skills (e.g. educating carers concerning taking care of themselves and ways to manage incontinence, medication management, and hydration) and centres around the needs of both the carer and the person with dementia. This project will translate COPE to the Australian context within not-for-profit, private and government care systems. We will examine facilitators and barriers at therapist, organisation and policy levels, explore funding models and build in features of sustainability. Outcomes of interest include dosage and feasibility, treatment fidelity to key features, acceptability of intervention to stakeholders, therapists and participants, engagement of champions, knowledge acquisition of staff providing the intervention, and cost utilisation. We shall employ a process evaluation using interviews, focus groups and observation.

This project will lead to greater understanding on how

regulations such as rules, standards, guidelines, conventions

It is expected the outcomes will enhance the effective delivery of care,

and prioritise the needs, desires and rights of people with dementia.

A series of policy recommendations on aged and dementia care

regulations will also result from this research.

and norms, influence and shape dementia care in different

Study Status: In Progress

# The effects of regulation on aged care services for people with cognitive decline



Lead Investigator: Professor Simon Biggs, Melbourne University Designated System Based Investigators: Ms Angela Raguz, Ms Meredith Gresham, Ms Rebecca Forbes & Dr Catriona Lorang, HammondCare



Sites: Dementia specific residential care homes: Erina, Hammondville, Horsley, Miranda, North Turramurra and Woy Woy



Duration: Feb 14 to Jun 18



Project Partners: Nil



Funding Source: Cognitive Decline Partnership Centre

Multi-Site Study

Study Status: The researchers have completed all data collection for this project, and are currently working on disseminating key research findings, and developing policy and practice recommendations.

## **Dementia**

# The experience of using a wash and dry toilet top bidet with frail older people and people living with dementia: clinical study



Researcher: Ms Meredith Gresham, HammondCare



Sites: Benetas', Mornington Aged Care Facility and HammondCare's Tulip wing at North Turramurra



Duration: Jun 11 to Sep 18



Project Partners: Dementia Collaborative Research Centre



Funding Source: Dementia Collaborative Research Centre (Assessment and Better Care) University of NSW, HammondCare Foundation

**Multi-Site Clinical Trial** 

**Study Status: In Progress** 

# Functional & symptomatic outcomes of psychogeriatric patients in Riverglen inpatient unit



Researcher: Associate Professor Janine Stevenson, HammondCare



Sites: Greenwich Hospital



Duration: Apr 14 to Jun 18



**Project Partners: Nil** 



Funding Source: Internally Supported

**Multi-Site Clinical Trial** 

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

This study aimed to examine the acceptance of bidets in

dementia specific care for residents and staff; the ability

of the bidet to clean and dry after voiding; the effects on

management of incontinence and cost of continence pads.

Eight bidets were installed and data collected on 14 residents.

During 2016 slow participant uptake has meant only 30 assessments have been completed (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.

The CHOPS program is designed to enable staff to have the

CHOPS program built on a 12-month pilot study in five NSW

Implementation occurred in 12 NSW Department of Health services

including Prince of Wales Hospital, Broken Hill Base Hospital and Coffs Harbour Hospital. Formative evaluation results demonstrate that the model is able to be successfully adapted across a number

skills and knowledge to identify, treat and care for older

people presenting to their hospitals with confusion. The

**Study Status: In Progress** 

acute hospitals.

of sites.

**Translational Outcomes:** 

# The care of Confused Hospitalised Older Persons (CHOPS) Program Implementation



Lead Investigator: Professor Susan Kurrle, University of Sydney Designated System Based Investigator: Associate Professor Colm Cunningham, Dr Catriona Lorang & Ms Rebecca Forbes, HammondCare



Site: Not applicable

Duration: Jul 13 to Jun 16



Project Partners: Nil



Funding Source: Cognitive Decline Partnership Centre

**Multi-Site Study** 

**Study Status: Completed** 

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# Systematic review and scoping study for the implementation of a national approach to dementia specific advance care planning



Lead Investigator: Professor Meera Agar, University of Technology Sydney Designated System Based Investigators: Ms Angela Raguz & Ms Catriona Lorang, HammondCare Researchers: Ms Adele Kelly, Ms Gail Yapp & Professor Josephine Clayton, HammondCare



Sites: Not applicable



Duration: Oct 13 to Dec 17



**Project Partners: Flinders** University



Funding Source: Cognitive Decline Partnership Centre

Multi-Site Research Project

#### Advance care planning in cognitive decline is a critical area for the clients for whom HammondCare provides care.

This project will explore the implementation of advanced care planning specifically in the person who has expected cognitive decline, and also mechanisms to ensure such plans are communicated to, and also respected within, the health care systems. During 2016 and 2018 researchers evaluated the evidence for advance care planning and identified what needed to be done to engage people with dementia in planning ahead The project then worked with community partners to develop a range of resources to support and promote planning ahead for people with dementia in a community and home-care setting. Resources are now being housed on the Start2Talk website (www.start2talk.com.au) to maximise reach to individuals with dementia and their caregivers.

#### **Translational Outcomes:**

The research findings and resources developed as part of this project can be used to improve the quality of care provided to people with dementia. Advance care planning allows the individual's preferences to be known and increases the likelihood that these will be followed. Providing care to people that is aligned with their preferences and values improves the quality of care and reduces stress and anxiety in carers. The project has been successful in creating increased awareness of the specific needs of people with dementia with regard to advance care planning. It is anticipated that this knowledge, and these resources, will increase the uptake of advance care planning and ensure the planning that occurs meets their needs into the future, ensuring that discussions occur early and relate to the wide variety of topics it is important to discuss.

**Study Status: Completed** 

# Understanding the real cost of long-term care models for older people with cognitive decline in residential settings



Lead Investigator: Professor Maria Crotty, Flinders University Designated System Based Investigators (DSBIs): Ms Meredith Gresham, Ms Angela Raguz, Associate Professor Colm Cunningham & Ms Rebecca Forbes, HammondCare



Sites: Erina & Woy Woy Residential Care Homes



Duration: May 14 to Jun 18



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



Funding Source: Cognitive Decline Partnership Centre

Multi-Site Study

This project will benefit HammondCare by providing an opportunity to develop an understanding of the key determinants of a good residential aged care experience from the perspective of people with dementia and their family members, which will both benefit those providing and designing services at HammondCare, as well as providing this information for use across the sector.

In addition, this will provide an opportunity for staff at HammondCare to participate in research and gain capacity in conducting research, an important benefit given the need for research in the future to improve the care of those with dementia.

Stage 2 & 3 (in progress): This project aims to determine the outcomes (specifically in quality of life, quality of care, and utilisation of healthcare resources) and the costs to operate alternative ways of providing residential aged care for people with

alternative ways of providing residential aged care for people with cognitive impairment and dementia. This will provide HammondCare with information on the outcomes provided by alternative ways of providing residential care for people with dementia.

Study Status: The researchers of this study took receipt of the health service utilisation data required for the INSPIRED study from all data custodians in December 2016. These data are being prepared for inclusion into the overall analysis and modelling. Collection of similar data in parallel from alternative sources where possible has allowed the researchers to evaluate the quality and completeness of some of these data and adjust for this in their analysis.

## **Dementia**

# Optimising the quality use of medicines for people with cognitive and related functional decline



Lead Investigators: Professor Sarah Hilmer, University of Sydney; Associate Professor Simon Bell, Monash University Designated System Based Investigators: Associate Professor Colm Cunningham, Ms Rebecca Forbes & Dr Catriona Lorang, HammondCare



Sites: Various HammondCare care homes.



Duration: Stage 1: Jun 14 to Aug 14 and Stage 2: Sept 14 to Dec 19



**Project Partners: Nil** 



Funding Source: Cognitive Decline Partnership Centre

Stage 1 (focus groups): Investigation into the beliefs of older adults and carers towards deprescribing.

Stage 2 (questionnaire): Investigation into the beliefs of older adults and carers towards deprescribing: validation of the DeprescriBe (Deprescribing Beliefs)

**Multi-Site Clinical Trial** 

This research project will generate new knowledge regarding how older adults and carers feel about the process of ceasing medications.

This may, in the future, lead to ways to better manage medications for people with and without dementia. This research will result in a validated questionnaire that will not only provide information in relation to beliefs about deprescribing but may be used as a tool to identify individuals who are more willing to deprescribe. The long term goal of this research is to develop a process that allows safe and effective cessation of medications that are no longer required and/or are high risk.

