Once again, 2018 has been a busy and fruitful year for HammondCare’s researchers, and for their collaborating partners. The 2018 Report includes 69 projects, of which 22 were new. Dissemination of research findings through academic publications and conference presentations has remained important throughout 2018, as has teaching and higher degree student supervision.

During 2018, HammondCare’s lead researchers, clinicians and managers gathered together for another biennial research colloquium, where priorities for new and meaningful areas of research were discussed and agreed to. This was an excellent event and one that augers well for the future.

2018 saw further streamlining of our research governance processes while ensuring that governance remains robust, and that research does not overly burden the people we serve or our staff.

Finally, I would like to thank everyone who was involved in the research effort during 2018, and particularly the people who generously participated in research projects. Without you, research is not possible.

Dr Annette Britton
Chair, HammondCare Research Committee
Collaboration is key

Good research and collaboration go hand-in-hand. In fact, collaboration is the driving force behind the 2018 HammondCare annual Research Report. Why? Because it allows for multiple perspectives and ways of thinking. It establishes innovative alliances between academics, service providers, consumers and policy makers. What’s more, it helps research to be relevant.

An academic perspective brings rigour to the process of research, ensuring that the design, methods, and analysis are scientifically sound, and the conclusions drawn are appropriate. Having academics on the team will positively contribute to the dissemination of the research findings through academic journal publication and conference presentation.

Service providers bring an element of realism to research projects. Their role is twofold. Firstly, to assist in the recruitment of participants, which allows the research to proceed. But even more importantly, they also have a role in ensuring that the research could, if the outcomes are worthwhile, be applied in the ‘real world’ setting. Service providers are also important in the dissemination of research findings to industry, complementing the dissemination strategies employed by academics.

Consumers play an invaluable role in the conduct of research. They help ensure that the research is meaningful to the people who might benefit, by assisting the research team to ask the right questions, and select and measure outcomes that are important. Consumers also help ensure that the language used in research projects is appropriate, accessible and relatable.

The perspective of policy makers is also key. They can ensure the questions being asked are ‘policy relevant’ – that is, that the findings will be of practical and valuable use to government or other funders. This is important, given the large number of competing priorities for the tax dollar.

By way of example, the reablement guidelines to support function for people living with dementia (presented on pages 8 and 9 of the 2018 annual Research Report) was successfully developed through a highly collaborative approach.

This project involved academics from the University of New South Wales and University of Sydney and three service providers including HammondCare, who led the project, along with Helping Hand and the Brightwater Care Group. Consumers, including people living with dementia and carers, past and present, were also involved. Furthermore input was sought from government policy makers. In summary, a truly 360° approach to collaboration.

I hope that you enjoy reading the 2018 HammondCare annual Research Report.
2018 RESEARCH UPDATE

TRANSLATING RESEARCH INTO BETTER CARE.

Supporting reablement for people living with dementia
Reablement through the eyes of a person living with dementia

Promoting mental wellbeing and positive ageing through the arts
The art of happiness

Working in collaboration
Talking End of Life... with people with intellectual disability (TEL)
The prevention of delirium in palliative care

The impact of a Dementia Assistance Dog Program
Webb’s story

Rebuilding hope for people living with pain
The power and pain of acceptance
Dementia is the greatest cause of disability in older Australians. Despite this, most research on reablement interventions excludes 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.

Supporting reablement for people living with dementia

The opportunity
Dementia is the greatest cause of disability in older Australians. Despite this, most research on reablement interventions excludes 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 Principals 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, have developed a practice handbook of reablement interventions based on the Guidelines. During the development phase, the Clinical Practice Guidelines were searched to extract studies associated with relevant recommendations on maintaining or improving function. We reviewed studies demonstrating positive intervention outcomes. Studies were then organised according to methodological quality, with the strongest studies collated to form the reablement programs in the Handbook.

In addition, a series of interviews were conducted with the aged care sector to explore current understanding and practice of reablement for people living with dementia. A 2-day collaborative workshop involving consumers, aged care representatives, allied health professionals, policy makers and academics, was also held.

This process finalised the eight reablement programs included in the Handbook, and outlined key information that would ensure applicability to ‘real-world’ intervention practices.

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

A Consumer Information Booklet was also developed to help people living with dementia, as well as their family and support people, better understand the role of reablement, and guide them in selecting the right services.

The outcome
The first edition of the Handbook, along with the Technical Guide and Consumer Information Booklet, was launched at the HammondCare International Dementia Conference in June 2018, and is now available online. The team is currently undertaking a review of the three resources with the project’s consumer advisory team, with updated versions to be released in May 2019.

The intended outcome of this project is that the Handbook will be used as an evidence-informed resource to help improve quality of life for people living with dementia. Prompting health professionals to offer research-supported reablement programs will help reduce funds being wasted on ineffective services. It will also provide an opportunity for people living with dementia to maintain their independence for longer, and to experience improved quality of life.

Case Study: Reablement through the eyes of a person living with dementia

Theresa Flavin is a Lived Experience Associate Consultant for HammondCare Dementia Centre. She is a woman with an innate passion for giving people living with dementia a voice, which stems from her own diagnosis of dementia at just 46 years of age.

Determined to empower other people with early dementia to manage independently, Theresa was a representative on the Reablement in Dementia project and involved in the development and revision of the resources in the Reablement Handbook.

“It was so reassuring to see that the common sense concepts of staying busy, connected and engaged as a way to maintain cognitive function was backed up by solid scientific research,” expresses Theresa.

Theresa also authored the foreword in the Consumer Information Booklet to help highlight the importance of reablement from the perspective of a person living with dementia.

“I hope that by having people living with dementia in a position of influence when developing the project’s resources has helped improved the clarity and accessibility of the material.

The booklet has hopefully made it more meaningful to the people living and working at the coalface of life with dementia and dementia care,” explains Theresa.

“It is my desire that the reablement resources will help inspire people living with dementia, their carers and service providers to implement practical strategies to maintain or even improve their quality of life, and their ability to be independent for as long as possible.”

Pictured: Theresa Flavin, Consultant for HammondCare Dementia Centre.
Promoting mental wellbeing and positive ageing through the arts

The opportunity
Arts on Prescription is a fun, engaging and practical program which aims to promote healthy and active ageing for older people in the Australian community who are experiencing certain health challenges. To determine the program’s effectiveness, a project evaluation was undertaken at HammondCare Wahroonga.

The research
HammondCare, in partnership with the University of New South Wales, successfully trialled and evaluated an Arts on Prescription program for older people with a diverse range of health and wellness needs between 2016 and 2018. The formal evaluation was published in the international journal, Health and Social Care in the Community, in late 2018.

The evaluation found that Arts on Prescription had a positive impact on mental wellbeing for participants. This was due to the program’s ability to foster wellbeing through activities that challenge and enhance creative ability and offer a sense of achievement in a social environment that promotes meaningful relationships with others.

The positive evaluation findings have encouraged the Arts on Prescription team to explore ways that the program can be sustainably delivered, and leverage new avenues to help people realise the value of participatory art.

The outcome
As a result of the positive evaluation findings, further opportunities to deploy the Arts on Prescription model have been pursued. One such opportunity has been at HammondCare Wahroonga, where residents living with dementia were invited to participate in an on-site Arts on Prescription program.

Two 8-week group visual arts programs, one 8-week creative movement program, along with a number of 6-week private sessions, were delivered by professional artists.

Residents who participated in the programs engaged in various art forms such as drawing, painting, printmaking, model-making, music and dance. In keeping with previous programs, participants developed a series of work that was displayed at an end of program exhibition, attended by family and friends.

Case Study: The art of happiness
Marion is an experienced artist who, due to living with dementia, has been unable to engage with her love of art for the last few years until moving into residential care.

In October 2018, Marion attended an Arts on Prescription group program run by artist Annette Innis, as well as a 6-week private program, with one-on-one visual art sessions with Annette.

Marion enjoys the sessions tremendously and finds peace through her engagement with art.

“I feel very relaxed and happy when I paint, and I want to encourage others to paint because it’s a great hobby,” says Marion.

Marion enjoys painting Australian landscapes as they remind her of a happy time in her life when she lived on a farm.

“When Marion is painting a landscape, it’s like she transports herself there again – to a place where she feels at peace,” Annette explains.

Each session with Marion enables Annette to see first-hand, Marion’s journey through dementia and some of the hurdles Marion experiences along the way. It is through this shared experience that Annette is able to offer Marion the practical support that allows her to do what she loves most.

“Dementia can act as a barrier in the way people traditionally communicate,” says Annette.

“Art opens up another avenue for communication, allowing the opportunity for self-expression and giving each participant a voice, a platform to be themselves, in a supportive, non-judgemental environment.”
Working in collaboration

Health and medical research is widely acknowledged and recognised for the invaluable benefits it brings to Australia and countries around the world. One of the key drivers in facilitating ground-breaking health and medical research is collaboration.

The alliance between organisations, institutions and individual professionals not only integrates new perspectives, skills and strengths, it aids innovation, communication and research engagement in order to achieve a successful outcome.

These stories demonstrate HammondCare’s commitment to conducting collaborative research with external researchers, institutions and organisations.

Talking End of Life
...with people with intellectual disability (TEL)

The opportunity
In 2013-2016 HammondCare collaborated with the University of Sydney and Unisson Disability (formerly Sunshine) on the Australian Research Council Linkage Project, Dying to Talk. The project evaluated the outcomes of training disability support professionals to encourage people with intellectual disability to learn about the end of life. However, the Dying to Talk training toolkit had limited reach and sustainability as it was designed only for face-to-face delivery.

Working in collaboration

The aim of Talking End of Life ...with people with intellectual disability (TEL) was to scale up the availability of the Dying to Talk toolkit by adapting it for online delivery.

The project team, led by Professors Roger Stancliffe from The University of Sydney, Josephine Clayton from HammondCare, Dr Michele Wiese from Western Sydney University, Ms Gail Jeltes from Unisson Disability and Professor Jennifer Tieman from Flinders University and CareSearch, were supported by funding from the Australian Government Department of Health under the Public Health and Chronic Disease Grant Program.

This collaborative partnership resulted in a successful knowledge translation project.

TEL comprises 12 modules on 3 topics including:

- How do I do this?
- Teaching how to understand end of life
- Teaching the planning options

Some of the module examples include cultural beliefs, loss, grief and mourning, and funeral wishes. Each module comprises problem solving tasks, case studies and short videos to illustrate key points.

One of TEL’s strengths is authenticity. Each case study is based on real experiences, and all videos feature people with intellectual disability and caregivers.

TEL is designed to enable individuals to complete any module, in any order, in their own time. If a group format is preferred, each module also has its own facilitator guide.

Throughout the development phase, HammondCare’s Professor Josephine Clayton offered invaluable advice about avenues for funding the project, linking with CareSearch (which hosts TEL on its website) and building the site content.

The outcome
TEL is a world-first, free, online resource with international reach and flexible delivery. Since its launch in May 2018, there has been widespread interest and uptake nationwide and across the world.

In January 2019, the project team conducted a webinar featuring TEL, hosted by the prestigious American Association on Intellectual and Developmental Disabilities (AAIDD). Throughout the remainder of 2019 a series of TEL workshops will be conducted in North America, the United Kingdom and Australia.

TEL’s international success is founded in the effective and ongoing collaboration between HammondCare, the various universities and the disability sector. A number of the videos featured in TEL were filmed on the site of Greenwich Hospital.
The prevention of delirium in palliative care

The opportunity
Delirium is a common and distressing syndrome affecting people experiencing advanced illness. People living with delirium can experience disturbances of attention and cognition, and have an increased risk of falling and death. If left untreated, delirium can result in high levels of distress for both the person living with delirium and for their family members and carers. The best treatment for delirium is prevention.

Working in collaboration
Researchers from the University of Technology Sydney, led by Dr Annmarie Hosie, collaborated with local HammondCare investigators Professor Melanie Lovell, Dr Cynthia Parr and Janelle Sanderson to pilot test non-pharmacological measures to prevent the onset of delirium in palliative care inpatients in the PRESERVE (Prevention of Serious Adverse Events) study. Greenwich Hospital was randomised to be the intervention site for the pilot study. The intervention focused on reducing the risk of delirium by ensuring patients who required glasses at Greenwich Hospital were wearing them, all hearing aids were in place, and that patients were well hydrated, moving regularly and frequently oriented.

To ensure the intervention was tailored to meet the needs and wishes of each individual patient, the entire interdisciplinary team was involved in the development and delivery of the intervention. The team comprised pastoral care, volunteers and family members.

