



Research Report 2018



Welcome

It gives me great pleasure to present the 2018 HammondCare annual Research Report.

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.

Dr Annette Britton

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

A handwritten signature in black ink, appearing to read 'Annette Britton', located below the printed name and title.

Contents.

Welcome from Dr Annette Britton	1
Foreword by Professor Christopher Poulos	5

TRANSLATING RESEARCH INTO BETTER CARE

Supporting reablement for people living with dementia	8
Promoting mental wellbeing and positive ageing through the arts	10
Working in collaboration	12
Talking end of life for people with intellectual disability	13
The prevention of delirium in palliative care	14
The impact of a dementia assistance dog program	16
Rebuilding hope for people living with pain	18

RESEARCH PROJECTS

Key research areas – overview	22
Successful grant applications and statistics	24
Palliative care	28
Dementia	36
Ageing, restorative care and reablement	50
Rehabilitation	54
Pain management	56
Advance care planning	58
Spiritual aspects of care	62
Teaching and academic professional activities	64

EDUCATION, PRESENTATIONS AND PUBLICATIONS

Education – higher research degrees	70
Education – academic degree supervision	70
Education – awards	70
Publications – books and chapters	71
Publications – journal articles	72
Publications – industry and magazine articles	75
Publications – technical and other reports	76
Presentations – academic conference and industry seminars	77
HammondCare service locations map	86



Consumers play an invaluable role in the conduct of research. They help ensure that the research is meaningful to the people who might benefit . . .

Professor Christopher Poulos

Foreword.

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.



Professor Christopher Poulos

MB BS (Hons) MSc PhD FAFRM (RACP)

Head of Research and Aged Care Clinical Services, HammondCare. Conjoint Professor, University of New South Wales (School of Public Health and Community Medicine)

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

Supporting reablement for people living with dementia

The opportunity

Dementia is the greatest cause of disability in older Australians¹. 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 Dementia² 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.

¹ Australian Institute of Health and Welfare, 2012.

² Guideline Adaptation Committee. Clinical Practice Guidelines for Dementia in Australia. Clinical practice guidelines and principals of care for people with dementia. Sydney; 2016.

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



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 evaluation of the Arts on Prescription program is free to view and accessible to the public online: <https://onlinelibrary.wiley.com/doi/full/10.1111/hsc.12669>

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.

Pictured: Dr Michele Wiese

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 Jeltres 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 focus is on measuring reported carer experiences and strain, service use and physical activity. Qualitative data will be collected through journal records and follow-up interviews. In contrast to the previous projects, the Dementia Assistance Dog Program will also focus on the cost of services used by participating couples.

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, 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 with 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 Malcom and I in many practical ways. He fetches Malcom's medication and even takes Malcom'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."

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.

The Core Strength Program has now been developed and is being offered to people with chronic pain who have completed our regular Pain Program. Many people who have attended the pain clinic previously indicated interest and applied to attend future programs.

The Core Strength program has been modified in accordance with feedback, and there is interest from outside HammondCare in using a program based on similar principles with people with other disabilities such as spinal cord and brain injuries.

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 travelling 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



2018 RESEARCH UPDATE

RESEARCH PROJECTS.

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 | OVERVIEW

01



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 (PaCCSC): 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.

02



Dementia

The Dementia Centre exists to improve the lives of people living with dementia, their families 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.

03



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.

Key research areas | OVERVIEW

04



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-base supporting the development of best practice models of community-based rehabilitation for this patient group. HammondCare researchers are also working on using the International Classification of Functioning, Disability and Health in various ways, and are playing a leading role in understanding the benefits of rehabilitation in people with a diagnosis of cancer.

05



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.

06



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.

07



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 7,000 GBP to HammondCare.

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

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

Cunningham C, Poulos C, Siddall P, Lorang C, Fitzgerald A. Cognitive Decline Partnership Centre. *Intervene Stage 2 - Pain management best practice in residential aged care.* Awarded \$8,200 from December 2018 for 10 months.

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 81,706.80 GBP to the University of Edinburgh over 18 months.

Piguet O, Fisher A, O'Connor C. Charles Perkins Centre Active Ageing Research Node Seeding Grant. *Positive Behaviour Support for individuals with frontotemporal dementia: a family education program.* Awarded \$20,571 from 2018 for 12 months.

Poulos C, Gresham M, Poulos R, Radoslovich H, Hudson W, Clemson L, Cameron I. Cognitive Decline Partnership Centre. *Dementia reablement guidelines and programs (Program extension).* Awarded \$24,262 from December 2018 for 10 months.

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

Continuing grants

Andrews S, Cunningham C, Poulos C, Siddall P, Fitzgerald A, Lorang C. *Intervene Phase 2 – Best practice pain management in residential aged care.* NHMRC Cognitive Decline Partnership Centre (CDPC). Awarded \$650,102 from 2016 – 2018.

Butow P, Andrew G, Girgis A, Kelly B, Hack T, Clayton J, Price M, Beale P, Viney R, Kirsten L. Cancer Institute NSW Translational Program Grant. *A sustainable and supported clinical pathway for managing anxiety and depression in cancer patients: developing and evaluating components and testing implementation strategies.* Awarded \$3,643,992 from July 2015 for 5 years (Year 1 \$730,264; Year 2 \$717,465; Year 3 \$724,127; Year 4 \$745,737; Year 5 \$726,398).

Christie J, Thompson-Bradley O. *Dementia Dog Program evaluation.* Funded by charitable donations to HammondCare until 2020.

Clayton J, Cunningham C. Palliative Care Australia. *Development of a resource to support people living with dementia to participate in decision-making about their end of life care.* Awarded \$110,000 from Nov 2017 to end June 2018.

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

Lovell M, Phillips J, Agar M, Boyle F, Davidson P, Lockett T, Currow D, Ryan L, McCaffery N, Shaw T. National Breast Cancer Foundation Grant. *Implementing a national clinical pathway for pain to ensure equitable, cost-effective, evidence-based, person-centred care for people with advanced breast and other cancers.* Awarded from NBCF \$939,139 Year 1: \$218,501 Year 2: \$242,694 Year 3: \$238,051 Year 4: \$239,893 from 2014-2018.

Phillips J, Shaw T, Lovell M, Davidson P, Boyle F, Lam L, McCaffery N. Cancer Australia. *Improving Patient Reported pain Outcomes through Health Practitioner Training (I-PROMPT): A phase 3 wait-listed randomised control trial.* Awarded \$342,483 from 2017 to 2019.

Poulos C, Gresham M, Poulos R, Radoslovich H, Hudson W, Clemson L, Cameron I. Cognitive Decline Partnership Centre. *Dementia reablement guidelines and programs* Awarded \$246,337 from 2017 to 2018.

Stancliffe R, Wiese M, Clayton J, Jeltse G, Tieman J. Australian Government, Department of Health National Palliative Care Project. *An online toolkit for carers and practitioners helping people with intellectual disability understand dying and death.* Awarded \$70,643 from April 2017 to end April 2018.

Statistics.