During 2016 development was completed on the "Goal-directed Medication review Electronic Decision Support System" (G-MEDSS, available at www.gmedss.com.) This tool aims to guide pharmacists and general practitioners and to provide clinical decision support for those receiving a medication review and to assist in meeting their goals and preferences. In order to validate the software interviews and focus groups are being held to ascertain the various participants perspectives on using the tool. The people being recruited for this include pharmacists, general practitioners, people with and without dementia. After completing the validation process G-MEDSS will be upgraded and trialled in a randomised controlled setting to evaluate the impact of the system as an intervention. In addition, Prof Sarah Hilmer and Dr Lisa Kouladjian O'Donnell are collaborating with the investigators on Activity 1 on a number of publications.

Study Status: Stage 1: Completed, Stage 2: In Progress

# **Ageing, Restorative Care+Reablement**

# A qualitative evaluation of The Jacaranda Cancer Rehabilitation Unit, Greenwich Hospital | New in 2017



Researchers: Dr Bruce Walmsley, Associate Professor Andrew Cole & Dr Najwa Reynolds, HammondCare; Professor Chris Poulos HammondCare & University of New South Wales



Site: Greenwich Hospital



Duration: Aug 17 to Feb 18



**Project Partners: None** 



Funding Source: Internally Funded

**Single-Site Evaluation Project** 

This study seeks to understand the subjective experiences of staff and patients of The Jacaranda Unit, in relation to inpatient cancer rehabilitation services.

In particular, it aims to understand (1) the negative / positive subjective interpretations of health professionals regarding their experiences of providing cancer rehabilitation services at The Jacaranda Unit, and (2) the negative / positive subjective interpretations of patients, regarding their expectations and experiences of receiving cancer rehabilitation services at The Jacaranda Unit. The project is a qualitative study involving focusgroups with staff, and pre-and post-inpatient stay interviews with patients. It is anticipated that around 10 health professionals providing cancer rehabilitation services, and 20 patients receiving cancer rehabilitation services, will participate. The Unit Manager will recruit: (1) medical and allied health staff with more than 6-months experience in the unit; (2) cancer rehabilitation patients referred to the unit, who can be interviewed pre- and postadmission. Following ethics clearance, (1) invited participants will be provided with study details and consent forms, (2) participant consent forms and demographic information will be collected, and (3) staff focus-groups and pre- and post-inpatient interviews will be conducted at a time convenient to all. It is expected that the study outcomes will inform whether the unit is meeting the needs of its patients, both actual and perceived, and provide insights on the experiences of the staff of the unit.

**Study Status: In Progress** 

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# **Ageing, Restorative Care+Reablement**

# Development of evidence-based dementia reablement guidelines and programs deliverable to people with mild to moderate dementia | New in 2017



Researchers: Professor Chris Poulos HammondCare & University of New South Wales; Ms Meredith Gresham, HammondCare; Associate Professor Roslyn Poulos, University of New South Wales; Ms Helen Radoslovich, Helping Hand; Ms Wendy Hudson, Brightwater Group; Ms Lindy Clemson, University of Sydney



Site: Clinical Training Centre, Hammondville



Duration: Jan 17 to May 18



Project Partners: University of New South Wales; Helping Hand; Brightwater group; University of Sydney



Funding Source: NHMRC Cognitive Decline Partnership Centre

Research Project

The recently released CDPC Clinical Practice Guidelines and Principles of Care for People with Dementia (Guideline Adaptation Committee, 2016) are 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 with dementia.

The next step is to operationalise these guidelines for the community and residential aged care sectors to enhance the use of evidencebased reablement interventions for people with mild to moderate dementia. This project will seek to gain an understanding of current provider knowledge and practice with respect to the meaning and utility of reablement for the person with dementia, as well as the perceived barriers to implementing reablement interventions. We will review the reablement interventions contained within the Clinical Practice Guidelines and Principles of Care for People with Dementia for suitability for implementation by aged care providers, and also review the literature for additional interventions published since, or not included within, the Practice Guidelines. We will produce a glossary of terms and bring together CDPC Partners and other stakeholders to produce a CDPC Practice Handbook for Reablement Interventions for People with Dementia, for use within the Australian aged care sector. An implementation plan for the Practice Handbook will also be

#### Study Status: In Progress

#### Arts on Prescription Project: Ethnographic evaluation of service | New in 2017



Lead Investigator: Associate Professor Roslyn Poulos University of New South Wales; Dr Bruce Walmsley & Associate Professor Chris Poulos, HammondCare



Site: GP Clinics Hammondville



Duration: Feb 17 to Apr 17



**Project Partners: Nil** 



Funding Source: Internally Funded

This project is additional to the already approved evaluation of 'Arts on Prescription' (AoP) – HC15430. It is an ethnographic investigation, seeking to understand how and in what ways a participatory arts program facilitates the development of eudaimonic wellbeing in older people with unmet health and wellness needs.

Therefore, it will observe the interactions between a visual artist and participants, and between participants themselves; and observe the development (or not) of participant confidence, skills, or sense of achievement over a 10-week visual art program. Participants will be community dwelling older people experiencing frailty, mental health, and/or early cognitive impairment, living near Hammondville, NSW. Referral to the program occurs through GPs, allied health/medical practitioners. Following ethic approval, participants will receive participant statement and consent forms. Only participants willing to be involved in the ethnographic study will be enrolled in the group; those not wishing to be involved will be enrolled in another group. The researcher will conduct six 30-minute video recorded observations during a 10-week visual art program at Hammondville, in weeks 1, 2, 4, 6, 8, and 10 of the program. An audio recorder / camera-recorder will be pre-set to run, for non-obtrusive recording and to minimise participant staging and anxiety. Speech and non-speech interactions (expressed noises, facial expressions, and body gestures) will form the data set for transcription and analysis (via Thematic Analysis: Braun & Clarke, 2006). Independent auditing and an audit trail will bring credibility to the findings.

#### **Single-Site Evaluation Project**

Study Status: In Progress

## **Ageing, Restorative Care+Reablement**

#### Enhancing prognosis communication with disabled elders | New in 2017



Researchers: Alexander Smith; Jason Karlawish; Sei Lee; Patricia Moran; Professor Josephine Clayton, HammondCare; Rebecca Sudore



Site: Department of Geriatrics, Palliative, and Extended Care, University of California, San Fransisco (UCSF) Division of Geriatrics, Department of Medicine



Duration: Jul 15 to Sep 17



**Project Partners: Nil** 



Funding Source: US National Palliative Care Research Center (administered by the University of Calfornia) Long-term prognosis informs clinical and personal decisions for older adults with late-life disability.

However, many clinicians worry that telling patients their prognosis may cause harm. This study will explore the safety of and reactions to prognosis communication in late-life disability using a mixed methods study design. Thirty-five older adults participated in the study. About half of the disabled older adults' self-estimates of prognosis were similar to calculated estimates. Discussing life expectancy led participants to express how they could alter their life expectancy, how they saw their present health, and their hopes and fears for the remaining years of their lives. Evidence of sadness or anxiety was rare.

#### **Translational Outcomes:**

These data suggest that in most cases, clinicians may safely offer to discuss prognosis. The findings of this study were recently published in the Journal of the American Geriatrics Society.

#### **Multi-Site Study**

**Study Status: Completed** 

# Investigating the implications of the aged care reforms, specifically care delivered in the home to older, low income rental tenants



Researchers: Ms Victoria Cornell, Centre for Housing, Urban and Regional Planning and University of Adelaide



Sites: HammondCare At Home Central Coast, Northern Sydney, Western Sydney, South West Sydney, South East Sydney



**Duration: Apr 16 to Feb 18** 



Project Partners: Nil



Funding Source: University of Adelaide and the Australian Housing and Urban Research Institute

**Multi-Site Study** 

Housing is fundamental to the wellbeing of everyone, particularly older people. The number of lower income people aged 65 and over living in rental households, as home ownership falls, is projected to exceed the supply of the social housing system. The decline in public housing dwellings and tight targeting of housing assistance to those with complex needs, means demand on the private sector and social housing provision is considerable.

Council on the Ageing has identified that a lack of affordable, suitable accommodation for older people will result in a crisis in aged care support and will have a major impact on capacity of other support and care services. However, little attention has been paid to the consequences for older people with limited control over their home due to tenure. Rental tenants often have restricted rights to modify/adjust their accommodation, limited discretionary income and a restricted understanding of government programs.

This study will investigate these issues and develop both policy and program recommendations through review of the published and grey literature examining the relationship between consumer-directed aged care and tenure; focus groups with tenants; and interviews with service providers about the challenges they expect to face in providing care to tenants and how they expect to overcome these. The research will result in identification of strategies to enable aged care and housing providers to better meet the needs of tenants; identify more effective mechanisms for service delivery; and generate strategies for informing older tenants how to maximise use of aged care support.