The outcome
The intervention was found to be feasible, and has paved the way for a randomised controlled trial. The process has increased the knowledge of the entire ward team about screening for and preventing delirium. As this is such a distressing and serious condition, this has improved the quality of care that HammondCare provides and enabled each team member, including volunteers and pastoral carers, to participate.
The impact of a Dementia Assistance Dog Program

The opportunity
People living with dementia and their carers need access to a range of practical support to manage activities of daily living. Feeling disconnected from communities is also common. The role of dogs in assisting people with a range of disabilities is well established, however in relation to dementia it remains a relatively new option with little evidence currently available of its potential impact.

The research
HammondCare are at the forefront of innovations in dementia support. That’s why we delivered the Dogs 4 Dementia program in Australia after seeing the pioneering Dementia Dog Project in Scotland. Dementia Dog is a charitable collaboration between Alzheimer Scotland and Dogs for Good. The project aims to explore and measure ways in which trained dogs can help improve quality of life for people living with dementia. This three year program is currently in its second phase, having been relaunched in Scotland in August 2016 with funding from the Life Changes Trust.

The Dementia Centre, HammondCare, were ideally placed to evaluate this program given our experience in this field. Our unique insights have enabled a comparison of dog program evaluations across Scotland and Australia. Findings across four outcome areas are considered: Carer support and carer burden, safety, socialising and maintained benefits. In the relaunched Dementia Assistance Dog project, eight fully trained assistance dogs will be placed with eight participating couples. The aim of the evaluation is to explore and measure how assistance dogs can help people to live well with dementia. Data will be collected before a dog is placed and at multiple time points thereafter (1, 3, 6, 9 and 12 months following a dog’s placement).

The outcome
In today’s economic and political climate, it is essential that new and innovative services not only highlight their physical and social benefits for individuals, families and communities, but also their cost effectiveness.

The average organisational costs for provision and lifetime support of a dementia assistance dog is 21,500 GBP. With regard to this program, the costs for five assistance dogs is approximately 67,500 GBP, with a further 40,000 GBP in ongoing support costs. This is a total cost of 107,500 GBP.

By July 2018, five dogs had completed the full training program, successfully becoming dementia assistance dogs. So far, the program has received a total of 34 enquiries.

The collected data will be used to highlight how an assistance dog can support individual self-management, resilience or better coping. It will also discuss how people living with dementia may be enabled to realise their citizenship roles within domestic, social and community settings.

The final report will be published in 2020. An interim report has been produced, and can be accessed online at http://dementiadog.org/

Case Study: Webb’s story

After completing his first year of socialisation, a 8-week old puppy Webb commenced early training with the Dogs for Good team at their Oxfordshire headquarters, where he was identified as having the perfect temperament and skills for the Dementia Assistance Dog Program.

Webb arrived in Scotland at the start of 2017 to complete his advanced training and learn specific skills to help someone living with dementia.

Webb now uses these skills and more on a daily basis with his new family, Imke and Malcolm, with whom he was matched and placed in September 2017.

Malcolm was diagnosed with dementia associated with Parkinson’s in 2016, which can present a number of daily challenges for both himself, and his wife and full-time carer, Imke.

“Webb helps Malcolm and I in many practical ways. He fetches Malcolm’s medication and even takes Malcolm’s socks off for him,” says Imke.

“Webb has not only introduced laughter back into our home, he has given me the strength to cope.”

Webb has also been learning how to roll the yoga mat out each morning to motivate Malcolm to do his physio exercises, as well as locating and opening the sitting room door to help Malcolm’s orientation.

Malcolm and Imke’s daughter says, “Webb has made a huge difference in both my dad and my mum’s life. Thank you to everyone involved in training Webb. Words cannot express how much he has improved our lives and how much he means to us.”

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Rebuilding hope for people living with pain

The opportunity
For many people, living with chronic pain has a major impact on their sense of meaning and purpose, and can leave them feeling crushed and without hope. While current pain programs help people manage their pain, they usually do little to address these other important issues.

The research
The Pain Clinic at Greenwich Hospital embarked on a new project to develop an innovative new program with the aim of addressing issues of meaning and purpose for people living with chronic pain. A multidisciplinary team including the pain specialist, physiotherapist and clinical psychologist at the Pain Clinic developed the structure and content of the program.

The content was largely based on the evidence from research investigating the phenomenon of post-traumatic growth. This research shows that a strong sense of meaning and purpose often comes from good social and sometimes spiritual connections, as well as making a contribution to others.

The program was facilitated by each of the team involved in its development, and a pilot study was conducted in order to evaluate people living with chronic pain. It comprised five sessions, one morning a week, for 5 weeks. Participants were introduced to the concepts, with times for reflection and group discussion. Questionnaires were completed to look for changes during the program. Once the program was completed, researchers interviewed participants to gain their feedback.

Information from the feedback, as well as the experience of the program facilitators, was then used to make modifications to improve and refine the program.

The outcome
The overall feedback from the interviews was overwhelmingly positive. Many participants found the information about important issues in living with pain useful, as these issues are not always addressed. They also described the benefits of reflecting and acting on insights during the program.

The number of programs that have been evaluated so far is small, and at this stage the information about the changes is limited. So far, the evaluation is indicating improvements in emotional wellbeing.

Case Study: The power and pain of acceptance
Mary Anne was on maternity leave caring for her two-year-old twins when she was diagnosed with transverse myelitis, an autoimmune disease that depletes the myelin sheath around nerves traveling in the spinal cord. As a result of her illness-induced spinal cord damage, Mary Anne was left with ‘incomplete paraplegia’.

In the wake of her diagnosis, Mary Anne felt frightened as no-one knew what the outcome would be.

Determined to carve a better life for herself, her two children and her husband, she attended a 12 week in-hospital rehabilitation program where she worked tirelessly at slowly learning how to walk again.

“I worked so hard to return to my previous normal. I kept thinking that one day I would wake up ‘cured’ and have all my physical functions back to the way they were. I wasn’t able to accept my ‘new normal’,” says Mary Anne.

“The injury killed my thoughts of returning to work, with my rehab becoming a full-time job.”

Things started to take a turn for the better when Mary Anne was put in touch with the Pain Clinic at Greenwich Hospital. She took part in the clinic’s Core Strength program which enabled her to physically, emotionally and spiritually accept herself again.

“The Core Strength Program gave me the first opportunity since my illness to really look at myself as a whole, and begin the journey of acknowledging myself as a person living with a disability. And the truth of that realisation being that I am not disabled, just different,” says Mary Anne.

“I can now appreciate that my illness didn’t leave me as a broken person, but as a strong, determined, resilient woman with gifts to offer.”

Pictured: Mary Anne
Key research areas
An overview

Grants and statistics
Successful grant applications and grants with continuing funding in 2018
Statistics

Palliative care
Three new projects in 2018 and continuing projects

Dementia
Thirteen new projects and continuing projects

Ageing, restorative care and reablement
Three new projects and continuing projects

Rehabilitation
One new project and continuing projects

Pain management
One new project and continuing projects

Advance care planning
One new project and continuing projects

Spiritual aspects of care
Continuing projects
Key research areas

**Palliative Care**
HammondCare is involved in a broad range of research in palliative care. Our research program aims to improve the quality of life and wellbeing for people living with life-threatening illness and their families. We conduct mixed methods and health services research to inform development of interventions to improve provision of palliative care in a variety of settings, as well as support families in their bereavement. One example is a recent study to investigate the lived experience of bereaved adults following anticipated deaths in hospital, home and residential aged care settings.

We also do translational research projects to embed evidence in practice – for example, pain guidelines, an anxiety and depression pathway, and a toolkit and national training program to facilitate team-based initiation of palliative care in general practice. In addition, we supervise PhD students’ research in a number of areas, with current examples including pain management and self-management strategies for breathlessness. We are active partners in the Palliative Care Clinical Studies Collaborative (PACCS): an international research network that aims to generate high quality research evidence to support the use of medicines and other interventions at the end of life to better manage or alleviate symptoms such as pain, confusion, breathlessness, appetite loss, and gastrointestinal problems. We collaborate with 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.

**Dementia**
The Dementia Centre exists to improve the lives of people living with dementia, their carers and staff by providing training, consultancy and evidence-based interventions. We 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 our 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.

**Ageing, Restorative Care and Reablement**
While population ageing means that, overall, people are living longer, it doesn’t mean that everyone experiences good health, free of disabling conditions, as they age. HammondCare’s research in ageing recognises this, and our focus is helping people gain the most from their ageing experience, taking a ‘whole person’ approach, and looking at ways that help maximise people’s functional ability and 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 are caregiver wellness, helping people achieve positive ageing through active participation in the arts, community-based restorative care programs for older people with frailty and chronic disease, and reablement programs for people living with dementia.

**Rehabilitation**
As the number of persons with disabilities increases rapidly, particularly, but not solely due to population ageing, 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 experienced total knee replacement. This paper has received international and local media attention and contributed to the development of the evidence-based 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.

**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.

**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 in different settings. This research is looking at ways to overcome the obstacles to ACP, developing and testing practical tools to help health professionals start conversations about ACP and team-based strategies to embed ACP in routine care.

**Spiritual Aspects of Care**
At HammondCare, we recognise that spirituality is a fundamental element of human experience. It encompasses each individual’s search for meaning and purpose in life. When facing pain, rehabilitation, mental health issues, or a disabling or life-threatening illness, people often struggle to make sense of what is happening to them. Spirituality also encompasses the connections one makes: with other people, nature, the sacred, including – but not exclusively – connections made within traditional religions. Viewed in this way, spirituality can be a key factor in how people cope with illness. We are interested in how people express their spirituality and are keen to find ways to better provide care in this essential dimension of health.
Successful grants and continuing funding

Successful grant applications

Christie J, Thompson-Bradley O, Cunningham C. Age UK ‘My Life, My Way’ Program. This 6 month review is funded by Age Northern Ireland and will report in March 2019. Awarded $70,000 GBP to HammondCare.


Marshall M, in collaboration with researchers from the Edinburgh Centre for Research on the Experience of Dementia at the University of Edinburgh, Upstream, PAMIS, Scottish Dementia Alumni. Disability Research on Independent Living and Learning (DRILL) Program and will report later in 2019. Going on the Go. The research is funded by the National Lottery. Awarded $170,880 to the University of Edinburgh over 18 months.


Continuing grants


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 $10,000 from Nov 2017 to end June 2018.


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 $10,000 from Nov 2017 to end June 2018.


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Statistics

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Palliative care

**Optimising end of life care for people living with dementia | New in 2018**

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

In this project, we will systematically review and synthesise findings from research literature regarding the important components of quality end of life care for older people living with dementia from the perspective of patients, families and care providers. In addition, we will explore the perspectives and views of HammondCare’s resident aged care staff, volunteers, general practitioners and family members of HammondCare’s residents, regarding the key elements required to enable quality end of life care for people living with dementia in residential aged care, and the strengths and gaps in current care provision.

We will conduct focus groups and individual interviews with the different participant groups and use qualitative methods to analyse responses. This will inform development of strategies for optimising end of life care for people living with dementia in our model of residential care. This project will provide a greater understanding of the key elements required to provide quality care at the end of life for people living with advanced dementia in residential aged care. A better understanding of these key elements will allow HammondCare to optimise the quality of end of life care for the people we serve in our residential aged care services. This research is also in strong alignment with HammondCare’s future directions and combines our key differentiators of dementia care and palliative care.

**Cancer pain assessment study | New in 2018**

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

HammondCare cares for people with pain and cancer across its services. This study will provide education for all our staff about assessing cancer pain. The education will be tailored to each individual staff member’s preexisting knowledge and information needs.

**Palliative care**

**Living after death: An exploration of the experiences of bereaved adults | New in 2018**

Most people in Australia die in circumstances where death is anticipated and where family members are expected to have worked through some of the significant changes that accompany a loss before death occurs. The assumption that grief is easier when death is expected stands in contrast to research which documents the profound impacts of bereavement, regardless of the circumstances of death.

This project will reveal the lived experiences of bereaved adults following an anticipated death, including experiences after deaths in hospital, at home and in residential aged care. Data will be collected from up to 50 family members using in-depth face-to-face interviews, video interviews and via written accounts.