JANUARY 2018 TO DECEMBER 2018

Research projects

69

- 16 Palliative care
- 26 Dementia
- 9 Ageing, restorative care and reablement
- 4 Rehabilitation
- 4 Pain management
- 7 Advance care planning
- 3 Spiritual aspects of care

Publications

98

- 24 Book and chapters
- 50 Journal articles
- 10 Industry and magazine articles
- 14 Technical and other reports

Education, grants and awards

153

- 8 Successful grant applications
- 4 Awards
- 2 Higher research degrees
- 9 Academic degree supervisions
- 121 Academic conferences and industry seminars
- 9 Grants with continuing funding in 2019

Palliative care

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



Researchers: Professor Josephine Clayton, Professor Chris Poulos, Dr Cindy Kok, Alison Ritchie, Dr Jessica Borbasi, Tim Dixon, Kelly Arthurs, Associate Professor Colm Cunningham, HammondCare; Professor Allison Tong, University of Sydney



Sites: Various HammondCare Residential sites



Duration: Nov 18 to Dec 19



Project Partners: University of Sydney



Funding Source: Internally funded

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

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

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

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

Study Status: In Progress

Palliative care

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



Researchers: Nathan MacArthur, HammondCare; Alex Broom; Emma Kirby; Jane Mowl



Sites: All HammondCare sites



Duration: Apr 18 to Mar 20



Project Partner: University of New South Wales



Funding Source: In the Researcher's Own Time; HammondCare In-Kind Support. The researcher received a scholarship from the HammondCare Centre for Learning and Research

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

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

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

Study Status: In Progress

Cancer pain assessment study | New in 2018



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



Sites: All HammondCare palliative care services



Duration: 2017 to 2019



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



Funding Source: Cancer Australia

This study 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.

Study Status: In Progress

The experience of refractory breathlessness on everyday life



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



Site: Greenwich Hospital



Duration: May 17 to May 18



Project Partner: University of Sydney



Funding Source: Research undertaken as part of a Masters of Occupational Therapy degree

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.

Study Status: Completed

Palliative care

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



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



Site: Braeside Hospital



Duration: Oct 17 to Dec 20



Project Partner: University of Technology Sydney



Funding Source: Cancer Australia

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

Delirium causes additional medical complications, excess mortality, high levels of patient and caregiver distress, and significant increases in health care costs. Delirium adversely affects cognition, awareness and communication ability at a critical time when being mentally aware and interacting with loved ones is crucial for quality of life.

The aim of the investigator-initiated, cooperative group trial is to determine the effectiveness of melatonin in preventing delirium (number of delirium free days during hospital admission achieved by reducing overall delirium occurrence, or reducing duration and severity of delirium if it occurs). Oral melatonin prolonged release (2mg) or placebo is taken at 2000 hours. Intervention will be commenced within 48 hours of admission and continued until any of the following: delirium occurrence, discharge, or for a maximum of 21 days if patient remains in hospital as in most cases any acute medical issues imparting a delirium risk have been resolved (e.g. while awaiting long-term care placement). Intention-to-treat analysis will be used for all statistical comparisons.

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

Study Status: In Progress

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



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



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

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.

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



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 (DIICCSRTE)

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 10 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 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.

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



Researchers: Professor David Currow, Flinders University; Professor Melanie Lovell, Dr Bridget Johnson, Dr Anthoulla Mohamudally, HammondCare



Site: Greenwich Hospital



Duration: Jul 16 to Jun 18. Closed at HammondCare but continuing at other sites



Project Partners: Flinders University; Palliative Care Clinical Studies Collaborative



Funding Source: National Health and Medical Research Council

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.

Study Status: Closed

Rapid report of pharmacovigilance program



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



Sites: Braeside Hospital and Greenwich Hospital



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



Project Partner: PaCCSC



Funding Source: Nil

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

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

During 2018 the series examining deprescribing Targin for pain was completed. This program provides data to an international study looking at benefits and adverse effects of medications for specific symptoms used daily in our HammondCare facilities. This feedback improves medication use.

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, mirtazepine for anorexia, and cyclizine 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.

Study Status: In Progress

Palliative care

Palliative care rapid response team: a hospital avoidance and enhanced care approach



Researchers: Robyn Keall, Professor Melanie Lovell, HammondCare



Sites: All HammondCare palliative care services



Duration: Jul 2017 to Jun 2018



Project Partners: Nil



Funding Source: Agency for Clinical Innovation

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

The Palliative Care Rapid Response Team (RRT) covered 7 days a week and utilised an enhanced, After Hours' telephone support line to provide 24/7 coverage which included visits from a palliative care nurse if needed and phone calls by a palliative care nurse (compared with a nurse manager in our usual model).

The RRT enabled:

1. Urgent admission to the service for patients who wish to be discharged from an acute hospital for end-of-life care, thereby reducing bed block
2. Assessment of patients who are reaching the terminal phase of their life from a predicted cause who wish to die at home, providing increased support to carers
3. Those who require out of business hours admission to a Palliative Care Unit but have deteriorated suddenly and wish to avoid acute hospital admission.

Translational outcomes: The enhanced service resulted in an increase in phone calls, an increase in weekend admissions to the palliative care unit and a reduction in acute hospital and emergency department admissions. It resulted in reduced health care costs. This has now been translated to practice and palliative care nurses are now taking after hours calls in the evenings and during the day on weekends rather than the nurse managers.

Study Status: Completed

The PRESERVE pilot study



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



Site: Greenwich Hospital



Duration: Jul 17 to Jun 18



Project Partner: University of Technology Sydney



Funding Source: National Breast Cancer Foundation

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 ACSQHC Delirium Clinical Care Standard (to be instituted for all Australian hospitals in January 2019), because the screening, diagnostic assessment and prevention strategies align with the Delirium Standard.

Study Status: Completed

Palliative care

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



Researchers: Dr Hilary Stiel; Professor Josephine Clayton, Dr Ben Forster, Dr Srivalli Nagarajan, HammondCare



Site: Off-site research



Duration: Aug 15 to Jun 18



Project Partners: Nil



Funding Source: Internally Supported

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.

Study Status: Completed

Stop cancer PAIN



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



Site: Off-site research



Duration: Nov 14 to Oct 19



Project Partners: University of Technology Sydney; University of Sydney



Funding Source: National Breast Cancer Foundation

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

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.

Study Status: In Progress

Palliative care

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



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



Site: Off-site research



Duration: Jun 15 to Jun 20



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



Funding Source: Cancer Institute New South Wales and funds administered by University of Sydney

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 control trial (RCT) and pre-post study.

An online portal has been created to operationalise the pathway, and has been piloted at a cancer service in Sydney.

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 980 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.

Study Status: In Progress

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



Researchers: Professor Roderick MacLeod, HammondCare; Jane Mowl, University of Notre Dame Australia (Sydney); Professor Liz Lobb, Christine Sanderson, Calvary Health Care Kogarah; Johan Dufloy, Department of Forensic Medicine



Sites: Greenwich Hospital and Neringah Hospital



Duration: Dec 15 to Aug 18



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



Funding Source: University Of Notre Dame, Australia

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.