Study Status: In Progress

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# **Ageing, Restorative Care+Reablement**

#### Best practice and the regulation of quality of care for older people



Researchers: Ms Lisa Trigg, London School of Economics and Political Science



Site: Hammondville



**Duration: Apr 16 to Mar 18** 



**Project Partners: Nil** 



Funding Source: National Institute of Health Research (England)

Governments have found it difficult to encourage providers of aged care to improve care quality. Many approaches have been tried, but it is not clear which are the most effective. These approaches include conducting inspections, encouraging competition between companies and publishing performance data and star ratings. Many of these are used to make sure that providers deliver basic levels of care.

The purpose of this study is to look at what governments can do to encourage providers to deliver care which is better than just the basic level of quality. To do this, the research is comparing the approaches taken by the governments of England and Australia.

Part of this study is to conduct interviews with providers in both countries who are known for delivering quality over and above the minimum standards required. The aim of these interviews is to understand more about why and how providers exceed the quality standards. This includes, for example, one or two facility managers, and staff who are engaged in specific roles associated with quality, such as Quality or Performance Improvement, Compliance or Learning and Development.

The aim of the study is to investigate how and why the approaches differ and to identify the advantages and disadvantages of each country's approach. This information can then help future efforts to improve the design of regulation and ultimately the quality of the experiences of both residents and staff in aged care.

**Single-Site Thesis Project** 

**Study Status: In Progress** 

#### **Arts on Prescription @ Home**



Researchers: Professor Chris Poulos, HammondCare & University of New South Wales, Associate Professor Colm Cunningham, HammondCare; Associate Professor Roslyn Poulos, University of New South Wales; Professor Elizabeth Beattie, Queensland University of Technology



Sites: HammondAtHome South West Sydney & South East Sydney



Duration: Feb 16 to Jun 18



Project Partners: University of NSW & Queensland University of Technology



Funding Source: Dementia Collaborative Research Centres-Consumers and Carers (Queensland University of Technology) The proposed participatory arts program (Arts on Prescription @ Home) is a novel pilot project, focussing on supporting carers by providing new and meaningful methods of engagement between the carer, the person with dementia for whom they care, and those around them. It builds upon a growing evidence base showing the positive role of participatory arts in promoting the health and wellness of older people with a range of conditions, including people with dementia and their carers.

AoP@home will provide six dyads with an eight week arts program, of around two hours per week, delivered in the home by a professional artist. Between sessions, participants will be provided with materials and support to pursue their individually tailored program.

As the nature of the cultural arts is highly personal, the artistic endeavour to be undertaken by each dyad will be designed in collaboration with the participants. Shared experiences and lasting memories will be created, helping carers, family and friends deepen their understanding of their loved one, and nurture respect and dignity through new found achievement.

Single-Site Research Project

**Study Status: In Progress** 

# **Ageing, Restorative Care+Reablement**

#### **Arts on Prescription evaluation**



Researchers: Professor Chris Poulos, HammondCare & University of New South Wales; Mr Damian Harkin & Ms Mary-Rose Birch



Site: Not applicable



Duration: Aug 15 to Feb 18



**Project Partners: Nil** 



Funding Source: NHMRC Cognitive Decline Partnership Centre

Research Project

'Arts on Prescription' is a service delivery project that will provide participatory arts to community-dwelling older people with unmet health and wellness needs who live in the Liverpool and Bankstown local government areas and in the local government areas surrounding North Turramurra.

The Arts on Prescription project aims to improve the health and welfare of older people with complex health or aged care needs. The project is classified as a service development project, the research component will aim to provide an evaluation of the project suitable for dissemination within the aged care, academic and arts communities. It should also provide data for a scientific publication about the impact of an Arts on Prescription project for older people.

During 2016 Arts on Prescription continued to deliver programs to

During 2016 Arts on Prescription continued to deliver programs to participants. Program evaluation continued, under the supervision of the UNSW evaluation team. The program concluded in April 2017 and the final project report was delivered to the Department of Health in August 2018. Academic publication of the evaluation should occur in 2018.

Study Status: In Progress

## Rehabilitation

#### HIHO 2 | New in 2017



Researcher: Dr Carol Connolly



Site: Braeside Hospital



Duration: May 17 to Dec 19



Project Partners: Whitlam Orthopaedic Research Centre; Fairfield Hospital; Campbelltown Hospital



Funding Source: Internally supported

Total Hip Arthroplasty (THA) is a treatment for people with disabling, painful hips. After surgery, patients participate in a number of models of rehabilitation.

There is no definitive evidence to support one model over another. Inpatient rehabilitation is far costlier than outpatient or domiciliary models. Members of this group recently explored the efficacy of different rehabilitation models following total knee arthroplasty, HIHO (Hospital Inpatient versus HOme-based rehabilitation). The study found that outcomes in the inpatient group were not superior to the home-based group. This study, HIHO 2, is based on HIHO and aims to compare the functional outcome of patients following THA. HO-Group (Home-based) attend three outpatient group exercise sessions (3, 5-6 and 8-10 weeks after surgery), a physiotherapist advances the exercises whilst tailoring them to the individual. HI Group (Hospital Inpatient and home-based) admitted to Braeside Hospital Rehabilitation ward for 10 days of inpatient multidisciplinary rehabilitation with approximately 2.5 hours of individual and group physiotherapy per day. Following discharge they will participate in a home-based physiotherapy program the same as the home-based group. The primary outcome is functional mobility at 26 weeks post-surgery. Secondary outcomes will include patient reported functional outcomes, quality of life, patient preference, patient satisfaction, patient perceived improvement. Measurements will be taken before surgery and after surgery at 3, 10, 26 and 52 weeks. Two nested studies will examine how much the 6MWT needs to change to be important and will explore the properties of a novel ICF based mobility assessment tool (IBMAT).

Single-Site Thesis Project

Study Status: In Progress

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## Rehabilitation

# ACTIveARM: Australian Constraint Therapy Implementation study of the ARM | New in 2017

Wegen & Wolf. 2015).

**Background: Constraint Induced Movement Therapy (CIMT)** 

significant improvements in upper limb function compared

to usual therapy, after only 2 weeks (Kwakkel, Veerbeek, van

stroke and traumatic brain injury (TBI) that produces

Despite this strong evidence, there is a gap between CIMT

research and practice (Fleet et al., 2014; Viana & Teasell, 2012).

Lack of therapist knowledge of CIMT has been identified as one

multiple health services in SWSLHD. Key research questions are: 1)

Do rehabilitation teams deliver more CIMT programs after receiving a CIMT implementation package? and 2) Do stroke and brain

injury survivors that complete a CIMT program achieve upper limb

The aim of this project is to evaluate a student-led outpatient

occasions of service and discharge reason) as well as patient

The objectives of this investigation are to increase service efficiency

and activity with timely access to therapy services. The clinic aims to facilitate hospital transfer of care, optimise patient functional outcomes and reduce representation rates of patients in the target

priority patient populations. This project hopes to help evaluate if student run clinics provide an increased case load while maintaining

the expected level of quality, satisfaction and efficiency of a NSW

rehabilitation physiotherapy clinic at Campbelltown and

Camden Hospitals in terms of service delivery (wait time,

outcomes consistent with published outcomes?

key barrier – one that is amenable to change with training. We aim to establish if a two-week publicly funded CIMT program can be translated into practice and sustained over two years across

is an effective intervention for upper limb recovery following



Researchers: Ms Lauren Christie, SWSLHD; Lionel Wong, HammondCare; Ms Annie McCluskey, University of Sydney; Ms Meryl Lovarini, University of Sydney



Site: Braeside Hospital



**Duration: Mar 17 to Dec 18** 



Project Partners: SWSLHD; University of Sydney



Funding Source: Internally supported

**Multi-Site Research Project** 

Study Status: In Progress

and student satisfaction.

hospital department.

## Student-led outpatient physiotherapy rehabilitation clinic



Researchers: Ms Renee Fortunato & Mr Paul Bowron, SWSLHD; Mr Mark Buhagiar, HammondCare; Professor Lucinda Chipchase & Mr Sascha Karunaratne, Western Sydney University



Site: Braeside Hospital



Duration: Feb 16 to Jun 18



**Project Partners: Nil** 



Funding Source: In researchers' own time

Multi-Site Research Project Study Status: In Progress

## Rehabilitation

#### FIM item redundancy



Researchers: Associate Professor Friedbert Kohler, HammondCare; Professor Hugh Dickson, Liverpool Hospital



Site: Braeside Hospital



Duration: Jan 16 to Jun 18



**Project Partners: Nil** 



Funding Source: In researchers' own time

**Single-Site Research Project** 

The FIM is a commonly used assessment tool to assess functional status of patients in the rehabilitation setting. Out of the total 18 functional items measured in the FIM, there are three items to measure transfer functions. It is proposed, based on results from a previous study, that there is a high correlation between the three transfer items.