In addition, 5 focus groups with professionals and volunteers will be facilitated. Focus group participants will be asked to reflect upon findings from Stage 1 and 2 of the research to examine how these findings fit with or challenge professional understandings of grief, and to identify ways in which they could enhance the provision of bereavement support. Through analysis of this rich data, this project will:

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

**The experience of refractory breathlessness on everyday life**

This research project focused on patients with refractory breathlessness. Exploring how it affected their everyday lives.

The findings identified the main themes:

1. Living on the edge, referring to the extreme feeling of breathlessness experienced by patients.
2. Social meanings of breathlessness, describing the significance of social support.
3. Reduced to the basics, referring to the effect breathlessness has on basic daily tasks.
4. Sources of security, which describes the measures participants take to protect themselves from their own breathlessness.

**Translational outcomes:** Participants noted the importance of functional participation for improved engagement and quality of life. There is scope to develop specific interventions and occupational therapy services incorporating self-management and equipment prescription for people with dyspnoea. A breathlessness plan self-management resource is in routine use in our services. An occupational therapist routinely sees people participating in our breathlessness program.
Palliative care

Randomised, double-blind, placebo-controlled phase 3 trial of oral melatonin for the prevention of delirium in hospital inpatients with advanced cancer

Delirium is a highly prevalent, medical emergency in advanced cancer. Despite being preventable in many cases, two-thirds of people with advanced cancer will have a delirium episode at some point whilst hospitalised. Delirium causes additional medical complications, excess mortality, high levels of patient and caregiver distress, and significant increases in health care costs. Delirium adversely affects cognition, awareness and communication ability at a critical time when being mentally aware and interacting with loved ones is crucial for quality of life.

The aim of the investigator-initiated, cooperative group trial is to determine the effectiveness of melatonin in preventing delirium (number of delirium free days during hospital admission achieved by reducing overall delirium occurrence, or reducing duration and severity of delirium if it occurs). Oral melatonin prolonged release (2mg) or placebo is taken at 2000 hours. Intervention will be commenced within 48 hours of admission and continued until any of the following delirium occurrence, discharge, or for a maximum of 21 days if patient remains in hospital as in most cases any acute medical issues impacting 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, mortality, 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.

Researchers: Dr Michele Wiehe, Dr Nathan Wilson, Bernadette Currie, Western Sydney University; Professor Roger Stancliffe, University of Sydney; Professor Josephine Olayton, HammondCare

Site: NSW wide project

Duration: Jan 17 to Jun 19

Project Partners: University of Western Sydney and University of Sydney

Funding Source: Western Sydney University Fellowship

Study Status: Manuscripts in preparation

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

People with intellectual disability are living longer, and like the general community, are experiencing illnesses requiring extensive periods of palliative care. This study, funded through a University of Western Sydney Women’s Research Fellowship Grant (2017), in collaboration with the University of Sydney and HammondCare, is being undertaken to understand the experience of multidisciplinary specialist palliative care teams in caring for people with intellectual disability who are dying.

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

Researchers: Dr Michele Wiehe, Dr Nathan Wilson, Bernadette Currie, Western Sydney University; Professor Roger Stancliffe, University of Sydney; Professor Josephine Olayton, HammondCare

Site: NSW wide project

Duration: Jan 17 to Jun 19

Project Partners: University of Western Sydney and University of Sydney

Funding Source: Western Sydney University Fellowship

Study Status: Manuscripts in preparation

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

The aims of this project were to determine:

1. If a planned Patient-Centred Family Meeting held soon after an inpatient admission to a palliative care unit, is feasible and acceptable to the patient, family and clinicians

2. If the selected outcome measures are suitable and feasible from the patient and family perspective.

Patients and their families were screened at Greenwich Hospital Palliative Care Unit between 1 November 2017 and 30 September 2018 for the VOICE Study. A total of 319 patients were screened and 30 patient-family dyads were recruited to the Study. A Patient-Centred Family Meeting was provided to the recruited patients at Greenwich Hospital and their invited family member. Prior to the meeting, the researcher met with the patient to determine their issues and concerns which they wished to discuss at the meeting with the relevant multidisciplinary team members.

Validated outcome measures were collected from both the patient and their families to assess satisfaction with quality of life at end of life, and their level of distress pre and post meeting. Semi-structured interviews were also undertaken with the patients as soon as possible after the meeting, and with the family member on Day 14 of the patient’s admission.

The Researcher also undertook individual face-to-face interviews with 10 clinicians who had participated in at least one Patient-Centred Family Meeting. At least one representative from each of the clinical groups working in the palliative care unit was interviewed.

Collection of the clinician interview data was completed in November 2018 at Greenwich and is currently being coded and analysed. This data will be compared with the clinician interview data from the control site which was completed in December 2018. It is envisaged that these findings will be reported in a peer review journal. The analysis of the patient and family qualitative data and quantitative measures has also commenced and these results will be also be published in a peer review journal.

As part of the VOICE Study, an online Survey has been developed to gain a better understanding of family meeting practices in specialist palliative care in NSW. The Survey will be distributed via palliative care professional networks in NSW. The Survey results will enable a comparison of current family meeting practices with the results from the intervention site where Patient-Centred Family Meetings were evaluated.

Data collected from the on-line Survey and the results from the VOICE Study are likely to increase the knowledge and understanding of family meeting practices in NSW.

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

Site: Greenwich Hospital

Duration: Aug 17 to Mar 18

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

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

Study Status: Data collection complete, analysis in progress
Palliative care

**BEAMS: A pragmatic, phase 3, multi-site, double-blind, placebo controlled, parallel arm, dose-increment randomised trial of regular low dose extended release morphine for chronic refractory breathlessness**

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 was 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 was to compare difference in steps per day measured using Fitbit between people taking once daily extended release oral morphine by dosing level.

The study closed at Greenwich Hospital in 2018 as it was not feasible to achieve the expected recruitment rate. It continues to recruit in other sites around the country.

**Rapid report of pharmacovigilance program**

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

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

During 2018 the series examining deprescribing Targin for pain was completed. This program provides data to an international collection continued in 2018 for the medication series: Amitriptyline for neuropathic pain, non-steroidal anti-inflammatory drugs for pain, benzodiazepines for breathlessness, midazolam for terminal agitation, mirtazapine for anorexia, and cetirizine for nausea. 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.

**The PRESERVE pilot study**

This study aimed to determine if a multicomponent non-pharmacological 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 was to inform whether a phase 3 efficacy trial of the intervention was 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 3 trial.

However, by participating in this trial, Greenwich Palliative Care Inpatient Unit is in a better position to meet the ACGME 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.

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**HammondCare Research Report 2018**
Palliative care

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

This project informed 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 was developed based on this research. These informed guidelines for communication strategies and highlighted areas for future research. This was a qualitative study. It involved interviews with 18 Australian palliative care physicians from a range of palliative care settings across Australia. Recruitment and analysis have been completed. A manuscript has been recently accepted for publication in Palliative Medicine, a leading international palliative care journal.

Translational outcomes: This study found that palliative care physicians from Australia experienced challenges when making decisions to transfer patients to nursing homes. The findings suggest that better integration of palliative care services and nursing home care is needed. Participants suggested several communication strategies that may be useful for other providers when discussing the transition of patients who require a palliative approach to their care to nursing homes. This study has informed further research and service initiatives being led by HammondCare that aim to improve end of life care for people in residential aged care settings.

Stop cancer PAIN

The aim of this study is to facilitate improved pain outcomes for people living with cancer pain and their families, improved health service delivery for cancer pain and improved staff knowledge. Since 2018, the study has been completed at four sites and is nearing completion. The aim of the project is to evaluate the implementation of the Australian Cancer Pain Assessment and Management guideline into cancer centres around the country in a randomised controlled trial. Guidelines need implementation strategies to encourage uptake. This study uses health professional education via Q stream, patient self-management resources and audit, as well as feedback to implement the guidelines to improve cancer pain.

Palliative care

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

This project will inform better and more streamlined psychosocial care of our patients. 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 a randomised controlled trial (RCT) and pre-post study. An online portal has been created to operationalise the pathway, and has been piloted at a cancer service in Sydney. The study protocol for a large multicentre cluster RCT has been published and the cluster RCT is now in progress in 12 cancer services across NSW. Each service works with the ADAPT team to tailor the “Clinical Pathway for the screening, assessment and management of anxiety and depression in adult cancer patients” Australian guidelines at their cancer service prior to introducing the recommendations over a 12-month implementation period. 10 services are now implementing the Clinical Pathway using the developed resources, with just under 1000 patients registered and routine screening completed 940 times. Survey and interview data from participating cancer services staff is providing valuable information on the success of the implementation planning and the practice reality. Study completion is planned for 2019/2020.

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

This research contributed 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 contributed towards service development and service delivery in the palliative and post death period. Data collection is complete from the participants. Data analysis is ongoing and presentations are being prepared for international conferences and publication. Results from this study will be used to guide bereavement interventions; this unique research will enable targeted approaches to be made when and where they are needed most.
Dementia

**GRADUATE trial - Phase 3, multicentre, randomised, double-blind, placebo-controlled, parallel-group, efficacy and safety study of GANTENERUMAB in patients with prodromal to mild Alzheimer’s disease | New in 2018**

Researchers: Associate Professor Stephen Macfarlane; Dr Madeleine Healy; Michael Kornhauser; Ella Modini

Site: Melbourne

Duration: Jun 18 to Jun 22

Project Partners: Medavante, Covance, Medidata

Funding Source: Internal Funding

Study Status: In Progress

**Dementia Assistance Dog Program Evaluation | New in 2018**

Researchers: Dr Julie Christie, Gaoiagh Thompson-Brodley, HammondCare

Site: NA

Duration: Jun 18 to Apr 20

Project Partners: Nil

Funding Source: Life Changes Trust

Study Status: In Progress

This project aims to explore and measure how assistance dogs can assist people living with dementia by placing eight fully trained dogs with eight couples living in Scotland. Dementia Dog is a collaboration between Alzheimer Scotland and Dogs for Good, combining professional expertise to pilot and develop new services for people living with dementia. Funded by charitable donations, Dementia Assistance Dogs are trained to live at home with families, where a person has an early stage diagnosis and lives with a full-time carer. The team are based at HMPT Castle Huntly open prison near Dundee, in Scotland where they work with the Scottish Prison Service and Paws for Progress to help train their Dementia Dogs. This 3 year pilot project aims to build evidence-based learning with the potential to replicate on a wider scale as funding becomes available. This evaluation program focuses on the impact of these assistance dogs in the lives of people with dementia and covers a range of topics including economic impact. The first report of the program is now available.
Dementia

**ANAVEX trial- A phase 2b/3, double-blind, randomised, placebo-controlled 48-week safety and efficacy trial of ANAVEX2-73 for the treatment of Alzheimer’s disease** | New in 2018

*Researchers:* Associate Professor Stephen Macfarlane; Dr Madeleine Healy; Dr Antony Sutherland; Michael Kornhauer; Ella Modini; Julia Lindner  
*Site:* Melbourne  
*Duration:* Aug 18 to Dec 21  
*Project Partners:* World Wide Clinical Trials, Prevail Infoworks, Bracket, 360-Biolabs  
*Funding Source:* Anavex Life Sciences  
*Study Status:* In Progress

This trial is currently being conducted at over 15 sites globally. 2. The Malvern site was the first site in the world to be initiated in the phase 2a study, Associate Professor Macfarlane and his team saw positive (and at times drastic) increases in cognition and functioning in study participants, and are pleased to be involved in the phase 2b/3 study. The study will be recruiting throughout 2019 and most likely 2020 and into early 2021. Some key achievements of the HammondCare site in relation to this study include: 1. Associate Professor Stephen Macfarlane has been appointed as the global study lead for this study 2. The Malvern site was the first site in the world to be initiated 3. Ours is the global No.1 recruiting site (most sites average 7-10 patients per study, whilst Malvern already has 31 patients on study and aims to recruit 40-50 patients) 4. This trial is currently being conducted at over 15 sites globally and will run for another 24 months.