Study Status: Completed

Palliative care

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



Researchers: Katherine Kelly; Kerry Gilsean, HammondCare



Site: Braeside Hospital



Duration: Jul 15 to Jun 18



Project Partners: Nil



Funding Source: Internally Supported

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

The data collection has been completed for both stages of the process. There is a set of agreed consensus statements for the role of speech-language pathologists in palliative care that have been endorsed. There are three separate manuscripts being drafted at present to report on all stages of the data collection. The plan is to submit them to the International Journal of Speech-Language Pathology for publication.

The research team was accepted to present on the consensus statements (the last piece of data collection) at the Speech Pathology Australia Annual Conference in Adelaide in May 2018.

Study Status: Data Collection Complete, Data Analysis in Progress

Dementia

TAURIEL trial - A phase 2, multicentre, randomised, double-blind, placebo-controlled, parallel-group, efficacy and safety study of MTAU9937A 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: May 18 to Dec 21



Project Partners: Bracket Global, Covance, Medidata



Funding Source: Genetech Inc.

Alzheimer's disease (AD) is the most common cause of dementia, affecting an estimated 4.5 million individuals in the United States and 26.6 million worldwide.

The disease is characterised pathologically by the accumulation in the brain of miss-folded proteins, namely β -amyloid (A β) plaques (outside the cell) and tangles (made up of a protein known as tau) inside the cell. In fact, the presence of these proteins are the hallmark findings in AD, first reported by Alois Alzheimer in 1906. It has been found that the distribution of misfolded tau proteins in AD patients correlates with a decline in cognition. It is believed that pieces of tau-tangles (within cells) exit the cell and spread to the rest of the brain. Therapies that reduce the spread of tau in the brain may alleviate cognitive dysfunction and block further neuronal cell death.

MTAU9937A is a tau monoclonal antibody that selectively binds to tau around the brain in order to stop or slow cell-to-cell spread and propagation of tau toxicities.

This trial is currently being conducted at over 40 sites globally and will run for 24 months.

Study Status: Closed to Recruitment

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: Hoffmann La Roche

It is well recognised that in comparison to other disease states, there is a real unmet medical need in finding a product to decrease the rate of decline of Alzheimer's disease (AD).

To date, only five medications have received marketing approval to treat the symptoms of AD and these only temporarily improve some clinical symptoms of AD in some patients but do not modify progression of the disease. Recent efforts have mostly focused on therapies targeting amyloid as these offer a compelling therapeutic targets. These therapies are based on the amyloid hypothesis that suggests that accumulation in the brain of a misfolded protein (called amyloid-b) is the cause of the condition. This accumulation in the brain begins well before the development of any signs and symptoms of dementia and are thought to cause a series of events within the brain such as inflammation and neurodegeneration. For these reasons, treatments that prevent, slow, or decrease the accumulation of brain amyloid-b are being tested as therapeutic agents in AD.

There is evidence to suggest that monoclonal amyloid-b antibodies may be able to remove and reduce the amount of the misfolded proteins in the brain. Consequently, therapies targeting this process have the potential to significantly alter the progression of the disease.

Gantenerumab, a fully human monoclonal antibody targeting all the different types of misfolded amyloid-b proteins is proposed to address this need.

This trial is currently being conducted at over 194 sites globally and will run for 24 months.

Study Status: In Progress

Dementia Assistance Dog Program Evaluation | New in 2018



Researchers: Dr Julie Christie, Oonagh Thompson-Bradley, HammondCare



Site: NA



Duration: Jun 18 to Apr 20



Project Partners: Nil



Funding Source: Life Changes Trust

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 HMP 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.

Study Status: In Progress

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 Kornhauser; 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

Associate Professor Macfarlane's study team has been involved in testing the ANAVEX2-73 molecule since 2014 and were heavily involved in writing and editing the previous phase 2a, and current phase 2b/3, protocols. ANAVEX2-73 is a novel compound that is thought to act on the sigma 1 intracellular receptor.

Its mode of action is unique in that most (if not all) other molecules developed thus far to treat Alzheimer's Disease target the removal of a single type of toxic protein (either beta amyloid or Tau). In contrast, ANAVEX2-73 is thought to remove all forms of misfolded proteins from brain cells.

While involved 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.

Study Status: In Progress

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

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?

Study Status: Completed

Dementia

Access to outdoors as a contributory factor in behavioural changes of people living with dementia in Australian residential aged care homes | New in 2018



Researchers: Juliet Kelly, HammondCare



Site: Pallister House



Duration: Feb 18 to Aug 18



Project Partners: Nil



Funding Source: In the researcher's own time with HammondCare In-Kind Support

This project developed knowledge and understanding about the issues affecting access to outdoors for people living in residential aged care. In supporting the achievement of this basic human right, HammondCare will be improving quality of life for people living with dementia in residential aged care (RAC).

This study arises from the researcher's experience that access to the outdoors for people living with dementia in Australian residential aged care homes is limited, despite evidence of innumerable benefits to health and wellbeing and reducing the experience of behavioural and psychological symptoms of dementia.

In particular, it aimed to explore the existing client data of a behaviour support service about access to the outdoors in order to understand the circumstances of limited access to the outdoors for people with dementia in residential aged care homes who are experiencing behavioural and psychological symptoms of dementia.

Client demographic data and reports by Dementia Consultants working in the behaviour support service were extracted where the Dementia Consultant had identified access to outdoors as a contributory factor to behavioural and psychological symptoms of dementia experienced by the client. This data represented client case studies. Qualitative thematic analysis of the reports was used to identify themes and subthemes.

39 client reports written by Dementia Consultants working in the behaviour support service and the corresponding demographic data were examined. The themes identified relating to access to outdoors included person with dementia themes with subthemes of home, work, interest or hobby and substance use; care home and staff themes with subthemes including organisational and operational, benefits of outdoors are unknown, building design and understanding rights, risks and restraint. A thematic diagram was created to illustrate the relation between these themes and discussed in relation to the literature in relation to access to the outdoors.

The thematic analysis of the Dementia Consultant reports demonstrated that the individual needs of the person living with dementia in relation to access to the outdoors are frequently overlooked by care home staff. Further research to understand how access to the outdoors can be enabled and the impact for people with dementia living in residential aged care homes is required in order to influence building standards and improve care practices.

Study Status: Completed

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 (RACHs).

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 care 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.

Study Status: Completed

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 20



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.

Study Status: In Progress

Guided by Excellence | New in 2018



Researchers: Professor Susan Kurrle, University of Sydney; Associate Professor Colm 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 75% complete and interviews are commencing nationally to capture a spread of geographic locations and service user types.

Study Status: In Progress

Dementia

Evaluation of HammondCare Caulfield | New in 2018



Researchers: Dr Meredith Gresham, Dr Cindy Kok, Dr Tom Morris, Sabrina Chao, 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 partake 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

Dementia

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. Hoped-for 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

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

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' program 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



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



Site: Malvern HammondCare Office



Duration: Aug 17 to Aug 20



Project Partner: Neurodegenerative Disorders Research Pty Ltd



Funding Source: Eisai Inc

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 (ISLT). An open-label Extension Phase will be available for subjects who complete the full 24 months of treatment in the Core study.