The aim of this study is to determine the agreement and correlation between the three transfer items indicating redundancy. A strong correlation of the transfer items will also affect the reliability and internal consistency of the whole FIM scale.

**Study Status: In Progress** 

## Sub-acute tools project: the development of an internationally valid ICF mobility outcome measure



Researchers: Associate Professor Friedbert Kohler, HammondCare; Dr Seema Radhakrishnan



Site: Braeside Hospital



Duration: Dec 12 to Jun 17



**Project Partners: Multiple** 



Funding Source: Otto Bock Healthcare Products and Ossur

**Multi-Site Study** 

Developing, testing and validating an ICF based mobility assessment tool.

HammondCare at Braeside is the coordinating centre for a worldwide multi-centre group of rehabilitation professionals that are aiming to develop and test a generally usable mobility assessment tool for disabled people around the world.

The study is in the final stages and is being prepared for publication. The ICF based mobility assessment tool has been presented at major international conferences in 2017.

Study Status: In Progress

### **SNAP rehabilitation and AROC data accuracy**



Researcher: Associate Professor Friedbert Kohler, HammondCare Aiza Iftikhar



Site: Braeside Hospital



Duration: Sep 15 to Jun 18



Project Partners: Nil



Funding Source: Internally supported

**Research Project** 

The Subacute Non-Acute Patient (SNAP) data collection and the Australasian Rehabilitation Outcome Centre (AROC) are instrument components of rehabilitation practice in Australia

Funding and benchmarking are based on the data collection. This study explores the accuracy and reproducibility of part of the data collection.

Study Status: The data for this project has been analysed and has been submitted to the Australasian Faculty of Rehabilitation Annual Scientific Meeting 2017 as an abstract for presentation. Part of the data analysed in this study was presented at the AFRM ASM in 2017. Further presentations on other components of the data analysed are pending.

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## **Pain Management**

#### Neurobiological, psychological and existential contributors to pain: an integrated approach



**Researchers: Professor Philip** Siddall & Professor Melanie Lovell HammondCare; Ms Mandy Corbett & Dr Phil Austin



Site: Greenwich Hospital



Duration: Feb 14 to Jun 18



**Project Partners: University of Sydney** 



Funding Source: Australian & NZ College of Anaesthetists

**Multi-Site Study** 

This grant has been awarded by the Australian & New Zealand College of Anaesthetists to support HammondCare in its development of an academic centre of excellence in pain medicine at HammondCare.

The award itself recognises HammondCare as a leading academic contributor to pain medicine and the funding will cover the salaries and associated costs of two researchers employed within HammondCare. The project itself aims to bring together the physical, psychological and spiritual contributors to pain. This emphasis particularly on the spiritual receives little attention within pain medicine and will help HammondCare in developing and disseminating an innovative approach to pain management that is in line with the HammondCare philosophy and ethos.

During 2016 the researchers have completed the collection of data from groups of people without pain, with chronic pain, with cancer and without pain and with cancer and pain. The results to date show that the level of existential and spiritual distress in people with pain is significantly higher than people without pain and as high as

**Study Status: In Progress** 

#### **Outpatient pain self-management program**



Researchers: Professor Philip Siddall & Ms Rebecca McCabe, HammondCare



Site: Greenwich Hospital



**Duration: May 11 to Dec 19** 



**Project Partners: Nil** 



**Funding Source: Internally** 

**Research Project** 

#### This project aims to collect data from people attending HammondCare's group pain program.

This is essential in disseminating the results of our program and establishing the value of the program, particularly as it takes a new approach. The very positive outcomes we have been achieving have already been noted by the Northern Sydney Local Health District and the NSW Agency for Clinical Innovation with Professor Philip Siddall invited to present the data at a state-wide meeting in November 2014. The results are crucial in validating our program. During 2016 the researchers evaluated outcomes from over 100 people who completed the pain program. The results match or exceed results from other pain clinics including a reduction in pain of over 30%. 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.

This project will help us understand the contribution of

On completion of our research it is hoped we can provide a new and simple technique for the assessment of persistent pain. By

doing so, it will enable us to identify potential targets for treatment.

During 2016 the researchers have developed and administered a new 'Pain Modulation Index', - a questionnaire that aims

to measure peoples ability to block out pain. Results show a

reasonable relationship with physiological tests, however the researchers are looking to refine the questionnaire further to make

**Study Status: In Progress** 

several different mechanisms.

### A clinically relevant tool for assessing pain modulatory pathways



**Researchers: Professor Philip** Siddall & Dr Phil Austin, **HammondCare** 



Site: Greenwich Hospital



Duration: Feb 14 to Jun 18



**Project Partners: University of** Sydney



Funding Source: Australia & NZ **College of Anaesthetists** 

**Multi-Site Research Project** 

it more accurate.

**Study Status: In Progress** 

## **Advance Care Planning**

#### The Advance Project: Initiating Palliative Care and advance care planning through training and resources for primary and chronic/complex care clinicians | New in 2017



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



Site: National Project with base at **Greenwich Hospital** 



Duration: Aug 17 to Jun 20



Consortium Members: CareSearch, Flinders University (Professor Jennifer Tieman), Advance Care Planning Australia, Austin Health (Dr Karen Detering), University of Queensland (Professor Geoff Mitchell), University of Technology Sydney (Professor Jane Phillips), University of Wollongong (Professor Elizabeth Halcomb), University of Sydney (Associate Professor Rachael Morton), La Trobe **University (Associate Professor** Virginia Lewis)



**Funding Source: Australian Government Department of** Health, National Palliative Care Project (administered by HammondCare)

**Multi-Site Research Project** 

Using funding from the same grant program, we already developed an innovative and evidence-based toolkit and multimodal training resource to enable General Practice Nurses to:

Promote awareness of Advance Care Planning (ACP) among older people and those with chronic/complex disease during routine

Identify patients who might be at risk of deteriorating and dying; Assess these patients' symptoms, important questions and

Assess their caregivers' needs and concerns; and Identify those who would benefit most from referral to specialist palliative care (PC) services.

This Project aims to extend the benefits from the initial Advance program by tailoring the toolkit and training to GPs, and other clinicians working in primary and chronic/complex care. The training will develop clinicians' skills in initiating conversations about ACP and screening for PC needs, facilitate earlier attention to ACP and palliative/supportive care in primary and chronic/complex care settings, and enable clinicians in these settings to more efficiently address patients and caregivers' identified needs and concerns about ACP and PC. A formal program evaluation will be conducted to inform ongoing implementation.

**Study Status: In Progress** 

#### Online Toolkit for carers and practitioners helping people with intellectual disability understand dying and death | New in 2017



Researchers: Professor Roger Stancliffe, University of Sydney; Dr Michele Wiese, University of Western Sydney: Professor Josephine Clayton, HammondCare; Ms Gail Jeltes; Professor Jennifer **Tieman, Flinders University** 



Site: National project



Duration: Apr 17 to Jun 18



**Project Partners: Nil** 

**Funding Source: Australian Government Department of** Health, Public Health and Chronic Disease Program (administered by University of Sydney)

**Multi-Site Research Project** 

This evidence-based online toolkit aims to provide carers and practitioners with information, evidence, resources and confidence to discuss dying and death with people with intellectual disabilities.

The online toolkit is an adaption of the previously evaluated faceto-face "Dying to Talk" education toolkit that was developed as part of an Australia Research Council funded research project. It will be accessible from the CareSearch website.

The development of the online toolkit will result in national reach, flexible delivery, and a freely available, sustainable resource for carers and practitioners.

Study Status: In Progress

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## **Advance Care Planning**

#### Development of a resource to support people living with dementia to participate in decision making about their end of life care | New in 2017



Researchers: Ms Tanya Clover, Ms Juliet Kelly, Professor Josephine Clayton, Associate Professor Colm Cunningham, in collaboration with **Palliative Care Australia** 



Site: Greenwich

**Duration: Nov 17 to Jun 18** 

**Project Partners: Nil** 



**Funding Source: Palliative Care** Australia

Working in collaboration with Palliative Care Australia, this project aims to develop a resource to support people living with dementia to participate in decision making about their

The project team will adapt the Aboriginal and Torres Strait Islander Discussion Starter, previously developed by Palliative Care Australia, to meet the specific needs of people with mild to moderate dementia. The draft resource will be amended to incorporate feedback from people living with dementia, obtained during individual consultations and focus groups. The resource will inform a wider body of work and study being conducted by Palliative Care Australia.