**Care Plans in Residential Care – beneficial or burdensome to the delivery of tailored and responsive care?** | New in 2018

*Researchers:* Nicola Nolan, HammondCare  
*Sites:* HammondCare Erina, Strathearn House, Wahroonga  
*Duration:* Mar 18 to Jul 18  
*Project Partners:* Nil  
*Funding Source:* In researcher’s own time  
*Study Status:* Completed

This project sought to explore whether a care plan document assists staff to know resident’s needs and preferences or whether it simply exists to satisfy the policy makers, funding bodies and regulators? Is tailored and responsive care stimulated or hindered by the development and upkeep of these documents? It is expected that residents living in residential aged care in Australia have a documented care plan to inform care. Managers, Registered Nurses (RNs), frontline care staff and Allied Health Practitioners (AHPs) currently have responsibility to develop, be familiar with and regularly review this document. For residents living with dementia within these aged care homes, their needs, preferences and goals are documented in this plan, with accompanying strategies and interventions. Aligned with the nursing process, there is also an associated cycle of regular review and evaluation. This project explored if this document is relevant and useful in the residential aged care environment. Is it accessed regularly? Is it used by all staff members? Do staff rely on this document to assist them to know the resident’s needs and preferences or does it simply exist to satisfy the policy makers, funding bodies and regulators? Is tailored and responsive care stimulated or hindered by the development and upkeep of the care plan document?
### Dementia

**Culture, institutions and dementia care: the experiences of migrant care workers from culturally and linguistically diverse populations** | New in 2018

**Researchers:** Omobola Adebayo, Curtin University; Dr Karen Heslop, Dr Bianca Brijnath; Dr Pam Nichols  
**Sites:** HammondCare Southwood, Bond House, The Meadows, Miranda  
**Duration:** Jul 18 to Nov 18  
**Project Partner:** Curtin University  
**Funding Source:** Curtin University

The findings from this study aim to enhance participation and inclusiveness of migrant care-workers. **Translational outcomes:** Evidence shows that higher proportions of migrant care workers are personal care assistants in the aged care sector. Given that migrant care workers often spend the bulk of their time in their roles as personal care assistants providing direct care to residents, it is essential to examine migrant care workers’ knowledge and experiences of dementia care and how culture shapes their understanding of care work. In addition, evidence shows that there are important cultural variations in the understanding of dementia among people from culturally diverse populations. This study explored how cultural perceptions of migrant care workers influence their dementia care provision in residential aged care homes (RACFs).

While several studies have been conducted on the dementia care experiences of family caregivers from migrant backgrounds, relatively few studies have been conducted on dementia care experiences of migrant care workers in RACFs. This study expanded the limited studies on migrant care workers dementia care experiences in institutional settings such as RACFs. Additionally, migrants are generally underrepresented in research; this study enhanced participation and inclusiveness of migrant care-workers in a diverse organisation such as HammondCare.

The rising prevalence of dementia in the aged care sector highlights the need to have sufficient care workers that are motivated to provide safe and high-quality care for people living with dementia. A large proportion of residents in RACFs have changed behaviours associated with their dementia and are being cared for by a migrant workforce with different cultural perceptions of dementia.

This research study generated findings that may be used to develop evidence-based recommendations that could improve the quality of dementia care in RACFs by exploring the mental and working conditions of care workers from different cultural backgrounds caring for people with dementia.

Migrant care workers have been recruited in high-income countries including Australia to address staff shortages and to meet the increased core demands in the aged care sector. Thus migrant care workers are valuable contributors to the aged care workforce. Enablers and barriers to migrant workforce retention in the aged care sector were examined in this research study.

These findings may inform policy makers and aged care management to better understand the workforce attrition and retention strategies of migrant care-workers in the aged care sector.

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### Dementia

**New Ways for Better Days: Tailoring activities for people living with dementia and their caregivers - Tailored Activity Program-Australia (TAP-Australia)** | New in 2018

**Researchers:** Associate Professor Sally Bennett, University of Queensland; Professor Lindy Clemson, University of Sydney; Professor Laura Gitlin, Drexel University; Professor Brenda Gannon, University of Queensland; Professor Trevor Russell, University of Queensland; Dr Maria O’Reilly, Central Queensland University  
**Site:** NA  
**Duration:** Jul 18 to Aug 10  
**Project Partner:** University of Queensland  
**Funding Source:** NHMRC – Boosting Dementia Research Grant

This project seeks to implement the tailored activity program across Queensland. The Tailored Activity Program (TAP) aims to help family and carers communicate effectively with their family member who is living with dementia, and help engage them in meaningful activities to reduce behavioural symptoms and improve carer outcomes.

TAP has been shown to be effective in supporting both the person living with dementia and their family members. Despite this, it is not available to consumers in Australia. This implementation project aims to investigate how TAP can be implemented within Australia, and build capacity within the Australian healthcare workforce to deliver TAP beyond the life of the project.

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### Guided by Excellence | New in 2018

**Researchers:** Professor Susan Kurrle, University of Sydney; Associate Professor Calm Cunningham, Dr Meredith Gresham, Dr Patricia Knight, Dr Tom Morris, HammondCare  
**Site:** NA  
**Duration:** Jul 18 to Sep 19  
**Project Partner:** University of Sydney  
**Funding Source:** Australian Government Department of Health

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

This research comprises two complementary activities:

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

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

The audit is 70% complete and interviews are commencing nationally to capture a spread of geographic locations and service user types.
### Dementia Care

#### Evaluation of HammondCare Caulfield | New in 2018

**Researchers:** Dr Meredith Gresham, Dr Cindy Kok, Dr Tom Morris, Sabrina Dho, Associate Professor Colm Cunningham, HammondCare  
**Site:** HammondCare Caulfield  
**Duration:** Oct 18 to Oct 19  
**Project Partners:** Nil  
**Funding Source:** HammondCare In-Kind Support

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

Old and frail residents may be relocated to new residential aged care facilities during their tenure. However, the process of relocating is known to be associated with negative outcomes for the residents, especially those with cognitive impairment.

This project aims to validate HammondCare’s model of care by evaluating the outcomes of residents, staff, and family following the move of residents from a traditional facility to a newly built HammondCare facility. A key feature of this new facility is that it adopts a unique cottage design similar to that of a home-like environment.

To investigate the impact of the move and of the new facility, residents scheduled for relocation will be invited to participate in a pre and post move observational study where a range of quality of life, depression, behaviour and care need assessments will be completed. Behaviour mapping will also be used to document location, level of engagement and affect of residents at various times of the day.

This study will contribute to and inform future improved care practices pertaining to this vulnerable group of people. It will also be instrumental in enhancing training and support for the people who care for people living with dementia.

**Study Status:** In Progress

#### Agents of Change: Creating National Quality Collaboratives to Improve Dementia Care | New in 2018

**Researchers:** Dr Kate Laver, Flinders University; Karen Cheung, Kate Matthews, HammondCare  
**Site:** Greenwich Hospital  
**Duration:** Oct 18 to Dec 19  
**Project Partner:** Flinders University  
**Funding Source:** NHMRC and the Cognitive Decline Partnership Centre

A new collaborative research project aiming to improve the implementation of key recommendations from the clinical practice guidelines for dementia.

The ‘Agents of Change’ project aims to improve post-diagnosis care for people living with dementia and their carers through implementing these three key recommendations from the Clinical Practice Guideline for dementia:
1. People living in the community should be offered occupational therapy  
2. People with dementia should be strongly encouraged to exercise  
3. Carers and family should have access to respite, and to programs to support and optimise their ability to provide care.

To achieve this, the project team have established a National Quality Collaborative, currently across 30 sites nationally, where training and support are provided to health professionals to implement these recommendations using evidence-based occupational therapy, exercise and carer support.

Part of the project will be an evaluation to assess the success and feasibility of using the National Quality Collaborative model to train “implementation clinicians” (health professionals from general practitioners, nurses, social workers, occupational therapists, physiotherapists, psychologists who are motivated to improve dementia care).

**Study Status:** In Progress

#### Test and refine Music Guidelines | New in 2018

**Researchers:** Dr Sandra Garrido, University of New South Wales; Holly Markwell, HammondCare; Professor Esther Chang, Professor Cathryn Stevens, Western Sydney University  
**Site:** HammondCare Wahroonga  
**Duration:** Nov 18 to Feb 19  
**Project Partners:** MARCS Institute, Western Sydney University  
**Funding Source:** MARCS Institute

Review current music guidelines.

Personalised music playlists are used across HammondCare Residential Services and by Dementia Support Australia. While evidence for the value of personalised music is encouraging, there is no systematised approach to guide staff on contra-indications, timing and dose of music interventions for people living with dementia. Care as to how music is used is especially relevant for people with responsive behaviour or Behavioural and Psychological Symptoms of Dementia. Evidence on personalised music is that negative outcomes (worsening of depressed mood/dysphoria) can occur particularly for people with dementia and current symptoms or past history of depression.

The MARCS Institute for Brain, Behaviour and Development, Western Sydney University has developed a set of guidelines to address this. This project aims to review the guidelines, provide feedback, and engage in a pilot study to test them. It is hoped that this project will assist us to make best use of music tailored for the benefit of the individual and positive impact on wellbeing, reduction in responsive behaviour or BPSD, and avoidance of any negative outcomes. Expected outcomes include reduced use of pharmacological treatment for BPSD and improved quality of life. If the pilot study proves useful then further funding could be jointly applied to run a randomised control trial.

**Study Status:** In Progress

#### Age NI ‘My Life My Way’ | New in 2018

**Researchers:** Dr Julie Christie, Associate Professor Colm Cunningham, Oonagh Thompson-Bradley, HammondCare  
**Site:** U.K.  
**Duration:** Nov 18 to Mar 19  
**Project Partners:** Nil  
**Funding Source:** Age UK Northern Ireland

A social return on investment evaluation building on service data and focusing on the experiences of people who use this service.

‘My Life My Way’ is a project providing support to older people living with dementia and their carers in the Belfast and Northern Health and Social Care Trust areas of Northern Ireland. The aim of this project is to promote the personal autonomy and decision making of hard to reach, older people living with dementia who are isolated and at high risk of disempowerment.

Volunteers offer signposting and provide relevant information about care options and entitlements which will allow the individual with dementia or their carer to make better informed decisions. It is anticipated this will empower older people who have been diagnosed with dementia as they gain improved personal choice, control and influence over decisions about their care as they recognise the dignity they deserve as they continue to live their life. ‘My Life My Way’ is a partnership project with the Big Lottery Fund and the Belfast and Northern Health and Social Care Trusts. This 6-month realist evaluation, which concludes in March 2019, looks at the impact of the My Life My Way programme from the perspective of people with dementia, carers, referrers and volunteers.

**Study Status:** In Progress
Dementia

MISSIONAD trial - A placebo-controlled, double-blind, parallel-group, 24-month study to evaluate the efficacy and safety of E2609 in people living with early Alzheimer’s disease

This study is a 24-month treatment, multicentre, double-blind, placebo-controlled, parallel-group study in EAD including mild cognitive impairment (MCI) due to Alzheimer’s disease (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 (LST). 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 1133 subjects will be randomised, in a double-blind manner, to receive either placebo or elenbecestat (E2609) 50mg per day (approximately 11 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.

Study Status: In Progress

Valuating and evaluating a quality of life (QOL) instrument for people living with dementia

This study developed a preference based measure (QOL-AD) to value quality of life for people living 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 living with a diagnosis of dementia or cognitive decline.

Data was 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
3. National online survey of 1000 people from the general population, stratified by age, gender, experience with dementia.

Participants were sourced through volunteer research forums and internally through HammondCare at Home.

Study Status: Completed

Dementia

The clinical utility of the electronic toilet-top bidet for Australian nursing home residents and staff

This study aimed to examine the acceptability of bidets in dementia specific care for residents and staff; the ability of the bidet to clean and dry after voiding; the effectiveness in management of incontinence and cost of continence pads. Eight bidets were installed and data collected on 14 residents. Indability to use a toiler independently has negative outcomes for older people, including being a primary risk factor for admission to residential care. Staff in residential settings toileting is the most common task undertaken each day and trying to assist an older person with dementia is frequently met with distress.

This research was the third part of an iterative mixed methods study to investigate the feasibility and clinical utility of the electronic toilet top bidet in Australian nursing homes.

This third study was a non-randomised controlled trial in two nursing homes with 49 residents and 73 staff. Results reinforced previous findings that this electronic bidet was acceptable for residents and staff, was reliable and cleaned adequately after elimination in the majority of toiler episodes. There was a significant reduction in workload associated with toileting for staff. Resistant behaviour improved during toileting and lower rates of constipation were observed. A serendipitous finding was that the use of the bidet stimulated voiding bowels and bladder and some staff reported the bidet as a potential adjunct intervention in managing incontinence.

Study Status: Completed

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

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

Over a decade of research has highlighted that pain is largely unrecognised and frequently undertreated in people living with dementia. Persistent problems with the identification, assessment and management of pain are associated with systemic and cultural barriers specific to the RAC setting. Issues of key concern that were addressed in this project are cultural barriers that 1. reduce the ability of Personal Care Assistants (PCAs), who provide the most direct and constant care to people with dementia, to effectively engage in pain management processes, and 2. constrain development of a culture that supports evidence-based pain management practices.