The Extension Phase will continue until commercial availability of elenbecestat (E2609), or until a positive risk-benefit assessment in this indication is not demonstrated. Full details of the Extension Phase will be available in a future protocol amendment. A total of 1330 subjects will be randomised, in a double-blind manner, to receive either placebo or elenbecestat (E2609) 50mg per day (approximately 1:1 randomisation ratio) for 24 months. Randomisation will be stratified according to region, clinical dementia staging with no more than approximately 25% of the randomised subjects diagnosed with the early stages of mild dementia due to AD, and concurrent AD medication use.

The study is designed to have more frequent visits focused on safety assessments during the first three months of treatment. Two longitudinal biomarker substudies will evaluate the effects of study treatment on the underlying pathophysiology of AD using amyloidPET and/or CSF biomarkers. Participation in the sub-study is optional and will require specific consent that will not affect enrolment or treatment in the main study.

Study Status: In Progress

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



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



Sites: Various HammondCare At Home offices and HammondGrove Independent Living Units



Duration: Sept 17 to Jun 18



Project Partner: Cognitive Decline Partnership Centre - Griffith University



Funding Source: NHMRC Cognitive Decline Partnership Centre

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



Researchers: Dr Meredith Gresham, HammondCare; Professor Lindy Clemson, Associate Professor Lee-Fay Low, University of Sydney



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



Duration: Jun 11 to Sep 18



Project Partner: University of Sydney



Funding Source: Australian Unity Heritage fellowship; HammondCare in kind and self funded PhD

This study aimed to examine the acceptance of bidets in dementia specific care for residents and staff; the ability of the bidet to clean and dry after voiding; the effects on management of incontinence and cost of continence pads. Eight bidets were installed and data collected on 14 residents.

Inability to use a toilet independently has negative outcomes for older people, including being a primary risk factor for admission to residential care. For 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 toilet episodes. There was a significant reduction in workload associated with toileting for staff. Resident 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



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



Sites: HammondCare Woy Woy and Caulfield



Duration: Jan 17 to Oct 18



Project Partner: Griffith University



Funding Source: Cognitive Decline Partnership Centre

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

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

Study Status: Completed

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.

Study Status: Completed

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.

Study Status: In Progress

Dementia

Dementia in the public domain



Researchers: Professor Simon Biggs, Professor Shelley Mallett, 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.

Study Status: Completed

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



Researchers: Peter Roach, Professor Melanie Lovell, 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

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

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

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

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

Study Status: In Progress

Dementia

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

We will conduct implementation research to integrate an evidence-based intervention, Care of Older Persons with Dementia in their Environments (COPE), within existing health systems in Australia and determine strategies for implementation and sustainability to enable wider dissemination.

COPE is a bio-behavioural program designed to improve function and has proven effective in reducing dependency and increasing engagement of the person with dementia and in improving carer wellbeing in a randomised trial in the US.

The program works at a very practical level using occupational therapy skills (e.g. problem solving issues such as poor toilet habits that result in stress and limited outings, environmental adaptations to facilitate safe behaviours and activity engagement, and joint problem solving with the carer to identify solutions and strategies) and complimentary nursing skills (e.g. educating carers concerning taking care of themselves and ways to manage incontinence, medication management, and hydration) and centres around the needs of both the carer and the person with dementia.

This project will translate COPE to the Australian context within not-for-profit, private and government care systems. We will examine facilitators and barriers at therapist, organisation and policy levels, explore funding models and build in features of sustainability. Outcomes of interest include dosage and feasibility, treatment fidelity to key features, acceptability of intervention to stakeholders, therapists and participants, engagement of champions, knowledge acquisition of staff providing the intervention, and cost utilisation. We shall employ a process evaluation using interviews, focus groups and observation.

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 Meredith Gresham, Associate Professor Colm Cunningham, HammondCare



Sites: HammondCare Erina and Woy Woy



Duration: May 14 to Jun 18



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



Funding Source: Cognitive Decline Partnership Centre

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.

Study Status: Completed

Dementia

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 Auret, 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 Meera Agar, University of Technology Sydney; Helen Radoslovich, 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

This project brought together a multidisciplinary team of clinicians, consumer representatives and researchers to examine supported decision-making as a means of promoting participation in healthcare decisions among people living with dementia.

Supported decision-making aims to assist people with cognitive impairment to maintain involvement in decision-making, typically through provision of a 'support person' (or persons).

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

This project investigated community perceptions towards supported decision-making in the context of cognitive impairment. People living with dementia, family and caregivers of people living with dementia and key health provider groups were interviewed and surveyed, to assess community perceptions and identify barriers to implementation.

Working groups of clinicians, consumers and policy-makers in each state met to discuss the research data, identify areas of current best practice, and establish strategies for broader implementation in each state. The researchers also studied existing laws, court cases and tribunal hearings across three Australian states (New South Wales, Western Australia and South Australia), to identify areas for future law reform.

Based on study findings, the investigators developed educational materials and practical resources to assist community members and healthcare providers to support decision-making among people with cognitive impairment.

Translational outcomes: During 2018, the research team focused on translating the findings from their analysis of legislation, policy and interviews with people living with dementia, family and carers, health and legal professionals. A number of peer reviewed publications have been submitted and three of these are now published. In addition a range of resources have been produced for professionals and the community.

A series of short videos explain the importance of supported decision-making from the perspective of people living with dementia and their family members. A guidebook for community members explains some of the tips and strategies shared by people living with dementia and family carers.

A policy guideline document explains the steps that aged care providers can take to reframe their policies to facilitate supported decision-making. These policy guidelines are cited by the Australian Aged Care Quality and Safety Commission in relation to the incoming accreditation standards for aged care providers (Standards 1 and 2).

A half-day training package for aged care providers has been developed and piloted, and is now being rolled out more broadly, in partnership with the NSW Public Guardian. The researchers are continuing to publish further work arising from the research, as well as presenting at a number of conferences during 2019.

Study Status: Completed

Dementia

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



Researchers: Professor Simon Biggs, Melbourne University Designated System Based Investigators; Angela Raguz, Dr Meredith Gresham, Rebecca Forbes, Dr Catriona Lorang, HammondCare



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



Duration: Feb 14 to Jun 18



Project Partners: Nil



Funding Source: Cognitive Decline Partnership Centre

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 regulations that facilitate 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 front line aged care staff and consumers. The team reviewed the qualitative data from the interviews and survey, identifying the framework of regulation and compliance.

Study Status: Completed

Ageing, restorative care & reablement

HammondCare Darlinghurst Research Project | New in 2018



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



Site: HammondCare Darlinghurst



Duration: Oct 18 to Jun 19



Project Partners: University of New South Wales and St Vincents Health Australia



Funding Source: Perpetual IMPACT Philanthropy

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 in to 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.