#### **Multi-Site Research Project**

#### National prevalence study of advance care planning documentation and self-reported uptake in Australia | New in 2017

**Study Status: In Progress** 

**Study Status: In Progress** 



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





Duration: Jan 17 to Jun 20



**Project Partners: Nil** 

**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. The results of this study will inform future steps towards improved ACP data collection methodology, ACP implementation strategies and evaluation processes.

#### **Multi-Site Research Project**

#### Advance care planning in incurable cancer patients with disease progression on first line chemotherapy



**Researchers: Professor Martin** Tattersall (Lead), University of Sydney, Professor Josephine Clayton (One of the Chief investigators), HammondCare

Site: Greenwich Hospital



Duration: Jul 13 to Jun 18



**Project Partners: Multiple including: Department of Cancer Medicine**; **USyd; Respecting Patient Choices** Program, Austin Hospital Victoria; CeMPED USyd



NHMRC administered by USyd

Funding Source: Funded by

**Multi-Site Randomised Clinical Trial** Study Status: In Progress

This multi-centre project will evaluate an advance care planning intervention for people with incurable cancer.

The intervention aims to help people with incurable cancer to be better prepared for their deaths, be able to participate in decisions about their care, enable their wishes for end of life care to be respected and reduce decision making burden for their loved ones.

Recruitment for this study was completed with 208 patient/family dyad participants. Data collection, including longitudinal follow up data for caregiver participants is complete. Analysis of data was completed in 2017. A manuscript, reporting on the study findings has been submitted for publication.

## **Advance Care Planning**

#### The Advance Project: initiating Palliative Care and Advance Care Planning: training and resources for General Practice Nurses



Researchers: Professor Josephine Clayton, Associate Professor Joel Rhee, Srivalli Nagarajan, Ms Jennifer Gavin & Ms Jolan Stokes, HammondCare



Site: National Project with base at **Greenwich Hospital** 



Duration: Feb 16 to Dec 17



**Project Partners: Caresearch** (Associate Professor Jennifer Tieman); **Austin Health Department of Advance** Care Planning (Dr Karen Detering); University of Queensland (Professor Geoffrey Mitchell); University of Technology Sydney (Professor Jane Phillips); University of Wollongong (Professor Elizabeth Halcomb); **University of Sydney (Associate Professor Rachael Morton and** Professor Timothy Shaw).



**Funding Source: Commonwealth** Department of Health, National **Palliative Care Project Grant** 

One of the biggest barriers to providing palliative care (PC) and implementing advance care planning (ACP) in primary care settings is general practitioners' time. We developed a toolkit and multi-component training resource to enable nurses working in general practice to: efficiently and sensitively promote awareness of ACP using screening; identify patients who may benefit from a palliative approach; assess symptoms; and help patients to identify their most important questions and concerns regarding ACP/PC. This will enable GPs to address these issues more efficiently. Further, the tools will help identify patients who might most benefit from referral to specialist PC services.

The toolkit was developed based on a literature review and input from our National and International advisory group. An online training resource is available from a project specific website www.caresearch. com.au/advance. In 2017 face-to-face training and individual telementoring was delivered nationally. Train-the-trainer materials have been developed and the program was evaluated, using a mixed methods approach, to inform ongoing implementation.

Feedback from general practice nurses about the acceptability. relevance and quality of the training was highly positive. A full and detailed evaluation report, including a health economic evaluation, was submitted to the Commonwealth Department of Health in January 2018. Manuscripts for submission to peer-reviewed journals are in preparation. Further funding has been received from the Commonwealth to continue providing training and support to general practice nurses, and to expand the project for other clinicians working in primary and chronic/complex care.

Study Status: Data collection, analysis and evaluation report complete, manuscripts in preparation.

#### **Multi-Site Research Project**

#### A toolkit to build the capacity of disability staff to assist adults with intellectual disability (ID) to understand and plan for their end of life



**Researchers: Professor Roger** Stancliffe, University of Technology Sydney; Dr Michele Wiese, University of Western Sydney; Professor Josephine Clayton, HammondCare; **Professor Sue Read & Ms Gail Jeltes** 



Site: Various sites



Duration: Oct 13 to Jun 18



**Project Partners: Department of** Disability and Community, Faculty of Health Sciences, University of Sydney; Sunshine; Keele University, UK



**Funding Source: Funded by Australian** Research Council administered by **University of Sydney** 

**Multi-Site Study** 

This project will inform better end of life care and education about dying for people with intellectual disability and their

It will strengthen ties with care providers in ID settings. This in turn will inform our palliative care services caring for people with ID. This project involves international collaborations with an expert in palliative care for people with ID from the UK.

A toolkit, including an award winning DVD partly filmed at Greenwich Hospital, and a training resource for face-to-face training of careworkers was developed. This training resource aims to enable care-workers to assist adults with intellectual disability to better understand dying and death. The face-to-face training was provided to care-workers, who then delivered the intervention to individual clients through discussion of end of life planning in everyday contexts. Data was collected using mixed methods to assess the impact of the training intervention on both staff and adults with intellectual disability. Feedback from both staff and clients has been very positive. The data from the formal evaluation was analysed in 2017.

#### **Translational Outcomes:**

Several manuscripts have been published reporting the findings. The manuscript reporting the final evaluation results is in preparation. Further funding was obtained, from the Commonwealth Department of Health, to develop an online version of the training resource to enable wider reach.

Study Status: Completed

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## **Spiritual Aspects of Care**

# Understanding spiritual encounters and requirements of patients living with serious illnesses | New in 2017



Researchers: Associate Professor Clare O'Callaghan, Associate Professor Natasha Michael, Dr Joanne Brooker & Dr Martina Weiz, Cabrini Health; Professor David Kissane, Monash University; Professor Josephine Clayton, Ms Bronwyn Raymond, Mr Steve Calder, Dr Fiona Stafford-Bell, Ms Julie Wilcock & Dr Sarah Thompson, HammondCare



Sites: Greenwich Hospital; Braeside Hospital; Neringah Hospital; Northern Beaches Palliative Clinic



**Duration: Aug 17 to Jun 18** 



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



Funding Source: Cabrini Health Foundation

**Multi-Site Research Project** 

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

Scant information on how Australian patients conceptualise spirituality and their requirements exists. 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: (a) examine quantitative associations between spiritual well-being, level of spirituality/religiosity, spiritual concerns and spiritual/religious support given; and (b) understand qualitatively how patient conceptualise their spirituality and religiosity; (c) explore qualitatively patients views about advancing spiritual care. The mixed methods design includes: semi-structured, anonymous surveys which will include a validated spiritual wellbeing 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: (a) provide insight into spiritual concerns amongst patients living with serious illnesses; and (b) 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.

**Study Status: In Progress** 

# Levels and associations of existential distress in people with persistent pain



Researchers: Professor Philip Siddall, Dr Mandy Corbett & Professor Melanie Lovell (Spiritual wellbeing in chronic and cancer pain), Ms Bronwyn Raymond, HammondCare; Ms Joan McClelland



Site: Greenwich Hospital



**Duration: May 13 to Jun 18** 



Project Partners: University of Sydney



Funding Source: Australian & NZ College of Anaesthetists

## This project is examining levels of spiritual wellbeing in people with chronic pain.

The aims of the project around issues of spirituality are in line with the HammondCare ethos, as an innovative approach to pain management. The different emphasis on spirituality that is emerging from this research has gained interest and positive support from pain consumer groups.

During 2016 the researchers examined the levels of existential wellbeing in people with spinal cord injury and pain. People with pain in addition to a spinal cord injury had the lowest levels of existential wellbeing. In addition, a strong sense of meaning and purpose was protective in coping with pain and a spinal cord injury. With one exception, none of the people who had a stong sense of meaning and purpose developed depression even if they had a spinal cord injury and severe chronic pain. We are now in the process of developing a program to assist people with pain and disability build resilience through stronger sense of identity and purpose.