These issues were addressed through a participatory action research approach. Researchers worked in partnership with Multi-Disciplinary Teams (MDTs) at four RAC sites, to develop strategies which targeted individual, group and organisational behaviours to facilitate the development of a culture that prioritises evidence-based pain management. Integral to this objective is the empowerment of PCAs as central stakeholders in the pain identification, assessment and management.

The project findings informed the development of a transferable MDT Pain Management Model that will support RAC services to translate best practice pain management evidence into practice, to improve the lives of people with dementia who experience pain.
Dementia

Understanding the factors influencing health professionals’ use of supported decision-making in the context of dementia care

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

Sites: Various HammondCare sites

Duration: Apr 17 to Jun 18

Project Partner: University of Western Australia

Funding Source: Cognitive Decline Partnership Centre

This study explored the experiences and perceptions of service providers in legal and healthcare sectors, with respect to decision-making and advance care planning among people living with dementia. In-depth qualitative interviews were undertaken with healthcare professionals and workers (e.g. general practitioners, geriatricians, nurses, social workers, occupational therapists, professional carers) and legal professionals (e.g. lawyers, client advocates and members of Guardianship/Administrative tribunals).

Participants were 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 informed development of educational resources to assist health care providers to support decision-making among people with cognitive impairment.

Translational outcomes: Data collection has been completed. 29 Australian health and legal professionals involved in providing care or services for people with dementia were interviewed. Analysis has been completed and a manuscript will soon be submitted for publication.

COGRX – Clinical trial of CT1812 in mild to moderate Alzheimer’s disease

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

Site: Malvern HammondCare Office

Duration: Apr 17 to Jun 19

Project Partner: Austin Health

Funding Source: Cognition Therapeutics Inc

This clinical trial is a randomised, double-blind, placebo-controlled trial of a new drug CT1812 in patients living 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.

Functional and symptomatic outcomes of psychogeriatric patients in Riverglen inpatient unit

Researchers: Professor Janine Stevenson, HammondCare

Site: Greenwich Hospital

Duration: Apr 14 to Jun 19

Project Partners: Nil

Funding Source: Internally Supported

Dementia

Dementia in the public domain

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

Sites: Various HammondCare sites

Duration: Feb 17 to Jun 18

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

Funding Source: Cognitive Decline Partnership Centre

This project conducted one-to-one interviews with people living 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.

Each interview was 30–60 minutes long and was conducted via phone or face-to-face. The project was part of our 3 year study which aimed to examine current public perceptions of dementia from a range of perspectives, critically assessed key components used in public campaigning, and further identified appropriate forms of public intervention to promote positive understanding of dementia as a social phenomenon.

End of life symptoms and care in people living with dementia, in an Australian context

Researchers: Peter Roach, Professor Melanie Lovett, Professor Steve Macfarlane, HammondCare

Site: Pallister House

Duration: Jul 17 to Mar 18

Project Partners: Nil

Funding Source: Internally Funded

During the development phase of this project, records from patients who died during their episode of care with Dementia Support Australia were identified. The characteristics of those who died were compared to similar cases who did not die, in order to determine whether the behavioural symptoms with which the two groups presented differed.

Cases were examined to identify those for whom palliative care services were engaged at the end of life.

Translational outcomes: This project identified factors associated with dying in people with behavioural and psychological symptoms of dementia and what factors were predictive of death. It enabled earlier referral to palliative care and optimal treatment at the end of life and what factors were predictive of risk of death.

Study Status: Completed

Translational outcomes: This project identified factors associated with dying in people with behavioural and psychological symptoms of dementia and what factors were predictive of death. It enabled earlier referral to palliative care and optimal treatment at the end of life.

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Study Status: In Progress

Translational outcomes: This project identified factors associated with dying in people with behavioural and psychological symptoms of dementia and what factors were predictive of death. It enabled earlier referral to palliative care and optimal treatment at the end of life.

Study Status: In Progress
Evidence-based programs to improve the wellbeing of people living 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 Jun 19

**Project Partners:** University of Sydney; Flinders University; Cognitive Decline Partnership Centre

**Funding Source:** Internally supported

**Study Status:** In Progress

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

**Researchers:** Professor Maria Crotty, Flinders University; Designated System Based Investigators (DSBIs); Dr Meaghan Gresham, Associate Professor Colm Cunningham, HammondCare

**Sites:** HammondCare Erina and Woy Woy

**Duration:** May 1 to Jun 18

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

**Funding Source:** Cognitive Decline Partnership Centre

**Study Status:** Completed

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 for managing behaviour and to engage of champions, knowledge acquisition of staff providing the intervention, and cost utilisation. We shall employ a process evaluation using interviews, focus groups and observation.

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, Sue Field, Associate Professor Meredith Blake, Professor Romola Bucks, Associate Professor Kirsten Arest, University of Western Australia; Professor Josephine Clayton, Dr Meredith Gresham, HammondCare; Kathy Williams, Dementia Australia Consumer Network; Professor Sue Kurrie, Professor Cameron Stewart, University of Sydney; Professor Maera Agar, University of Technology Sydney; Helen Rodaslovitch, Helping Hand Aged Care; Angelita Martini, Brightwater

**Sites:** Pallister House and Greenwich Hospital

**Duration:** Jan 16 to Dec 18

**Project Partner:** Cognitive Decline Partnership Centre

**Funding Source:** Cognitive Decline Partnership Centre

**Study Status:** Completed

This project benefited 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 living 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 provided 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 and 3 (in progress) This project aimed 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 cognitive impairment and dementia. This provided HammondCare with information on the outcomes provided by alternative ways of providing residential care for people with dementia.
Dementia

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

This project led to a greater understanding on how regulations such as rules, standards, guidelines, conventions and norms, influence and shape dementia care in different settings. The outcomes enhanced the effective delivery of care, and prioritise the needs, desires and rights of people living with dementia. A series of policy recommendations on aged and dementia care regulations resulted from this research. Aged care services are required to conform to a range of regulatory frameworks. This project examined the aged care regulatory framework and the role of regulation in the care of people with dementia and the aged care provider's compliance process. Stakeholders were interviewed to gauge their opinions on the advantages and disadvantages of regulation and their effects on the quality of care, as well as the effects of regulation. The findings are being used to inform policy makers in government and regulatory bodies in the development of appropriate regulation that promotes seamless forms of care and support for those with cognitive decline and their carers. The researchers examined:

1. What are the benefits and adverse effects that occur as a result of regulation in residential and community aged care?
2. How can the centre produce evidence to help regulators create more effective regulation that facilitates high quality care for people with cognitive decline?

The project took place over 3 years, beginning with interviews with senior managers and policy experts to identify key areas where difficulties with regulation were encountered. Interviews, along with an online survey were conducted with frontline aged care staff and consumers. The team reviewed the qualitative data from the interviews and survey, identifying the framework of regulation and compliance. The project partners were: Nil.

Researchers: Professor Chris Poulos, Dr Allison Rawlends, Angela Raguz, HammondCare; Associate Professor Roslyn Pouls, University of New South Wales; Associate Professor Steven Faux, St Vincents Health Australia

Site: HammondCare Darlinghurst

Duration: Oct 18 to Jun 19

Ageing, restorative care & reablement

HammondCare Darlington Research Project | New in 2018

This qualitative research project will provide evidence to inform the development of models of care for the new 42 bed nursing home for homeless older people and associated community aged care services in Darlinghurst. The project will also feed into the conceptualisation of outcome indicators for the evaluation of care that will be provided in the Darlinghurst home, once operational. Thirty participants are recruited from all levels of government, service providers and advocacy bodies in the homelessness and aged care sectors, research and policy personnel, as well as key roles within HammondCare. The expertise of agencies providing residential and day services for older people experiencing homelessness is valuable in orienting HammondCare’s model of care for a different demographic. Residents of Darlinghurst will have complex needs due to significant co-morbidities and losses during the life cycle. Recommendations from the study will address areas such as care needs, health and psychosocial implications of homelessness, assessment, the home environment, behaviour management, and staff training and support.

Researchers: Professor Kathy Eager, University of Wollongong; Professor Chris Poulos, HammondCare Investigator

Site: HammondCare Erina, North Turramurra and Hammondville (Southwood)

Duration: Oct 18 to Dec 18

Study Status: Completed
Ageing, restorative care & reablement

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

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

Site: Greenwich Hospital

Duration: Aug 17 to Feb 18

Project Partners: Nil

Funding Source: Internally Funded

This study sought to understand the subjective experiences of staff and patients of The Jacaranda Unit, in relation to inpatient cancer rehabilitation services. In particular, it aimed 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 was a qualitative study which involved focus-groups with staff, and pre- and post-inpatient interviews with patients. In health professionals providing cancer rehabilitation services, and 22 patients receiving cancer rehabilitation services, participated. The Unit Manager recruited: 1. medical and allied health staff with more than 6-months experience in the unit; 2. cancer rehabilitation patients referred to the unit, who were interviewed pre- and postadmission. Following ethics clearance, 1. invited participants were provided with study details and consent forms; 2. participant consent forms and demographic information was collected; 3. staff focus groups and pre- and post-inpatient interviews were conducted at a time convenient to all. The study outcomes informed whether the unit meeting the needs of its patients, both actual and perceived, and provided insights on the experiences of the staff of the unit.

Study Status: Completed

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

Researchers: Professor Chris Poulos HammondCare; University of New South Wales; Dr Meredith Gresham, HammondCare; Associate Professor Rasliy Poulos, University of New South Wales; Helen Radoslovich, Helping Hand; Northern Beaches Lightwater Group; Professor Lindy Clemson, University of Sydney; Associate Professor Kathy McMillan, University of Toronto; Professor Ian Cameron, University of Sydney

Site: Clinical Training Centre, Hammondville

Duration: Jan 17 to May 19

Project Partners: University of New South Wales; Helping Hand; Lightwater Group; University of Sydney; Dementia Support Australia

Funding Source: NHMRC Cognitive Decline Partnership Centre

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 living with dementia.

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

This project sought to gain an understanding of current provider knowledge and practice with respect to the meaning and utility of reablement for the person living with dementia, as well as the perceived barriers to implementing reablement interventions. We reviewed the reablement interventions contained within the Clinical Practice Guidelines and Principles of Care for People with Dementia for suitability for implementation by aged care providers, and also reviewed the function of tools and interventions published since, or not included within, the Practice Guidelines. Together with 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.

The Handbook and supporting resources, a Consumer Information Booklet and the Technical Guide were launched at the International Dementia Conference in 2018. A process of review in consultation with our consumer advisors is currently underway, with the second editions anticipated for release in May 2019.

Study Status: In Progress

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

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

Site: HammondCare

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 was 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 compared the approaches taken by the four countries with which we have worked. The aim of the interviews was to understand more about why and how providers exceed the quality standards. This includes, for example, the training of care staff and other support and care services. However, little attention has been paid to the consequences for older people with limited control over their home environment. To do this, the research compared the experiences of people living with dementia, as well as the perceived barriers to implementing reablement interventions. We reviewed the reablement interventions contained within the Clinical Practice Guidelines and Principles of Care for People with Dementia for suitability for implementation by aged care providers, and also reviewed the function of tools and interventions published since, or not included within, the Practice Guidelines. Together with 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.

The aim of this study was to understand how and why governments can do to encourage providers to deliver care which is better than just the basic level of quality. To do this, the research compared the approaches taken by the four countries with which we have worked. The aim of the interviews was to understand more about why and how providers exceed the quality standards. This includes, for example, the training of care staff and other support and care services.

This study investigated these issues and developed 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 resulted in identification of strategies to enable aged care and housing providers to better meet the needs of tenants; identified more effective mechanisms for service delivery; and generated strategies for informing older tenants on how to maximise use of aged care support.

Study Status: Completed

Ageing, restorative care & reablement

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

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

Site: 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

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 compared to those in owner occupied housing, means demand on the private sector and social housing provision is considerable.

The aim of the Ageing has identified that a lack of affordable, suitable accommodation will place older people 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 implications for older people with limited control over their home environment. To do this, the research compared the experiences of people living with dementia, as well as the perceived barriers to implementing reablement interventions. We reviewed the reablement interventions contained within the Clinical Practice Guidelines and Principles of Care for People with Dementia for suitability for implementation by aged care providers, and also reviewed the function of tools and interventions published since, or not included within, the Practice Guidelines. Together with 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.