Study Status: In Progress

Ageing, restorative care & reablement

Impact of influenza in aged care facilities | New in 2018



Researchers: Professor Raina McIntyre, University of New South Wales; Professor Chris Poulos, HammondCare; Dr Abrar Chughtai; Professor William Rawlinson; Aye Moa; Auryisia Hii



Sites: HammondCare Hammondville, Miranda, Wahroonga, Turramurra



Duration: Jan 18 to Dec 19



Project Partners: University of New South Wales (Sydney); South Eastern Area Laboratory Services; Australian National University; NHMRC Centre for Research Excellence; Integrated Systems for Epidemic Response



Funding Source: Sanofi Pasteur

Each year, the flu causes serious infection, which can lead to substantial illness and death, particularly in the elderly. This study will measure the vaccine effectiveness of the standard flu vaccine (in 2017) and the new high dose flu vaccine being introduced for residents and staff aged over 65 years in 2018 in aged care facilities.

The aim of this study is to observationally evaluate the effectiveness of the high dose vaccine compared to the standard dose by comparing the influenza attack rate in 2017, 2018 and 2019 in residential aged care settings.

Study Status: In Progress

Resource Utilisation Classification Study (RUCS) - Study 3 | New in 2018



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



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



Duration: Oct 18 to Dec 18



Project Partner: University of Wollongong



Funding Source: Australian Health Research Institute

HammondCare was a participant in the RUCS Study 3, which aimed to describe the range of care needs for residents in aged care homes across Australia using the newly developed classification system. It involved external assessors conducting resident assessments in a nationally representative sample of 80 care homes.

The findings from the study will be released by the University of Wollongong in early 2019.

Study Status: Completed

Arts on Prescription evaluation



Researchers: Associate Professor Roslyn Poulos, Ms Sally Marwood, University of New South Wales; Associate Professor Andrew Cole, HammondCare; Dr Simon Opher, Professor Stephen Clift, Canterbury Christ Church University



Sites: South Western Sydney and Northern Sydney



Duration: Aug 15 to Feb 18



Project Partner: University of New South Wales



Funding Source: Australian government Department of Social Services

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

The project concluded in 2017 with the evaluation occurring during 2018.

Translational outcomes: Project findings were published in the International Journal, Health and Social Care in the Community, and has been made available in open access format.

HammondCare continues to provide Arts on Prescription programs under various funding models.

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 stay interviews with patients. 14 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, and 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 is 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 Roslyn Poulos, University of New South Wales; Helen Radoslovich, Helping Hand; Wendy Hudson, Brightwater Group; Professor Lindy Clemson, University of Sydney; Associate Professor Kathy McGilton, 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; Brightwater 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 review the literature for additional 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

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



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



Duration: Apr 16 to Feb 18



Project Partners: Nil



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

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

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

This study 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 how to maximise use of aged care support.

Study Status: Completed

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



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



Site: Hammondville



Duration: Apr 16 to Mar 18



Project Partners: Nil



Funding Source: National Institute of Health Research (England)

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

The purpose of this study 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 governments of England and Australia.

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

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

Study Status: Completed

Ageing, restorative care & reablement

Arts on Prescription @ Home



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



Sites: HammondCare At Home South West Sydney and South East Sydney



Duration: Feb 16 to Jun 18



Project Partners: University of New South Wales and Queensland University of Technology



Funding Source: Dementia Collaborative Research Centres-Consumers and Carers (Queensland University of Technology)

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.

Study Status: Completed

Rehabilitation

Assessment of EVOLVE criteria for quality use of medicines in older rehabilitation patients | New in 2018



Researchers: Dr Kathryn Sutton, Royal North Shore Hospital



Site: Greenwich Hospital



Duration: Apr 18 to Oct 18



Project Partners: Royal North Shore Hospital



Funding Source: Nil

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 comorbidities 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.

Study Status: In Progress (Data Analysis And Writing Up)

Rehabilitation

ACTiveARM: Australian Constraint Therapy Implementation study of the ARM



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



Site: Braeside Hospital



Duration: Mar 17 to Dec 19



Project Partners: SWSLHD; University of Sydney



Funding Source: Internally supported

Background: Constraint Induced Movement Therapy (CIMT) is an effective intervention for upper limb recovery following stroke and traumatic brain injury (TBI) that produces significant improvements in upper limb function compared to usual therapy, after only 2 weeks (Kwakkel, Veerbeek, van Wegen and Wolf, 2015).

Despite this strong evidence, there is a gap between CIMT research and practice (Fleet et al., 2014; Viana and Teasell, 2012). Lack of therapist knowledge of CIMT has been identified as one key barrier – one that is amenable to change with training.

We aim to establish whether a 2-week publicly funded CIMT program can be translated into practice and sustained over two years across multiple health services in SWSLHD. Key research questions are:

1. Do rehabilitation teams deliver more CIMT programs after receiving a CIMT implementation package?
2. Do stroke and brain injury survivors that complete a CIMT program achieve upper limb outcomes consistent with published outcomes?

Study Status: In Progress

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



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



Site: Braeside Hospital



Duration: Dec 12 to Jun 17



Project Partners: Multiple



Funding Source: Otto Bock Healthcare Products and Ossur

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

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

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

The paper is being resubmitted following review and awaiting publication.

Study Status: Completed

FIM item redundancy



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



Site: Braeside Hospital



Duration: Jan 16 to Jun 18



Project Partners: Nil



Funding Source: In researchers' own time

The FIM is a commonly used assessment tool to assess functional status of patients in the rehabilitation setting.

Out of the total 18 functional items measured in the FIM, there are three items to measure transfer functions. It is proposed, based on results from a previous study, that there is a high correlation between the three transfer items.

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

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.

A theoretical model decreasing the transfer items from three to one does not significantly change the internal consistency of the FIM.

Study Status: Completed

Pain management

Evaluation of the core strength program | New in 2018



Researchers: Professor Phil Siddall, Skye Dong, Rebecca McCabe, HammondCare; Jessie Dezutter, 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

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 state-wide meeting in November 2014. The results are crucial in validating our program.

During 2016 the researchers evaluated outcomes from over 100 people who completed the pain program. The results match or exceed results from other pain clinics including a reduction in pain of over 30%. An unexpected but interesting finding was that one of the best predictors of a reduction in pain during the program was the person's level of spiritual wellbeing.

This project 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

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 and pain. The results to date show that the level of existential and spiritual distress in people with pain is significantly higher than people without pain and as high as 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

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

Advance care planning

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



Researchers: Dr Karen Detering, University of Melbourne; Veronica Mera, Rodney Berg, Kat Comito, Kim Buck, HammondCare

Sites: Braeside, Greenwich, Neringah Hospital

Duration: Oct 18 to Dec 18

Project Partner: Austin Health

Funding Source: In-kind support

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.

Study Status: In Progress

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



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

Site: National Project with base at Greenwich Hospital

Duration: Aug 17 to Jun 20

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

Funding Source: Australian Government, Department of Health

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.