Single-Site Research Project

Study Status: In Progress

## **Spiritual Aspects of Care**

Understanding spiritual encounters and requirements of caregivers of patients with an incurable, serious illness: Implications for service provision | New in 2017



Researchers: Clare O'Callaghan, Natasha Michael, Cabrini Health; Professor Josephine Clayton, Ms Bronwyn Raymond, Mr Steve Calder, Dr Fiona Stafford-Bell, Ms Julie Wilcock & Dr Sarah Thompson, HammondCare; Daviniah Seah, Frances Bellemore, Pennelope West, St Vincent's Hospital Sydney



Sites: Greenwich Hospital; Braeside Hospital; Neringah Hospital; Northern Beaches Palliative Clinic



Duration: Oct 17 to Jun 18



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



Funding Source: Cabrini Health

Multi-Site Research Project

Spirituality refers to how people experience meaning, purpose, and connectedness to that considered significant (possibly religion).

Scant information exists on how caregivers of people living with advanced illnesses conceptualise spirituality and their related requirements. Finding meaning and religiosity can support coping with adversity. This is a mixed methods study utilising a crosssectional survey to examine: (a) qualitatively how caregivers (informal) of patients with advance disease conceptualise their spirituality, religiosity, and spiritual requirements (concerns, needs) and whether they are being addressed; (b) differences in spiritual concerns and requirements across caregivers who align with different religious groups, including no religion (c) relationships between caregivers' spiritual wellbeing, levels of spirituality, spiritual concerns, and spiritual support received; and (d) caregivers' recommendations to health care providers for improving spiritual and religious support. The anonymous semi-structured survey includes: a validated spiritual wellbeing 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 open-ended questions. Australia's Palliative Care Strategy asserts that healthcare needs to address 'spiritual requirements' of those affected by serious illnesses. Findings are anticipated to: (a) provide insight into spiritual concerns amongst caregivers' of patients living with serious illnesses; and (b) inform evidencebased 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. This is a multisite study, also including Cabrini Health and St Vincent's Hospital Sydney. Forty participants will be recruited through HammondCare.

**Study Status: In Progress** 

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# **Teaching+professional activities**

## Professor Philip Siddall

Director of the Pain Management Service + Director of Medical Services As well as his roles as Director of the Pain Management Service and Director of Medical Services at Greenwich and Neringah Hospitals, Phil is Conjoint Professor in Pain Medicine at the University of Sydney. He teaches in the University of Sydney Graduate Medical Program and Postgraduate Program in Pain Management as well as teaching trainees in anaesthesia, pain medicine and rehabilitation. During 2017, he presented lectures to doctors, nurse and allied health practitioners in general practice, anaesthesia, pain medicine and aged care.

In 2017, Phil also served as a member of a number of local, national and international committees including co-chair of the NSW Agency for Clinical Innovation Pain Management Network, the nomination committee of the International Association for the Study of Pain and the Court of Examiners for the Faculty of Pain Medicine of the Australian & New Zealand College of Anaesthetists.

Director of Centre for Learning & Research in Palliative Care

## **Professor Josephine Clayton**

Josephine is Senior Staff Specialist Physician in Palliative Medicine at HammondCare's Greenwich Hospital and Professor of Palliative Care at the University of Sydney. In 2017 Josephine was appointed as Director of HammondCare's Centre for Learning & Research in Palliative Care. In this role, she has responsibility for development of research and educational activities across HammondCare's palliative care sites. She is also Chair of the National and International Advisory Group and Director for HammondCare's Advance Project for initiating palliative care and advance care planning (ACP) in primary care settings www.caresearch.com.au/advance. This project is funded by the Australian Government in a National Palliative Care Project and is being led by HammondCare in collaboration with various health organisations and universities across Australia.

In 2017, Josephine served on a number of International, National, State and local committees in the field of palliative care and advance care planning including the Scientific Committee for the International Society of Advance Care Planning and End-of-life Care Conference, held in Banff, Canada in September 2017 and a consensus panel for development of American Society of Clinical Oncology Patient-Physician Communication Guidelines. She was an invited participant in an Australian Government think tank to find innovative ways to improve palliative care in aged care.

Josephine contributes to teaching various health professionals about palliative care and advance care planning locally, nationally and internationally and has a strong interest in teaching end-of-life communication skills. She is also contributing to a revision of palliative care teaching for medical students across the University for Sydney for the new Medical Curriculum from 2020.

Head of Research and Aged Care Clinical Services for HammondCare

## **Professor Christopher Poulos**

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, UNSW; 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 UNSW postgraduate and undergraduate teaching programs and has presented widely at national and international conferences. He is the co-convenor for a new post-graduate course, Contemporary Issues in Ageing, within the Master of Public Health degree. He also consults to government on aspects of aged care and to the private health insurance sector on contemporary rehabilitation models.

# **Teaching+professional activities**

Teacher + Lecturer

## Professor Janine Stevenson

Professor Stevenson teaches, lectures and conducts tutorials for undergraduates at Sydney University as well as participating as lecturer and supervisor on the faculty of the Master of Medicine in Psychotherapy Program also at Sydney University. She also conducts workshops for trainees for the College of Psychiatry and supervises registrars. She lectures for the Brain and Mind Institute and conducts interviews of foreign trained doctors for the college of psychiatry. She both writes, prepares and marks college and university exams as well as conducting oral examinations of medical students and psychiatry trainees.

Medical
Director of the
Greenwich
Palliative Care
Services

#### Professor Melanie Lovell

In 2017, Melanie was Medical Director of the Greenwich Palliative Care Services; Senior Staff Specialist in Palliative Medicine; Clinical Associate Professor, University of Sydney; and Adjunct Professor in the Faculty of Health, University of Technology, Sydney. She is Lead Investigator in a National Breast Cancer Foundation study to implement the National Cancer Pain Management Guideline in cancer centres around the country. Melanie is the Director of the Greenwich Clinical Trials Unit and in this role is Principal Investigator for a number of clinical trials.

She is actively involved in research organisations including the Trials Management Committee and Publications committee of the national Palliative Care Clinical Studies Collaborative. She is on the Management Committee of Sydney Vital, the Northern Sydney translational cancer research centre. Melanie continues to chair the Working Party for the Australian Cancer Pain Guideline.

She was a member of the Royal Australasian College of Physicians Spirituality Curriculum Working Party and the New South Wales Health Scope of Practice Committee for Palliative Medicine.

#### Professor Roderick MacLeod

Consultant in Palliative Care

Rod MacLeod is a consultant in palliative care for HammondCare and Honorary Professor in the Sydney Medical School. He spends part of the year in New Zealand where he is a specialist in palliative medicine at Hibiscus Hospice, Auckland and Honorary Professor in the University of Auckland's Department of General Practice and Primary Health Care. He has given talks to the public and professionals on a number of aspects of end of life care in both Australia and New Zealand. He is a reviewer for a number of international journals and grant giving bodies. Three of his PhD students have successfully completed their studies this year. Rod has also been involved in a number of research projects in aspects of palliative and end of life care.

Senior Staff Specialist -Rehabilitation + Chief Medical Officer

#### Associate Professor Andrew Cole

Andrew continues in his substantive roles with HammondCare as Senior Staff Specialist (Rehabilitation) and Chief Medical Officer, and is a Conjoint Associate Professor at the University of New South Wales in the School of Public Health & Community Medicine. Until March 2017, he convened the Aged Care & Rehabilitation teaching block in Phase 2 of the UNSW MD program, and continues with regular teaching of medical students in Med 4 at Kensington, Hammondville and St George campuses. During 2017, he also presented lectures 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 and Thailand.

Andrew continued to serve as a member of several national and international Rehabilitation Medicine peak bodies throughout 2017. He is currently President and Chair of Council of the Australasian Faculty of Rehabilitation Medicine (AFRM) of the Royal Australasian College of Physicians. He continues as a member of the Education Committee of ISPRM.

62 Teaching+Professional Activities

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# **Teaching+professional activities**

## Associate Professor Freidbert Kohler

President of the International Society for Prosthetics and Orthotics

Associate Professor Kohler's professional activities included taking over the Presidency of the International Society for Prosthetics and Orthotics in May. The society has a vision of a world where all people have equal opportunity for full participation in society.

Leading the establishment and further development of the Age and Ageing clinical academic group within the Sydney Partnership for Health, Education, Research and Enterprise has required a significant investment of time and effort but will facilitate research and translation of research into practice for the benefit of aged care and rehabilitation patients.

Continued engagement with NSW Health in Activity Based Funding generally and the Leading Better Value Care initiative specifically, from the perspective of clinicians and encouraging broader clinician input into this has been broadly appreciated.

Increasing clinician engagement in clinical governance across HammondCare Health and Hospitals has resulted in further improvement quality, safety and risk profiles within the Hospitals sector.