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Ageing, restorative care & reablement

Arts on Prescription @ Home

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 living 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 living with dementia and their carers.

Arts on Prescription @ Home provided six dyads with an 8 week arts program, of around 2 hours per week, delivered in the home by a professional artist. Between sessions, participants were provided with materials and support to pursue their individually tailored program.

The findings from the Arts on Prescription @ Home pilot are currently being prepared for academic publication.

Rehabilitation

Assessment of EVOLVE criteria for quality use of medicines in older rehabilitation patients

In this project we have selected three EVOLVE criteria that highlight medicines that are likely to be targets for deprescribing in post-acute older inpatients undergoing rehabilitation: benzodiazepines, antipsychotics and proton pump inhibitors. This project will utilise established EVOLVE criteria and research evidence to improve quality use of medicines and reducing unnecessary adverse drug reaction to our admitted population at Greenwich Rehabilitation Service.

The average age of admitted patients was 78 years old in 2017 with > 85% with more than one comorbidity and > 50% with at least one complication that affected the Rehabilitation program. Active planned review of polypharmacy in this population will provide leadership in evidence based care. Ongoing transfer of critical pharmacological intervention information to General Practitioner will lead onto improving clinical handover.

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 study has demonstrated that there is a very high correlation among the three transfer items scores, with the statistical analysis indicating that there is absolute agreement between the scores.
**Outpatient pain self-management program**

**Researchers:** Professor Philip Siddall, Rebecca McCabe, HammondCare

**Site:** Greenwich Hospital

**Duration:** May 11 to Dec 18

**Project Partners:** Nil

**Funding Source:** Internally Supported

This project aimed 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 statewide meeting in November 2016. 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 indicating a reduction in pain of over 35%. 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 has enabled us to identify factors within the program which are contributing to positive outcomes. This has led to further improvements that have meant that our chronic pain program consistently achieves outcomes that place us as one of the most effective pain programs in Australia.

**Study Status:** Completed

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

**Researchers:** Professor Philip Siddall, Dr Phil Austin, HammondCare; Associate Professor Paul Wrigley, Dr Ali Asghari, Dr Dan Costa, Royal North Shore Hospital

**Site:** Greenwich Hospital

**Duration:** Feb 14 to Jun 18

**Project Partner:** University of Sydney

**Funding Source:** Australian and New Zealand College of Anaesthetists

This project helped us understand the contribution of several different mechanisms. On completion of our research, it is hoped that 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 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 it more accurate.

Further refinements have now been completed. These have resulted in a questionnaire that now has a stronger relationship with physiological tests of pain pathways. This refined questionnaire has been submitted for publication.

**Study Status:** Completed

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**Pain management**

**Evaluation of the core strength program | New in 2018**

**Researchers:** Professor Phil Siddall, Skye Dong, Rebecca McCabe, HammondCare, Jessie Dezsutter, University of Leuven in Belgium

**Site:** Greenwich Hospital

**Duration:** Apr 18 to Apr 21

**Project Partners:** Nil

**Funding Source:** Donor support and HammondCare in-kind support

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

There is now a growing body of evidence around the concept of posttraumatic growth - that positive psychological change can be experienced when faced with highly challenging life circumstances. A key component of posttraumatic growth appears to be the presence of a strong sense of purpose. This process and the fostering of a strong sense of purpose appear to be highly relevant and potentially helpful for people living with pain. Despite this, these concepts have received little attention in this field.

The aim of this project is to draw on the literature to develop a new evidence-based program that incorporates strategies identified as factors associated with posttraumatic growth and in particular fostering a stronger sense of purpose.

**Study Status:** In Progress

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**Pain management**

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

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

**Site:** Greenwich Hospital

**Duration:** Feb 14 to Jun 18

**Project Partner:** University of Sydney

**Funding Source:** Australian and New Zealand College of Anaesthetists

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

The project aimed to bring together the physical, psychological and spiritual contributors to pain. Emphasis on the spiritual receives little attention within pain medicine and has been helpful for HammondCare in developing and disseminating an innovative approach to pain management that is in line with the HammondCare philosophy and ethos.

In 2016, the researchers completed the collection of data from groups of people without pain, with chronic pain, with cancer and without pain and with cancer. 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 those with cancer.

The information from this study has been used to inform the development of a new program that builds resilience in people living with chronic pain by fostering a stronger sense of meaning and purpose. This program is now being delivered in the Pain Clinic with very positive results.

**Study Status:** Completed
Advance care planning

Prevalence of Advance Care Directives in Australian health and residential aged care services | New in 2018

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

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

Using funding from the same grant program, we already developed an innovative and evidence-based toolkit and multi-modal 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 health assessments.
- Identify patients who might be at risk of deteriorating and dying.
- Assess these patients’ symptoms, important questions and concerns.
- Assess their caregivers’ needs and concerns.
- 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.

In 2018, a toolkit with several new resources for primary care clinicians, patients and carers were developed to enable better primary health care through team-based initiation of advance care planning and palliative care.

Advance care planning

Online Toolkit for carers and practitioners helping people with intellectual disability understand dying and death

This evidence-based online toolkit aimed 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 adaptation of the previously evaluated face-to-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 resulted in national reach, flexible delivery, and a freely available, sustainable resource for carers and practitioners.

Translational outcomes: This is a landmark project to enable Australians with intellectual disability to understand the concept of death and their own mortality, and be appropriately supported to comprehend and cope with end-of-life issues.

In a world-first, the team have developed a research-based online resource to support people with intellectual disability understand end-of-life. The resource is called “Talking End of Life”, with people with intellectual disability (TEL). TEL is a free online toolkit to help staff and caregivers teach people with intellectual disability about end of life in everyday contexts. TEL is available at https://www.cansearch.com.au/TEL.

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

Working in collaboration with Palliative Care Australia, this project aimed to develop a resource to support people living with dementia to participate in decision making about their end of life care.

The project team, consisting of HammondCare staff, Palliative Care Australia staff and people with dementia and their carers, worked with HammondCare staff and Palliative Care Australia staff to develop a resource to support people living with dementia to participate in decision making about their end of life care.

The draft resource was amended to incorporate feedback from people living with dementia, obtained during individual consultations and focus groups. The resource informed a wider body of work and study being conducted by Palliative Care Australia.

Translational outcomes: The team from HammondCare were commissioned by Palliative Care Australia to develop a set of tools to support aged care staff to commence conversations with their clients about end-of-life preferences. The resources were refined through consultations with aged care providers, peak body representatives and people living with dementia and their carers. Palliative Care Australia is now undertaking a study to evaluate the new resources with aged care staff who care for people living with dementia to discuss their end of life wishes.
Advance care planning
National prevalence study of advance care planning documentation and self-reported uptake in 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.

Phase 1 of the study is complete. 2285 patient records were audited from a variety of settings, including general practice, hospital and residential aged care. The paper reporting the results of phase 1 was accepted for publication in 2018. The study represents one of the most detailed and comprehensive estimates to date on the prevalence of advance care directives among older people in Australia. Phase 2 of the study included 101 sites and 4187 records across Australia. Analysis of Phase 2 is in progress.

Study Status: In Progress

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

This multi-centre project evaluated an advance care planning intervention for people with incurable cancer. 208 patient/family dyads participated in this multi-site randomised controlled trial of a nurse facilitated advance care planning intervention for patients with incurable cancer. The results of this study were published in the British Journal of Cancer in 2018.

The intervention increased the prevalence of documentation about patients’ wishes for end of life care and increased communication between patients, oncologists and family members about these topics. However, there were no differences in family members’ perceptions that the patient’s wishes for end of life care were met or about the quality of death. There were also no differences in patient or family member satisfaction with care. Rates of referral to palliative care were high in both groups (57% in the intervention group versus 64% in the control group) and no patients received aggressive care at the end of life in either of the groups.

Translational outcomes: The results of this trial suggest that an early ACP intervention, facilitated by a nurse external to the clinical team, has limited additional benefits in cancer services where aggressive end of life care is rare and where access to palliative care is routine and widespread.

More research is needed to determine the best ways to incorporate early advance care planning into routine cancer care by the clinical team caring for the patient.

Study Status: Completed

Advance care planning
The Advance Project: initiating palliative care and advance care planning: training and resources for General Practice Nurses

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.

Translational outcomes: The toolkit was developed based on a literature review and input from our National and International advisory group. Online training modules, face-to-face training and individual role-mentoring from a specialist palliative care nurse were delivered nationally. The program was evaluated, using a mixed methods approach, to inform ongoing implementation.

Over 500 nurses in general practices across all states and territories of Australia were upskilled through the Advance Project multicomponent training program.

Feedback about the training was overwhelmingly positive, with nurses highly rating the quality and relevance of resources and training to their clinical practice and value for their patients. In addition, there was evidence from the evaluation of significant improvements in nurses’ confidence, comfort, knowledge and attitudes towards initiating conversations about advance care planning and assessing patients’ and carers’ palliative care needs. Nurses also reported positive impacts for their patients and carers following implementation of the resources in their clinical practice. At follow-up the majority of participants (>90%) indicated their intention to continue to implement the tools and skills learnt in the Advance Project training program. Some practice-level barriers to implementation of the resources in routine practice were identified, and various strategies were suggested for overcoming these barriers. Participating nurses recommended that the training should be extended to include GPs and practice managers to enable a systematic and team approach to initiating ACP and assessing and addressing patients’ and carers’ palliative and supportive care needs in general practice.

The evaluation results have informed refinements to the resources and training for general practice nurses. Further funding was received from the Commonwealth to expand the project for other clinicians working in primary care.

Study Status: Completed
### Spiritual aspects of care

**Understanding spiritual encounters and requirements of patients with an incurable, serious illness:** Implications for service provision

**Researchers:** Clare O’Callaghan, Natasha Michael, Cabrini Health; Professor Josephine Clayton, Bronwyn Raymond, Steve Calder, Dr Fiona Stafford-Bell, Julie Wilcock, Dr Sarah Thompson, HammondCare; Dovinhah Seath, Frances Bellemore, Pennelope West, St Vincent’s Hospital Sydney.

**Sites:** Greenwich Hospital; Brasside Hospital; Neringah Hospital; Northern Beaches Palliative Clinic.

**Duration:** Oct 17 to Jun 19

**Project Partner:** Cabrini Health; St Vincent’s Hospital Sydney.

**Funding Source:** Cabrini Health.

Findings are anticipated to:
1. Qualitatively how caregivers (informal) of patients with advance disease conceptualise their spirituality, religiosity, and spiritual requirements (concerns, needs) and whether they are being addressed
2. Differences in spiritual concerns and requirements across caregivers who align with different religious groups, including no religion
3. Relationships between caregivers’ spiritual wellbeing, levels of spirituality, spiritual concerns, and spiritual support received
4. Caregivers’ recommendations to health care providers for improving spiritual and religious support.

The anonymous semi-structured survey includes a validated spiritual wellbeing measure (FACT-Sp2), 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.

**Study Status:** Recruitment Completed, Analysis in Progress

### Spiritual aspects of care

**Understanding spiritual encounters and requirements of patients living with serious illnesses**

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

**Sites:** Greenwich Hospital; Brasside Hospital; Neringah Hospital; Northern Beaches Palliative Clinic.

**Duration:** Aug 17 to Jun 19

**Project Partner:** University of Sydney.

**Funding Source:** Cabrini Health Foundation.

**Study Status:** Recruitment Completed, Analysis in Progress

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 1. examine quantitative associations between spiritual well-being, level of spirituality/religiosity, spiritual concerns and spiritual/religious support given; and 2. understand qualitatively how patient conceptualise their spirituality and religiosity.

5. 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 how to connect participants with what is valued. Australia’s Palliative Care Strategy asserts that healthcare needs to address ‘spiritual requirements’ of those affected by serious illnesses.

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

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

This project examined levels of spiritual wellbeing in people with chronic pain.

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

In 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 strong sense of meaning and purpose developed depression even if they had a spinal cord injury and severe chronic pain.

The information from this study has been used to inform the development of a new program that builds resilience in people living with chronic pain by fostering a stronger sense of meaning and purpose. This program is now being delivered in the Pain Clinic with very positive results.

**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 Partner:** University of Sydney.

**Funding Source:** Australian and New Zealand College of Anaesthetists.

**Study Status:** Completed
### Teaching and professional activities

**Professor Josephine Clayton**

Josephine is Director, Centre for Learning and Research in Palliative Care and Senior Staff Specialist Physician in Palliative Medicine for HammondCare, and Professor of Palliative Care at the University of Sydney. She is Director and Chair of the National and International Advisory Groups for the Advance Project for initiating palliative care and advance care planning (ACP) in primary care settings www.theadvanceproject.com.au. This project is funded by the Australian Government and led by HammondCare in collaboration with various health organisations and universities across Australia.