The new toolkit was officially recognised as an accepted clinical resource by the Royal Australian College of General Practitioners and endorsed by the Australian Primary Health Care Nurses Association. A comprehensive interactive, self-directed eLearning module for General Practitioners was developed to enable General Practitioners to initiate advance care planning and palliative care. The learning module was accredited by the Royal Australasian College of General Practitioners and the Australian College of Rural and Remote Medicine. Learning modules were also developed for general practice managers to enable them to support GPs and general practice nurses to implement the resources in general practice. The resources and learning modules are available from the new website for the project www.theadvanceproject.com.au

Study Status: In Progress

Advance care planning

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



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

Site: National project

Duration: Apr 17 to Jun 18

Project Partners: University of Sydney, Western Sydney University, Flinders University (CareSearch), Unison Disability

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

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 every day contexts. TEL is available at <https://www.caresearch.com.au/TEL/>

Study Status: Completed

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



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

Site: Greenwich Hospital

Duration: Nov 17 to Jun 18

Project Partners: Palliative Care Australia; Dementia Australia

Funding Source: Palliative Care Australia

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 adapted the Aboriginal and Torres Strait Islander Discussion Starter, previously developed by Palliative Care Australia, to meet the specific needs of people living with mild to moderate dementia.

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 are supporting people living with dementia to discuss their end of life wishes.

Study Status: Completed

Advance care planning

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



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



Sites: National



Duration: Jan 17 to Jun 20



Project Partner: Advance Care Planning Australia



Funding Source: Australian government national palliative care project (as part of funding for Advance Care Planning Australia)

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

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



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



Site: Greenwich Hospital



Duration: Jul 13 to Jun 18



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



Funding Source: Funded by NHMRC administered by USyd

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 (97% in the intervention group versus 96% 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



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



Site: National Project with base at Greenwich Hospital



Duration: Feb 16 to Dec 17



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



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

One of the biggest barriers to providing palliative care (PC) and implementing advance care planning (ACP) in primary care settings is general practitioners' time.

We developed a toolkit and multi-component training resource to enable nurses working in general practice to: efficiently and sensitively promote awareness of ACP using screening; identify patients who may benefit from a palliative approach; assess symptoms; and help patients to identify their most important questions and concerns regarding ACP/PC. This will enable GPs to address these issues more efficiently. Further, the tools will help identify patients who might most benefit from referral to specialist PC services.

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 tele-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 (79%) 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 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; Braeside Hospital; Neringah Hospital; Northern Beaches Palliative Clinic



Duration: Aug 17 to Jun 19



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



Funding Source: Cabrini Health Foundation

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; 3. explore qualitatively patients views about advancing spiritual care.

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

Findings are anticipated to:

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.

Study Status: Recruitment Completed, Analysis in Progress

Levels and associations of existential distress in people with persistent pain



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



Site: Greenwich Hospital



Duration: May 13 to Jun 18



Project Partner: University of Sydney



Funding Source: Australian and New Zealand College of Anaesthetists

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.

Study Status: Completed

Spiritual aspects of care

Understanding spiritual encounters and requirements of caregivers 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; Davinia Seah, Frances Bellemore, Penelope West, St Vincent's Hospital Sydney



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



Duration: Oct 17 to Jun 19



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



Funding Source: Cabrini Health

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

Scant information exists on how caregivers of people living with advanced illnesses conceptualise spirituality and their related requirements. Finding meaning and religiosity can support coping with adversity.

This is a mixed methods study utilising a cross-sectional survey to examine

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-Sp12), researcher devised spiritual concerns lists, selected questions from another study (Balboni, JAMA, 2013) to examine pre-post diagnosis religious behaviours and spiritual support received, and other study specific open-ended questions. Australia's Palliative Care Strategy asserts that healthcare needs to address 'spiritual requirements' of those affected by serious illnesses.

Findings are anticipated to:

1. Provide insight into spiritual concerns amongst caregivers' of 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. This is a multisite study, also including Cabrini Health and St Vincent's Hospital Sydney.

Study Status: Recruitment Completed, Analysis in Progress

Teaching and professional activities

Director of Centre for Learning and Research in Palliative Care

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.

Medical Director of the Greenwich Palliative Care Services

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 committees 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.

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

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.

Teaching and professional activities

Head of Research and Aged Care Clinical Services for HammondCare

Professor Christopher Poulos

Chris is Head of Research and Aged Care Clinical Services for HammondCare. He is also a Conjoint Professor in the School of Public Health and Community Medicine, Faculty of Medicine, 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. He 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.

Director of the Pain Management Service and Director of Medical Services

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.

Director Aged Care Psychiatry

Professor Janine Stevenson

Janine is involved in curriculum development, lecturing and supervising in the Master of Medicine (in Psychotherapy) Program for Sydney University. She also leads tutorials and lectures for medical students, and post-grad students at the BMRI and HETI, as well as involvement in examining both medical students and registrars. She is on the RANZCP committee for examinations and CSIMGE and lectures internationally as well as supervising psychiatrists in China via Skype.

Senior Staff Specialist - Rehabilitation and Chief Medical Officer

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

Director of The Dementia Centre

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 is a Conjoint Associate Professor at the University of New South Wales in the School of Public Health and Community Medicine. He is also a member of the Wicking Strategic Review Panel. Colm is widely published in the areas of pain management in dementia, environmental design that supports people with dementia, dementia and delirium, behavioural and psychological symptoms of dementia, dementia and intellectual disabilities and night care.

President of the International Society for Prosthetics and Orthotics

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.

Co-convenor of the Advanced Training Program in Aged Psychiatry

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 (FPOA) within the RANZCP. He remains actively involved in Alzheimer's disease clinical trials as a site Principal Investigator.

Music Engagement and Positive Ageing

Dr Kirsty Beilharz

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.

Teaching and professional activities

Co-founder of the Dementia PhD forum

Dr Julie Christie

Julie is a Region Manager UK and Europe at the Dementia Centre (UK) as well as a 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, for the Society of British and International Design, and as 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.

Head of Research and Design HammondCare

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.

Chief Executive HammondCare

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.

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

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 Clemson 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



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

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

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.

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

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

Poulos C, 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.

Awards



Cole 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.

Morgan-Jones P, MacLeod R, Ellis P, Lynch J, (2018). *Lobster for Josino: Fabulous food for our final days*. Sydney, Australia. HammondCare Media. Gourmand World Cookbook Awards in category B02 Best Cookbook of the Year for Australia, and category D12 Seniors Cookbook.

Publications

Books and chapters



Beilharz K, (2018). Applications of Trinitarian analogy in contemporary thought and the potential for Eucharistic encounter in Olivier Messiaen's music' in *Phronema*, Journal of St. Andrew's Greek Orthodox College, Vol. 33 No.2 December 2018.

Beilharz K, Music Engagement and Music Therapy. (2018). In: **MacLeod R**, Van den Block L (ed.s) *Textbook of Palliative Care* (Springer Cham) https://doi.org/10.1007/978-3-319-31738-0_39-1, pp.1-22 08/06/2018 ISBN 978-3-319-31738-0 (Biomedical and Life Sciences).

Beilharz K, Poulos C, Poulos R, **Fodera J, Cole A, MacLeod R**, (2018) Creative Art Making in Palliative Care. In: MacLeod R, Van den Block L. (eds.) *Textbook of Palliative Care*. Springer, Cham. DOI https://doi.org/10.1007/978-3-319-31738-0_38-1 Online ISBN978-3-319-31738-0.