Head of Dementia Centre

## Associate Professor Colm Cunningham

Colm 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 a Conjoint Associate Professor at the University of NSW in the School of Public Health and Community Medicine. As part of his role at UNSW, Colm delivered a lecture to Masters of Public Health Students in the "PHCM9617 Contemporary Issues in Ageing" course. The focus of this presentation was on recent innovations in long-term care around dementia care.

Co-convenor of the Advanced Training Programme in Aged Psychiatry

#### Associate Professor Steven Macfarlane

Associate Professor Macfarlane is active in medical student teaching at Monash University and is co-convenor of the Advanced Training Programme in Aged Psychiatry for Victoria. He sits on a number of committees for the Royal Australian and New Zealand College of Psychiatrists (RANZCP), including the Committee for Research, the Members' Advisory Council, and the Supported Decision-Making subcommittee. He is Chair of the Faculty of Old Age Psychiatry (FPOA) within the RANZCP. He remains actively involved in Alzheimer's Disease clinical trials as a site Principal Investigator.

Music Engagement + Positive Ageing

### Dr Kirsty Beilharz

Kirsty has prepared two chapters for the forthcoming Palliative Care Textbook (Springer). Her book, Music Remembers Me: Connection and Wellbeing in Dementia presents both didactic and practical approaches to music in dementia care. She is also involved with the new Masters Degree in Positive Ageing at the Faculty of Medicine, UNSW with Professors Chris and Ros Poulos; holds a conjoint appointment at the UNSW; and sits on the Research Committee of the Sydney College of Divinity; and the Federal Government Australian Research Council.

# **Teaching+professional activities**

Co-founder of the Dementia PhD forum

#### Dr Julie Christie

Julie is a Visiting Research Fellow at the University of Edinburgh and an Adjunct Lecturer at the University of New South Wales. She also delivers guest lectures at universities in Scotland and was delighted to meet social work students at Dundee University for the first time in 2017. Julie's teaching contributions this year have focused on social work research, practice and theory, adult support and protection, citizenship and digital citizenship, co-production and resilience in the context of dementia. She is the co-founder of the dementia PhD forum on twitter #demphd. This forum, the first of its kind in the dementia field, brings together researchers, academics, people living with dementia and people interested in dementia.



# **Education, publications+presentations**

## Education

Higher Research Degrees

Awards+Best Poster Presentation

Academic Degree Supervision

## **Publications**

Books+Chapters

Journal Articles

Industry+Magazine Articles

Technical+Other Reports

## **Presentations**

Academic Conference+Industry Seminars



## **Education**

## Higher Research Degrees



Student Name: Dr Kirsty Beilharz

Degree: PhD candidate

University: Sydney College of Divinity

Thesis Title: Trinity & Metaphysics: Mystery, Given-ness and Mimesis – Interdisciplinary Analogy in

Reasoning a Contemporary Epistemology.

Supervisors: Rev. Dr. David Höhne and Professor Dr. Philip Kariatlis

Student Name: Ms Meredith Gresham

Degree: PhD candidate

University: The University of Sydney

Thesis Title: An investigation of the clinical utility of the electronic bidet for Australian nursing home

residents and staff.

Supervisors: Professor Lindy Clemson and Associate Professor Lee-Fay Low.

Student Name: Dr Martin Kennedy

Degree: PhD candidate

University: University of Lancaster, UK

Supervisor: Dr Sarah Brearley and Dr Catherine Walshe

Thesis Title: Junior hospital medical officers' experience of making clinical decisions regarding

patients with advanced, irreversible, progressive and life limiting medical conditions.

### Academic Degree Supervision



Clayton J; Student Name: Marcus Sellars, PhD Thesis: *Delivering patient-centred advance care planning in chronic kidney disease (CKD): the perspectives of patients, caregivers and healthcare providers*; University of Sydney, Sydney, commenced part-time candidature in July 2014. Awarded University of Sydney Postgraduate Award Scholarship in 2016.

Clayton J, co-supervisor with Trevena L, Student Name: Emily Deck, General Practitioner Academic Post: Starting the conversation: assisting general practice registrars with initiating advance care planning. University of Sydney, Sydney. Awarded an Australian Government Department of Health, scholarship for 2017.

Dickson HG, Kohler F, Jim Xu, PhD, Development of an ICF Core Set for individuals following an amputation, UNSW, Sydney, 7th year.

Kohler F, Thoms J, Naylor J, Carol Connolly, PhD, Hospital Inpatient versus home based rehabilitation following total hip replacement, UNSW, Sydney, 1st year.

Kohler F, Dickson HG, Seema Radhakrishnan, PhD, Development of an International Classification of Function, Disability and Health based mobility assessment tool, UNSW, Sydney, 6th year.

Supervision team Philips J, Luckett T, Wang A and Lovell M. PhD Xiangfeng Xu (Renee) University of Technology, Sydney. Developing a cultural specific education program for Chinese background cancer patients on pain management: a mixed methods study.

Supervision team Agar M, Phillips J and Lovell M. PhD: Jessica Lee University of Technology Sydney, *Improving outcomes for people living with neuropathic cancer pain: a mixed methods doctoral research project.* 

Supervision team MacLeod R, Glasgow N, Phillips C, Wiles R; Student Name: Dr Suzanne Rainsford, PhD Thesis: A rural perspective on quality end of life care. Australian National University, Canberra. Commenced 2015. Awarded 2018.

Supervision team **MacLeod R**, Arroll B and others; Student Name: Ms Elaine Rogers, PhD Thesis: Does a multi-targeted approach of supportive care improve the cancer cachexia status in lung cancer patients? University of Auckland. Awarded 2018.

Supervision team Goodyear-Smith F, **MacLeod R** and others; Student Name: Ms Yvonne Bray, PhD thesis: Transnationals' experience of end of life care in New Zealand. University of Auckland. Awarded 2018.

## **Education**

#### **Academic Degree Supervision**



**Poulos C,** Faux SG and Harris I (Supervisors). Student Name: Dr Jane Wu, PhD Thesis: *Early Rehabilitation in Trauma and Critical Illness*. Faculty of Medicine, The University of New South Wales. 2013-2019.

**Siddall P,** co-supervisors Wrigley P, Kellow J, Hush J; Student Name: Clint Marlborough, PhD: Musicality in Psychotherapy, University of Sydney, Sydney, 2013-2017.

**Stevenson J,** Student Name: Melissa Hulme, Master Science: *Childhood trauma, social support, personality disorders and outcome across three psychiatric wards,* Macquarie University, Sydney, 2017-2020.

**Stevenson J,** co-supervisors McClean L, Student Name: Clint Marlborough, Doctoral Thesis: *Musicality in Psychotherapy*, University of Sydney, Sydney, 2017-2020.

#### **Awards**



**Cole A,** The Haim Ring Memorial Award – Individual. Awarded by the International Society of Physical and Rehabilitation Medicine (ISPRM) 'for strong engagement in hosting international visitors and exchanges'. Awarded at the Buenos Aires ISPRM Annual Scientific Meeting, May 2017.

Clayton J, Multicultural Health Communication Service (MHCS) Award, NSW Government, awarded to the Clinical Excellence Commission (NSW) in September 2017 for communication tools for terminally ill patients and their families entitled "Asking questions can help: an aid for people approaching the last days of life" and "Asking questions can help: an aid for friends or carers of people approaching the last days of life". Professor Josephine Clayton led the development of these communication tools on behalf of the Clinical Excellence Commission. The tools were translated into Arabic, Chinese Simplified, Chinese Traditional, Greek, Hindi, Italian, Korean, and Vietnamese; and are freely available online http://www.cec.health.nsw.gov.au/quality-improvement/people-and-culture/last-days-of-life/information-for-patients.

**Gresham M,** Winner - Three Minute Thesis Competition, University of Sydney, Faculty of Health Sciences.

## **Publications**

### **Books+Chapters**



Beilharz K. Music Remembers Me: Connection and Wellbeing in Dementia, Sydney Australia, HammondCare Media, May 2017, ISBN: ISBN 978-0-9945461-1-1.

**Beilharz K.** (2017) 'Grace and Nurture: Connecting and Engaging Through Music in Dementia Care' in Doru Costache, Darren Cronshaw, James R. Harrison (Ed.s) Well-being, Personal Wholeness and the Social Fabric, Cambridge: Cambridge Scholars Press, 2017) ISBN-13: 978-1-4438-9858-4) pp. 184-208.

Christie J. Social Work with Older People in Cree, V and Smith M. (eds) Social Work in a Changing Scotland. First Edition. Oxford, England. Routledge. February 2018. ISBN 9781315100821.