In 2018, Josephine served on a number of National committees in the field of palliative care and ACP, was Scientific Committee member for the ACP International Conference, and invited to deliver the 25th annual Japanese Hospice and Palliative Care International Workshop on the topic of ACP.

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

**Professor Melanie Lovell**

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

During 2018, she was on the ANZSPM conference convening and scientific committee and continues her active participation in the Palliative Care Clinical Studies collaborative in the scientific, publications and trials management committees.

Melanie was on the Management Committee of Sydney Vital, the Northern Sydney Translational Cancer Research Centre. Melanie continued teaching students at University of Sydney palliative care and cancer pain assessment and management. She has three current PhD students with University of Technology Sydney and edited a section on symptom control of a new textbook of palliative medicine. She continues to be Chair of the National Cancer Pain assessment and management guideline.

**Professor Roderick MacLeod**

Rod is a Senior Consultant, HammondCare and Honorary Professor at the Sydney School of Medicine. He spends much of the year in New Zealand where he is a specialist in palliative medicine at Harbour 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. He is one of two Editors in Chief for a major reference work Textbook in Palliative Care published this year by Springer. Rod has also been involved in a number of research projects in aspects of palliative care and end of life care.

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### Teaching and professional activities

**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, University of New South Wales; and a Visiting Professorial Fellow with the Australian Health Services Research Institute (AHSRI), University of Wollongong.

Chris has an active teaching role in the areas of rehabilitation, reablement and restorative care, and the role of arts in health and aged care. He contributes to the University of New South Wales postgraduate and undergraduate teaching programs and has presented widely at national and international aged care and rehabilitation conferences. He is the co-convenor for a new postgraduate course, Contemporary Issues in Ageing, within the Master of Public Health degree, and also consults to government on aspects of aged care and to the private health insurance sector on contemporary rehabilitation models. During 2018, Chris assumed Executive responsibility for the Hammond College, the training and education arm of HammondCare, bringing together research, policy and education.

**Professor Philip Siddall**

As well as his role as Director of the Pain Management Service at Greenwich Hospital, HammondCare, 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 2018, he presented lectures to doctors, nurse and allied health practitioners in general practice, rehabilitation, anaesthesia and pain medicine. In 2018, Phil also served as a member of state and national professional committees in the areas of state-wide policy development, service implementation and specialist training including co-chair of the NSW Agency for Clinical Innovation Pain Management Network and the Court of Examiners for the Faculty of Pain Medicine of the Australian and New Zealand College of Anaesthetists.

**Professor Janine Stevenson**

Janine is involved in curriculum development, lecturing and supervising in the Master of Medicine (in Psychotherapy) Program and Postgraduate Program in Pain Management as well as teaching trainees in anaesthesia, pain medicine and rehabilitation. During 2018, she continued with regular teaching of medical students in Med 4 at Kensington and the Clinical Studies collaborative in the scientific, publications and trials management committees. Janine is involved in curriculum development, lecturing and supervising in the Master of Medicine (in Psychotherapy) Program and Postgraduate Program in Pain Management as well as teaching trainees in anaesthesia, pain medicine and rehabilitation. During 2018, she continued with regular teaching of medical students in Med 4 at Kensington and the Clinical Studies collaborative in the scientific, publications and trials management committees.

**Associate Professor Andrew Cole**

Andrew continues in his substantive roles with HammondCare as Senior Staff Specialist (Rehabilitation) at Greenwich Hospital and Chief Medical Officer (20 hours per week), and is a Conjoint Associate Professor at the University of New South Wales in the School of Public Health and Community Medicine. In 2018, he continued with regular teaching of medical students in Med 4 at Kensington and St George campuses. During 2018, 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, Greece and the USA. Andrew continued to serve as a member of several national and international Rehabilitation Medicine peak bodies throughout 2018. He is currently AFRM Past-President and AFRM representative on the Fellowship Committee of the Royal Australasian College of Physicians. He continues as a member of the Education and WHO Liaison Committees of the ISPRM.
**Teaching and professional activities**

**Associate Professor Colm Cunningham**
Colm is the Director of HammondCare’s Dementia Centre. He holds dual tertiary posts – as a Visiting Fellow in Dementia Design and Practice at the University of Edinburgh, School of Health in Social Science, and as a Conjoint Associate Professor at the University of New South Wales in the School of Public Health and Community Medicine. He is also a member of the Wicking Strategic Review Panel. Colm is widely published in the areas of pain management in dementia, environmental design that supports people with dementia, dementia and delirium, behavioural and psychological symptoms of dementia, dementia and intellectual disabilities and night care.

**Associate Professor Friedbert Kohler**
Friedbert is the Director of Medical Services-Hammond Health and Chair of Age and Ageing Clinical Academic Group of the Sydney Partnership for Health, Education, Research and Enterprise. Friedbert is actively involved in promoting better awareness of elder abuse and in the development of a coordinated approach to elder abuse.

Friedbert’s work has included a continued emphasis on models of care in translational change in the clinical practice arena with a focus on enhancing specialty services in acute wards and increasing community based services. His work has sought to better understand the journey of an elderly patient requiring hospital admission and in developing community services to minimise the requirement of admission into hospitals. Presentations to colleagues overseas, particularly China, have been instrumental in sharing the insights and outcomes related to this work.

**Associate Professor Stephen Macfarlane**
Stephen is the Head of Clinical Services for HammondCare’s Dementia Centre. He is active in medical student teaching at Monash University and is co-convenor of the Advanced Training Program in Aged Psychiatry for Victoria. Stephen 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 (FOPA) within the RANZCP. He remains actively involved in Alzheimer’s disease clinical trials as a site Principal Investigator.

**Dr Julie Christie**
Julie is a Region Manager UK and Europe at the Dementia Centre (UK) as well as visiting Research Fellow at the University of Edinburgh and Adjunct Lecturer, University of New South Wales. Julie’s teaching contributions this year have focused on social work research, practice and theory, co-production, the role of the Mental Health Officer in practice, and resilience in the context of dementia. This year Julie was welcomed as a member of the British Society of Gerontology, as a member of the Healthcare Design Advisory Council, and a reviewer for the Journal of Research in Nursing and the Dementia Journal. She is currently working on her book Promoting Resilience in Dementia Care: A person-centred framework for assessment and support planning, which complements her current teaching materials in this field. Julie has been involved in a number of writing projects co-authored by people with dementia, including a paper submitted for peer review on accessible design, dementia and human rights.

**Dr Meredith Gresham**
Meredith is an Occupational Therapist and Head of Research and Design for HammondCare’s Dementia Centre. She is a Designated Systems Based Investigator for the NHMRC Cognitive Decline Partnership Centre. Meredith has worked in many areas of dementia care over the last 30 years, including clinical care, family carer support, advocacy, service development and research. Meredith’s research interests span family carer education, policy and service development for people with severe behavioural and psychosocial symptoms of dementia, environmental design, the use of novel technologies in aged care and the use of clinical care guidelines. The overarching theme of her research has been embedding research outputs into practice that make tangible, positive differences in the lives of people living with dementia and their supporters.

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

Stephen is currently a member of the Aged Care Sector Committee (Quality Sub Group), responsible for shaping the direction of the Aged Care Sector Roadmap and reframing the concept of ‘quality’ in aged care. He is a member of the Advisory Council to the Aged Care Quality and Safety Commission and served on the Technical Advisory Group informing the development of the Single Aged Care Standards that are set to come into use on 1 July 2019. Stephen was also a member of the Aged Care Workforce Strategy Taskforce, which delivered its Workforce Strategy in mid-2018.

Having written and contributed to a number of books on dementia care, aged care design and the role of charities, Stephen continues to be actively involved in Government councils, consultative committees, peak industry bodies and research partnerships. He frequently attends and presents at national and international aged care, health and dementia care conferences. In 2018, this included a panel interview at the International Dementia Conference, a discussion on palliative care at the Centre for Independent Studies Consilium and a reflection on the impact of the Cognitive Decline Partnership Centre (CDPC) research at the CDPC Annual Conference.

**Kirsty holds a conjoint appointment at the University of New South Wales and sits on the Research Committee of the Sydney College of Divinity. During 2018 she prepared two chapters for the forthcoming Palliative Care Textbook (Springer). Her own 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 Master’s Degree in Positive Ageing at the Faculty of Medicine, University of New South Wales.**
2018 RESEARCH UPDATE

EDUCATION

PUBLICATIONS & PRESENTATIONS.

Education
Higher research degrees
Academic degree supervision
Awards

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

Presentations
Academic conference and industry seminars
Awards

Coale A, Australasian Faculty of Rehabilitation Medicine Past-President Medal. Awarded at the Annual Scientific Meeting of the Rehabilitation Medicine Society of Australia and New Zealand (RMSANZ) in Auckland, November 23rd 2018.

Cunningham C, Australasian Journal on ageing Book of the Year (My Home, My Life), Australasian Journal on Ageing.

Kohler F, Honorary OAM, Governor General of Australia 26 January 2018.


Education

Higher research degrees

Student name: Ms Meredith Gresham
Degree: PhD to be conferred April 2019
University: 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 Clemen and Associate Professor Lee-Fay Low

Student name: Reverend Peter Archer
Degree: PhD candidate (enrolled 2018)
University: University of Aberdeen
Thesis title: "With all your heart and with all your soul and with all your mind": In what ways does participation in creative activity intended to engage all the senses help to augment the spiritual experience of Christian worship for people experiencing advanced dementia within a high care dementia setting?
Supervisors: Professor John Swinton

Academic degree supervision


Dickson H, Kohler F, Student Name: Jim Xu, PhD, Development of an ICF Core Set for individuals following an amputation, University of New South Wales, Sydney, 8th year.

Kohler F, Dickson H, Student Name: Seema Radhakrishnan, PhD Title: Development of an International Classification of Function, Disability and Health based mobility assessment tool, University of New South Wales, Sydney, 7th year.

Luckett T, Phillips J, Lovell M, Student Name: Bronwyn Raymond, PhD Title: Self-management Strategies for Breathlessness, University of Technology Sydney.

McClean L, Stevenson J, Student Name: Clint Marlborough, PhD Title: An investigation of the musically of conversations during psychotherapy, The University of Sydney.

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

Poulos G, Faux S, Harris I, Student Name: Dr. Jane Wu, PhD Title: Early Rehabilitation in Trauma and Critical Illness, Faculty of Medicine, The University of New South Wales.

Walker R, Egan R, Ross J, MacLeod R, Student Name: Lis Latta, PhD Title: Preparing for Palliative Care: Undergraduate medical and nursing education in palliative and end of life care in New Zealand. University of Otago.

Publications

Books and chapters


Gresham M, Poulos G, Poulos R, Maurice C, Supporting independence and function in people living with dementia: A consumer information booklet; Sydney Australia; HammondCare Media, June 2018.


Publications

Books and chapters


Journal articles


Accepted December 2018.

Barnier A, Harris C, *Dementia in aged care: A systematic review.*


Publications

Industry and magazine articles


Pirello G, Cunningham C. “I can relax now, as I know he is safe”. Australian Ageing Agenda. March – April 2018. p50-51.

Technical and other reports


Presentations

Academic conference and industry seminars

Abela M, Vernon A. David’s Story: Understanding and Addressing Behaviour. 11th International Conference on Frontotemporal Dementia, Sydney Australia, 11th November 2018.

Abela M, Vernon A. Dementia Support Australia – We are here to help, 11th International Conference on Frontotemporal Dementia, Sydney Australia, 11th November 2018.


Arthurs K. The Advance Project Overview: Building capacity of primary care clinicians and general practices to provide better care through team-based initiation of ACP and palliative care. Advance Care Planning Australia Seminar, Royal Brisbane and Women’s Hospital, Brisbane Australia, 30th November 2018.
Presentations

Academic conference and industry seminars

Arthur K. Building Capability, Confidence and Fostering Partnerships in Residential Aged Care to improve End of Life Care. International Conference on Palliative Dementia Care, Belfast, Northern Ireland. 8-10 May 2019.

Arthur K. Clarke O. Caring for People in their Last Year of Life in Northern Sydney Delivering End of Life Care into Residential Aged Care homes. Palliative Care Nurses Australia Conference, Brisbane, Australia. 20-21 May 2018.