Clayton J, Luckett T, Detering K, Advance Care Planning in Palliative Care. In **MacLeod R**, Van den Block L (eds.) *Textbook of Palliative Care*. Springer International Publishing, 2018.

Detering K, **Clayton J**, Advance Care Planning in Australia. In Thomas K, Lobo B, Detering K (eds.) *Advance Care Planning in End of Life Care, 2nd Edition*, Oxford University Press, Oxford, UK, 2018.

Ellis P, Allen J, (2018). Swallowing Difficulties. **MacLeod R**, Van den Block, L. 1st Ed, *Textbook of Palliative Care*, 2018, Springer International Publishing, June 2019, 1-21. 10.1007/978-3-319-31738-0_19-1.

Franklin A, Lovell M, (2018). Pain management in **MacLeod R**, Van den Block L. *Textbook of Palliative Care*. Springer.

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

Houston A, **Christie J**, (2018). *Talking Sense. The impact of sensory changes and dementia*. Sydney, Australia: HammondCare.

Houston A, **Duggan N, Cunningham C**, *My Home, My Life: Practical Ideas for People with Dementia and Carers*. Sydney, Australia. HammondCare Media, ISBN: 9780994546197.

MacLeod R, (2018). Approach and Nature of Palliative Care. In: **MacLeod R**, Van den Block L, (eds) *Textbook of Palliative Care*. Springer, Cham https://doi.org/10.1007/978-3-319-31738-0_3-1

MacLeod R, Latte E, (2018). Education and Palliative Care, Overview. In: **MacLeod R**, Van den Block L. (eds) *Textbook of Palliative Care*. Springer, Cham https://doi.org/10.1007/978-3-319-31738-0_95-1.

MacLeod R, Lovell M, (2018). Symptom Control in **MacLeod R**, Van den Block, L *Textbook of Palliative Care*. Springer.

MacLeod R, Macfarlane S, *The Palliative Care Handbook (Ninth Edition)*, Sydney, HammondCare Media, June 2018, ISBN: 9780648241577.

MacLeod R, Van den Block L (editors), (2018). *Textbook of Palliative Care*. Springer, Cham. <https://doi.org/10.1007/978-3-319-31738-0> ISBN 978-3-319-31738-0.

Marshall M, (2018). *Toilet Talk*. Sydney, Australia: HammondCare.

McNair D, Pollock R, Cunningham C, (2018). *Enlighten*. Sydney, Australia. HammondCare Media, ISBN: 9780994546173.

Morgan-Jones P, MacLeod R, Ellis P, Lynch J, (2018). *Lobster for Josino: Fabulous food for our final days*. Sydney, Australia. HammondCare Media.

O'Connor C, Poulos C, Gresham M, Poulos R, *Supporting independence and function in people living with dementia: A technical guide to the evidence supporting reablement interventions*; Sydney Australia; HammondCare Media, June 2018; ISBN: 978-0-6483387-2-7.

Pollock A, (2018). *The Room Outside*. Sydney, HammondCare.

Poulos C, Gresham M, Poulos R, **O'Connor C**, *Supporting independence and function in people living with dementia: A handbook of reablement programs for service providers*; Sydney Australia; HammondCare Media; June 2018; ISBN: 978-0-6483387-0-3.

Siddall P, MacLeod R, (2018). *Physical, Psychological/Psychiatric, Social, and Spiritual Problems and Symptoms*. In: **MacLeod R**, Block L. (eds.), *Textbook of Palliative Care*. Springer International Publishing AG, Basel: pp. 1-17.

Publications

Books and chapters



Sinclair C, Bucks R, Blake M, Williams K, **Clayton J**, Auret K, Radoslovich H, Callaghan S, Field S, Kurrle S. We've always thought of one another: Relational perspectives on autonomy and decision-making among people with dementia and their family carers. In Macdonald G, Mears J (eds.) *Dementia as Social Experience: Valuing Life and Care*. Routledge, Taylor and Francis, Oxon UK, 2018.

Vun O, McAllister L, **Nagarajan S**, (2018). Allied Health Academics' Understandings of Internationalization at Home: A Case Study. In Timothy Hall, Tonia Gray, Greg Downey, Michael Singh (eds.), *The Globalisation of Higher Education, Developing Internationalised Education Research and Practice*, (pp. 365-378). Cham: Palgrave Macmillan.

Journal articles



Austin P, Macdonald J, **MacLeod R**, 2018 *Measuring spirituality/religiosity in clinical settings: a scoping review of available instruments*. Religions 9(3), 70; doi:10.3390/rel9030070.

Barnier A, Harris C, **Morris T**, Savage G, *Collaborative facilitation in older couples: Successful joint remembering across memory tasks*. Frontiers in Psychology. December 2018; 9: 1-12. doi:10.3389/fpsyg.2018.02385.

Bauer M, Fetherstonhaugh D, Haesler E, Beattie E, Hill K, **Poulos C**, *The impact of nurse and care staff education on the functional ability and quality of life of people living with dementia in aged care: A systematic review*. Nurse Education Today. 2018 August; 67:27-45 (Epub 2018 Apr 23).

Bourne E, McAllister L, **Nagarajan S**, Short K, *The effect of speech-language pathology students on clinician time use and activity*. International Journal of Speech-Language Pathology, 2018.1-12.

Butow P, Shaw J, Shepherd H, Price M, Masya, L, Kelly B, Rankin N, Girgis A, Hack R, Beale P, Viney R, Dhillon H, Coll J, Kelly P, **Lovell M**, Grimison P, Shaw T, Luckett T, Cuddy J, White F, ADAPT Program Group (Butow P, Shaw J, Price M, Shepherd H, Masya L, Rankin N, Girgis A, Kelly B, Hack T, Viney R, **Clayton J**, Beale P, Kirsten L, Dhillon H, Grimison P, Murphy M, Newby J, Stubbs J, Orr K, Lindsay T, Andrews G, Shaw J, Coll J, Allison K, Cuddy J, White F, Geerligs L, **Lovell M**, Luckett T, Baycheck K, Piro D, Pearce A, Yim J). *A study protocol. Comparison of implementation strategies to influence adherence to the Clinical Pathway for screening, assessment, and management of anxiety and depression in adult cancer patients (ADAPT CP): a cluster randomised controlled trial*. BMC Cancer. 18:1077 Epub https://doi.org/10.1186/s12885-018-4962-9.

Cardoso B, Roberts B, Malpas C, Vivash L, Genc S, Saling M, Desmond P, Steward C, Hicks R, Callahan J, Brodtmann A, Collins S, **Macfarlane S**, Corcoran N, Hovens C, Velakoulis D, O'Brian T, Hare D, Bush A, *Supranutritional sodium selenate supplementation delivers selenium to the central nervous system: results from a randomized controlled pilot trial in Alzheimer's disease*; Neurotherapeutics; 16(1):192-202.

Chow J, Gonzalez-Arce V, Knight A, **Kohler F**, Duggan J, Sykes A, *Transforming Telehealth through Enhanced General Practices Partnerships*. International Journal of Integrated Care 2018; 18(s1):24. DOI: http://doi.org/10.5334/ijic.s1024.