Cole A. (2017) 'Degenerative Movement Disorders of the Central Nervous System' Ch. 45 in 'Braddom's Rehabilitation Care: A Clinical Handbook' 1st Edition; Cifu DX, Lew HL (eds), Elsevier, Atlanta ISBN: 9780323479042.

Detering K, Clayton J. Advance Care Planning in Australia. In Thomas K, Lobo B, Detering K(eds) Advance Care Planning in End of Life Care, 2nd Edition, IN PRESS Oxford University Press, Oxford, UK, accepted March 2017.

## **Publications**

#### **Books+Chapters**



Kerr D & Cunningham C, Night-time care: A practice guide, Sydney Australia, HammondCare Media, 2017, ISBN 9780987189219.

Macfarlane S, Sutherland A, *Sleep in the Institutional Facility*, Mansfield DR (ed.), 1st edition, Sleep Medicine. IP Communications, Victoria, P 438-442.

MacLeod R, Foreword in Ashfield J 2017 Dictionary of End of Life Care. You Can Help Publishing ISBN 978-0-9944664-9-S.

McNair D, Pollock R & Cunningham C, Enlighten: lighting for older people and people with dementia, Sydney Australia, HammondCare Media, 2017, ISBN 9780994546173.

Urban K, Clayton J, Kissane D. "Communication about transitioning patients to palliative care". In Kissane D, Bultz B, Butow P, Finlay I (eds) Handbook of Communication in Oncology and Palliative Care, Oxford, 2nd edition Oxford University Press, February 2017, page numbers 131-138.

Walczak A, Butow B, Clayton J. Communication at the end-of-life. In Cooper N, Frain J (eds) ABC of Clinical Communication. 2017, Wiley Publishing, Chichester, UK, page numbers: 55-60.

#### Journal Articles



Austin P, Macleod R, **Siddall P,** McSherry W, Egan R. *Spiritual care training is needed for clinical and non-clinical staff to manage patients' spiritual needs*. Journal for the Study of Spirituality. 2017;7:50-63. doi.org/10.1080/20440243.2017.1290031.

Beilharz K, Trinitarian Iconography in Messiaen's Music and Applications of Trinitarian Imagery in Contemporary Thought, Phrenoma Journal of St. Andrew's Greek Orthodox Theological College, 2018 (in press).

Buhagiar M, Naylor J, Harris I, Xuan W, **Kohler F,** Wright R, Fortunato R. *Effect of Inpatient Rehabilitation vs a Monitored Home-Based Program on Mobility in Patients With Total Knee Arthroplasty.* The HIHO Randomized Clinical Trial. JAMA 2017; 317(10):1037-1046. https://doi:10.1001/jama.2017.1224. IF 37.6840; Citations 7.

Buhagiar M, Naylor J, Simpson G, Harris I, **Kohler F.** *Understanding consumer and clinician preferences and decision making for rehabilitation following arthroplasty in the private sector.* Jun 2017 BMC Health Services Research 2017; 17:415; DOI 10.1186/s12913-2379-9. IF 1.827; Citations 0.

Corbett M, Lovell M, Siddall P. The role of spiritual factors in people living with chronic pain: A qualitative investigation, Journal for the Study of Spirituality. 2017; 7:142-153. doi.org/10.1080/20 440243.2017.1370908.

Dillon M, Fortington L, Akram M, Erbas B, **Kohler F.** *Geographic Variation of the Incidence Rate of Lower Limb Amputation in Australia from 2007-12.* PloS One 12 (1) 01 Jan 2017. https://doi.org/10.1371/journal.pone.0170705. IF 3.0570; Citations 0.

Estacio C, Butow P, Lovell M, Dong S, Clayton J. What is symptom meaning? A framework analysis of communication in palliative care consultations. Patient Education and Counseling 2017, 100 (11): 2088-2094 doi: 10.1016/j.pec.2017.05.006. Epub 2017 May 5. PMID 28619270.

Forster B, Proskurin H, Kelly B, Lovell M, Ilchef R, Clayton J. Psychiatry trainees' views and educational needs regarding the care of patients with life limiting illnesses. Palliative and Supportive Care 2017 Apr;15(2):231-241. doi: 10.1017/S1478951516000365. Epub 2016 Jun 20. PMID: 27320847.

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Haliburn J, **Stevenson J,** Halovic S. *Integration in the Psychodynamic Psychotherapy of Severe Personality disorders:the Conversational Model. J of Personality Disorders* 2017 (doi:10.1521/pedi\_2017\_31\_290).

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Kohler F, Knight A, Gonzalez-Arce V, Chow J. *Retrospective Analysis of Telemonitoring (RATE)*. International Journal of Integrated Care. 2017;17(3):A13. DOI: http://doi.org/10.5334/ijic.3125.

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#### Journal Articles



Luckett T, Spencer L, Morton R, Pollock C, Lam L, Silvester W, Sellars M, Detering K, Butow P, Tong A, Clayton J. Advance care planning in chronic kidney disease: a survey of current practice in Australia. Nephrology (Impact Factor 1.796), 2017 Feb; 22(2):139-149. doi: 10.1111/nep.12743. PMID: 26860214.

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Mitchell G, Senior H, Rhee J, Young S, Teo PCK, Murray S, Boy K, **Clayton J.** *Using intuition or a formal palliative care needs assessment screening pathway in general practice to predict death within twelve months: a randomised controlled trial.* Palliative Medicine 2017 Mar 1:269216317698621. [Epub ahead of print] PMID: 28452570.

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Wilson D.M, Cohen J, MacLeod R. & Houttekier D. 2017 Bereavement Grief - A Population-based Foundational Evidence Study. Death Studies DOI:10.1080/07481187.2017.1382609.

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Watanabe K, Hemmi A, Tajitsu T, Narita J, **MacLeod R.** 2017 *Prospective neurological analyses of 287 patients with advanced cancer in home care*. Hospice and Home Care 25(1) 49-54.

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Clayton J, Media Interview: "Support for organisations to make planning ahead routine in community care", article in Community Care Review, Australian Ageing Agenda 6/4/17, http://www.australianageingagenda.com.au/2017/04/06/support-organisations-make-planning-ahead-routine-community-care/.

## **Presentations**

#### Industry+Magazine Articles



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## Academic Conference+Industry Seminars



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### Academic Conference+Industry Seminars



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### Academic Conference+Industry Seminars



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## **Presentations**

## Academic Conference+Industry Seminars



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## Academic Conference+Industry Seminars



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## **Service locations**

#### Residential Care

Frina NSW Scone NSW Horsley NSW Wahroonga NSW Hammondville NSW Woy Woy NSW Caulfield **vic** Miranda **NSW** North Turramurra NSW

Health+Hospitals

Braeside **NSW** Mona Vale NSW Greenwich **NSW** Wahroonga NSW

#### HammondCare At Home

Batemans Bay NSW Merimbula **NSW** Bathurst **NSW** Narara **NSW** Baulkham Hills NSW North Gosford NSW North Turramurra NSW Broken Hill NSW Cardiff **NSW** Nowra **NSW** Coffs Harbour NSW Scone NSW Hammondville **NSW** St Marys **NSW** Horsley NSW Wahroonga **NSW** Lindfield NSW North Melbourne VIC Manly **NSW** Brisbane QLD Mudgee **NSW** Canberra ACT Miranda **NSW** 

#### Research+Education

Braeside **NSW** Hammondville **NSW** Greenwich **NSW** Malvern vic

#### Dementia Support Australia (DSA)

Gold Coast QLD Greenwich **NSW** Hammondville NSW Cairns (ARRCS) QLD Sunshine Coast QLD Horsley NSW Newcastle **NSW** Malvern **vic** Drouin VIC St Marys **NSW** Ballarat vic Howlong NSW Dubbo **NSW** Shepparton vic Coffs Harbour NSW Canberra ACT Gosford NSW Hobart TAS Broken Hill NSW Launceston TAS Tamworth **NSW** Adelaide SA Brisbane QLD Perth WA Townsville (ARRCS) QLD Darwin (ARRCS) NT

#### **Palliative Care Home Support Packages**

311 rural and remote towns within NSW

#### Sites in planning

Western Melbourne VIC Bega **NSW** Darlinghurst NSW

Caulfield (Dementia Specific Residential) VIC

Perth

Cardiff **NSW** Canberra CBD ACT **Darwin** 

17,251

people cared for across Australia, through our nationwide operations



Gold Coast



Cairns |

Townsville •



80 Service locations

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