Arthur K. Building Capability, Confidence and Fostering Partnerships in Residential Aged Care to Improve End of Life Care. Palliative Care New South Wales Conference, Kiama, Australia. 8-10 November 2018.

Austin P. Siddal P. Wrigley P. Ashghari A. The psychometric evaluation of a self-report measure aiming to assess levels of central sensitivity. Australian Pain Society Annual Scientific Meeting, Adelaide, Australia, 11 April 2018. [warded best poster in meeting prize].


Beilharz K. Yurman Flourishing until death: Living well until the very end’ at Australasian Centre for Wesleyan Research Conference, September, Sydney Australia (2018).


Clayton J. Invited to design and facilitate a 2-day workshop on advance care planning for the 2019 Annual Japanese Hospice and Palliative Care International Workshop, Peace House Hospice, Japan on Feb 24 – 25, 2018 (paid travel expenses and honorarium). Only two international facilitators invited (the other facilitator was Dr Karen Detering, Medical Director of Advance Care Planning Australia).


Clayton J. Invited presentation about the Advance Project to the Commonwealth Department of Health’s National Advance Care Planning Interjurisdictional Interest Group (via teleconference), 8 May 2018.

Clayton J. Invited presentation about the Advance Project to the Commonwealth Department of Health’s National Palliative Care Interjurisdictional Interest Group (via teleconference), 30 May 2018.

Clayton J. Invited presentation at the “Advance Care Planning: can I start the conversation?” workshop, Australian Primary Health Care Nurses Association Conference, 10 May 2018.


Cole A. American Congress Rehabilitation Medicine, Dallas, USA; Sep 30 - Oct 3 2018. a. “Normal Ageing, or Disease-induced Changes?” 30.10.2018.


Presentations
Academic conference and industry seminars


Houston A, Seeing dementia through a different spectrum, Care and Dementia Environments Conference, Birmingham, March 2018, Renary.

Houston A, Cunningham C, Agent Houston Reports from the Field, HammondCare International Dementia Conference Sydney Australia 7th June 2018.


Judd S, A Good Death, The Ethics, Emotions and Economics of Palliative Care, Consilium for the Centre for Independent Studies, Byron Bay, NSW, 9-11 August 2018.

Judd S, From concept to outcomes: some thoughts on the CDPCP in retrospect, Cognitive Decline Partnership Centre Annual Conference 2018, Evidence For Change, implementing dementia care, Canberra, Australia, 16 October 2018.


Kohler F, Overview of the work of the International Society of Prosthetics and Orthotics, Asian Prosthetic and Orthotic Scientific Meeting, 7-9 November 2018, Bangkok, Thailand.


Kohler F, ISPO developments following the Introduction of the WHO Standards in prosthetics and Orthotics, ISPO Global Educators meeting, 16-20 September 2018, Göttingen, Germany.

Presentations

**Academic conference and industry seminars**

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<tr>
<th>Presenter</th>
<th>Title</th>
<th>Event</th>
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<tbody>
<tr>
<td>Marshall M</td>
<td>Designing for complexity</td>
<td>Care and Dementia Environments Conference, Birmingham</td>
<td>March 2018</td>
</tr>
<tr>
<td>Marshall M</td>
<td>Dementia Care in Australia</td>
<td>Practical Approach to Neurodegenerative Diseases Conference, Brno</td>
<td>March 2018</td>
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<tr>
<td>Marshall M</td>
<td>Importance of a timely diagnosis with a focus on collaboration</td>
<td>Practical Approach to Neurodegenerative Diseases Conference, Brno</td>
<td>March 2018</td>
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<tr>
<td>Marshall M</td>
<td>Let’s talk about toilets</td>
<td>Alzheimer Scotland Conference, Edinburgh</td>
<td>June 2018</td>
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<tr>
<td>Morris T, Daffos P</td>
<td>Using AI and smartphone technology to deliver better pain management</td>
<td>Driving Performance in Aged Care IT, Sydney</td>
<td>April 2018</td>
</tr>
<tr>
<td>Morris T</td>
<td>Barrier A, Harris C, Savage B</td>
<td>Poster Presentation: Remembering together: Evidence for distributed cognition in long-married elderly couples</td>
<td>HammondCare International Dementia Conference, Sydney Australia</td>
</tr>
<tr>
<td>Morris T</td>
<td>Using smartphones to detect pain in people with dementia</td>
<td>Australian Association of Gerontology 55th Conference</td>
<td>November 2018</td>
</tr>
<tr>
<td>Morris T, Gresham M, Alford M, Cunningham C</td>
<td>Poster Presentation: Identifying and modifying factors that lead to severe behaviours in people with dementia</td>
<td>NHMRC National Institute for Dementia Research Australian Dementia Forum, Sydney</td>
<td>April 5 June 2018</td>
</tr>
<tr>
<td>O’Connor B</td>
<td>Behavioural Changes: Supporting Quality of Life through the Tailored Activity Program (TAP) and Positive Behavioural Support</td>
<td>15th International Conference on Frontotemporal Dementias, Sydney</td>
<td>November 2018</td>
</tr>
<tr>
<td>O’Connor B, Gresham M, Pooulas R, Clemson L, McIlton K, Cameron I, Hudson W, Radosovich K, Jackman J, Pooulas C</td>
<td>How do you choose “In the age of choice”? – Dementia reablement guidelines to support function in people with mild to moderate dementia</td>
<td>International Dementia Conference, Sydney</td>
<td>July 2018</td>
</tr>
<tr>
<td>Pollock A</td>
<td>The Room Outside</td>
<td>Care and Dementia Environments Conference, Birmingham</td>
<td>March 2018</td>
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<tr>
<td>Pollock A</td>
<td>Outdoor design considerations</td>
<td>Care and Dementia Environments Conference, Birmingham</td>
<td>March 2018</td>
</tr>
<tr>
<td>Pollock R</td>
<td>DesignSmart: Products that work for people with dementia</td>
<td>Care and Dementia Environments Conference, Birmingham</td>
<td>March 2018</td>
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<tr>
<td>Pollock A</td>
<td>The Room Outside</td>
<td>University of Edinburgh, Scotland</td>
<td>March 2018</td>
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<tr>
<td>Pollock A</td>
<td>Care plans – Why going outside should be included</td>
<td>Scottish Caring and Dementia Conference, Edinburgh</td>
<td>April 2018</td>
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</tbody>
</table>

**Presentations**

**Academic conference and industry seminars**

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<th>Presenter</th>
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<tbody>
<tr>
<td>Poulos C</td>
<td>The development of reablement programs – Translational challenges</td>
<td>Cognitive Decline Partnership Centre (CDPC) Annual Conference, Canberra</td>
<td>October 15–16, 2018</td>
</tr>
<tr>
<td>Poulos C</td>
<td>Rehabilitation, Resilience Care and Reablement in Dementia – What is there to offer?</td>
<td>International Dementia Conference, Sydney Australia</td>
<td>June 7–8, 2018</td>
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<tr>
<td>Rainsford S, Glasgow N, Phillips C</td>
<td>MacLeod R, Wiles R</td>
<td>Dying in a safe place is more important than dying at home. An ethnographic study of rural patients and family caregivers. 10th World Research Congress of the European Assoc. of Palliative Care, Bern, Switzerland</td>
<td>September 2018</td>
</tr>
<tr>
<td>Rainsford S, Phillips C, Glasgow N, MacLeod R, Wiles R</td>
<td><em>This is Mum's home now</em>. Residents’ and families’ experiences on dying in rural residential aged care, 10th World Research Congress of the European Assoc. of Palliative Care, Bern, Switzerland</td>
<td>September 2018</td>
<td></td>
</tr>
<tr>
<td>Razmovski-Naumovski V, Agar M</td>
<td>Medical Cannabis Investigator Team (Lovell M)</td>
<td>Designing Medicinal Trials in Palliative Care</td>
<td>Palliative Care Clinical Studies Collaborative Annual Forum, Sydney</td>
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<tr>
<td>Siddall P</td>
<td>Opioid prescription misuse: The issues, solutions and way forward</td>
<td>NSW Agency for Clinical Innovation Forum, Sydney</td>
<td>May 2018</td>
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<tr>
<td>Siddall P</td>
<td>Pharmacological management of neuropathic pain: an update</td>
<td>Australian Pain Society Annual Scientific Meeting, Sydney</td>
<td>April 2018</td>
</tr>
<tr>
<td>Siddall P</td>
<td>Opioid safety: The NSW experience</td>
<td>Queensland Clinical Senate Symposium; Managing the Pain of Opioids, Brisbane</td>
<td>September 2018</td>
</tr>
<tr>
<td>Siddall P</td>
<td>Spiritual well-being and its relationship with pain, depression and life satisfaction</td>
<td>International Spinal Cord Society Annual Scientific Meeting, Sydney</td>
<td>April 2018</td>
</tr>
<tr>
<td>Siddall P</td>
<td>Developing new models of care for managing SCI pain</td>
<td>International Spinal Cord Society Annual Scientific Meeting, Sydney</td>
<td>September 2018</td>
</tr>
<tr>
<td>Stanciliffe R, Wiese M, Read S, Jette G, Clayton J, Barton R</td>
<td>Do no harm: Anxiety, depression and fear of death when discussing end of life with people with intellectual disability</td>
<td>Australasian Society of Intellectual Disability, Gold Coast</td>
<td>November 2018</td>
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<tr>
<td>Stevenson J</td>
<td>Healthy Ageing</td>
<td>Chickendocs Conference, Shanghai</td>
<td>China, April 2018</td>
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<tr>
<td>Stevenson J</td>
<td>Psychotherapeutic Management of Personality Disorders</td>
<td>Chickendocs Conference, Shanghai</td>
<td>China, April 2018</td>
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<tr>
<td>Stevenson J</td>
<td>Trauma, Dissociation and Personality Disorders</td>
<td>RANZCP Annual Congress, Auckland, NZ</td>
<td>May 2018</td>
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<tr>
<td>Tichawangana R, Chau S</td>
<td>Pain management in residential aged care: an overview of the Intervene Phase 2 Project</td>
<td>Australian Physiotherapy Association, North Ryde</td>
<td>23rd October 2018</td>
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</tbody>
</table>
Presentations

Academic conference and industry seminars

Service locations
Where and how we care

RESIDENTIAL CARE
Erina NSW  North Turramurra NSW
Horsley NSW  Scone NSW
Hammondville NSW  Waiwera NSW
Miranda NSW  Woy Woy NSW
Newcastle NSW  Cawthorne VIC

HEALTH
Braeside NSW  Mona Vale NSW
Greenwich NSW  Waiwera NSW

HAMMONDCARE AT HOME
Batehaven NSW  North Turramurra NSW
Bathurst NSW  Northern Rivers / Kyogle NSW
Broken Hill NSW  Nowra NSW
Cardiff NSW  Picton NSW
Coffs Harbour NSW  Port Macquarie NSW
Hammondville NSW  Scone NSW
Horsley NSW  St Leonards NSW
Lindfield NSW  St Marys NSW
Manly NSW  Waiwera NSW
Merimbula NSW  Wentworth Falls NSW
Miranda NSW  North Melbourne VIC
Narara NSW  Canberra ACT
North Gosford NSW  Brisbane QLD

RESEARCH AND EDUCATION
Braeside NSW  Hammondville NSW
Greenwich NSW  Malvern VIC

DEMENTIA SUPPORT AUSTRALIA (DSA)
Albury NSW  Cooma QLD
Broken Hill NSW  Gold Coast QLD
Coffs Harbour NSW  Sunshine Coast QLD
Dubbo NSW  Townsville QLD
Greenwich NSW  Ballarat VIC
Hammondville NSW  Bendigo VIC
Horsley NSW  Geelong VIC
Newcastle NSW  Gippsland VIC
North Gosford NSW  Malvern VIC
North Turramurra NSW  Wodonga VIC
Nowra NSW  Canberra ACT
St Leonards NSW  Devonport TAS
St Marys NSW  Hobart TAS
Tamworth NSW  Dubbo SA
Tweed Heads NSW  Wembly WA
Brisbane QLD  Darwin NT

PALLIATIVE CARE HOME SUPPORT PACKAGES
332 rural and remote towns within 7 Local Health Districts in NSW

16,557 people cared for across Australia, through our nationwide operations
Good research and collaboration go hand-in-hand.

In fact, collaboration is the driving force behind the 2018 HammondCare annual Research Report.

Professor Chris Poulos