Chow J, Gonzalez-Arce V, Knight A, **Kohler F**, *Retrospective analysis of Telemonitoring in Wollondilly*, Australian Journal of Integrated Care 2018; 26(2) 150-157.

Christie J, *Review: Student Participation at Helping Hand Aged Care: taking clinical placement to the next level*. Journal of Nursing Research, 2018. 23 (2-3), 306-307.

Dear B, Nicholson Perry K, **Siddall P**, Middleton J, Johnson J, Katte L, Monypenny F, Karin E, Gandy M, Titov N, *The Spinal Cord Injury (SCI) Pain Course: Exploring the feasibility of an Internet-Delivered Pain Management Program for adults with spinal cord injury (SCI)*. Spinal Cord, 2018 56:931-939 doi: 10.1038/s41393-018-0146-3.

Detering K, Buck K, Ruseckaite R, Kelly H, Sellars M, Sinclair C, **Clayton J**, Nolte L, *Prevalence and correlates of advance care directives among older Australians accessing health and residential aged care services: Multi-centre audit study*. IN PRESS BMJ Open, accepted December 2018.

Journal articles



Estacio C, Butow P, **Lovell M**, **Dong S**, **Clayton J**, 2018. *Exploring symptom meaning: perspectives of palliative care physicians*. Supportive Care in Cancer. 26. 10.1007/s00520-018-4126-0.

Geraghty T, **Cole A**, Bowring G, *'Predictors of inpatient rehabilitation after total knee replacement: an analysis of private hospital claims data'* Medical Journal of Australia. doi. org/10.5694/mja2.12066.

Gresham M, Clemson L, *Electronic bidets are acceptable and useful for cleaning after toileting in nursing homes; a feasibility study*; Australian Occupational Therapy Journal; In Press.

Gresham M, Heffernan M, Brodaty H, *The Going to Stay at Home program: Combining dementia caregiver training and residential respite care*; International Psychogeriatrics; November 2018; 30:11, 1697-1706; 18th July 2018; doi.org/10.1017/S1041610218000686.

Halovic S, Korner A, McLean L, Chapman C, Haliburn J, **Stevenson J**, Butt D, Graham P, Malloch S, Phillips T, Meares R, *Development of the CoMTAS Conversational Model Therapy Adherence Scale*. Psychodynamic Psychiatry, 46(4) 511-536, 2018.

Hosie A, Phillips J, Kochovska S, Brassil M, Noble B, Kurrle S, Cumming A, Caplan G, Chye R, Le B, Ely E, Lawlor P, Bush S, Davis J, **Lovell M**, Brown L, Fazekas B, Cheah S, Edwards L, Agar M, *'Multicomponent non-pharmacological intervention to prevent delirium for hospitalised people with advanced cancer: study protocol for a phase II cluster randomised controlled trial'*, British Medical Journal Open, accepted Nov 28, 2018.

Johnson S, Butow P, Bell M, Detering K, **Clayton J**, Silvester W, Kiely B, Clarke S, Vaccaro L, Stockler M, Beale P, Fitzgerald N, Tattersall M, *A randomized controlled trial of an advance care planning intervention for patients with incurable cancer*. British Journal of Cancer (Impact factor 6.176), 2018 Nov; 119 (10):1182-1190. doi: 10.1038/s41416-018-0303-7. Epub 2018 Oct 29. PMID: 30369600.

Kohler F, McDougall A, Duggan J, McDonald K, Liaw S-T, Simmons D, et al. *Integrating Health Care – Our Journey Continues*. International Journal of Integrated Care 2018; 18(s2):309. DOI: http://doi.org/10.5334/ijic.s2309.

Korner A, Mclean L, Haliburn J, Williamson M, Philips T, Graham P, Lianos G, Crisante L, Bains J, **Stevenson J**, Touma K, Halovic S, *Holding the space, protecting the personal*. Australasian Journal of Psychotherapy. 2018 Vol36 No.1 p8-21.

Li D, **Nagarajan S**, Du Toit S, *A Pilot Investigation of Occupational Therapy Students' Perceptions of Their Impact on Services to Older Adults*. International Journal of Practice-based Learning in Health and Social Care, 2018. 6(2), 14-30.

Lovell M, Birch M, Luckett T, Phillips J, Davidson P, Agar M, Boyle F, *Screening and audit as service-level strategies to support implementation of Australian guidelines for cancer pain management in adults: a feasibility study*. Pain Management nursing. Accepted May 13th 2018 https://doi.org/10.1016/j.pmn.2018.05.004.

Luckett T, Davidson P, Green A, Marie N, Birch M, Stubbs J, Phillips J, Agar M, Boyle F, **Lovell M**, *Development of a cancer pain self-management resource to address patient, provider and health system barriers to care*. Journal of Supportive and Palliative Care. Accepted 13th August 2018.

Luckett T, Phillips J, Agar, M, Lam I, Davidson P, McCaffrey N, Boyle F, Shaw T, Currow D, Read A, Hosie A, **Lovell M**, (2018) *Protocol for a phase III pragmatic stepped wedge cluster randomised controlled trial comparing the effectiveness and cost-effectiveness of screening and guidelines with, versus without, implementation strategies for improving pain in adults with cancer attending outpatient oncology and palliative care services: the Stop Cancer PAIN Trial* BMC Health Services Research 18(1):558.

Macfarlane S, **Cunningham C**, *Management of behavioural and psychological symptoms in the real world: the experience of Dementia Support Australia*; Pending Publication.

MacLachlan M, Banes D, Bell D, Borg J, Donnelly B, Fembek M, Ghosh R, Gowran R, Hannay E, Hiscock D, Hoogerwerf E, Howe T, **Kohler F**, Layton N, Long S, Mannan H, Mji G, Odera Ongolo T, Perry K, Pettersson C, Power J, Delgado Ramos V, Slepčková L, Smith E, Tay-Teo K, Geiser P, Hooks H, *Assistive technology policy: a position paper from the first global research, innovation, and education on assistive technology (GREAT) summit*. Disability and Rehabilitation: Assistive Technology 2018; 13(5):454-466.

Publications

Journal articles



McCabe R, Murray R, Austin P, Siddall P, (2018) *Spiritual and existential factors predict pain relief in a pain management program with a meaning-based component*, Journal of Pain Management, 2018 11:163-170.

McAllister L, **Nagarajan S**, Scott L, Smith L, Thomson, K, (2018). *Developing Measures of Placement Quality in Allied Health, Dentistry, Medicine, and Pharmacy*. International Journal of Practice-based Learning in Health and Social Care, 6(2), 31-47.

Mitchell G, Senior H, **Rhee J**, Young S, Teo PCK, Murray S, Boy K, **Clayton J**, *Using intuition or a formal palliative care needs assessment screening pathway in general practice to predict death within twelve months: a randomised controlled trial*. Palliative Medicine (Impact Factor 3.685), Palliat Med. 2018 Feb;32(2): 384 - 394. doi: 10.1177/0269216317698621. PMID: 28452570.

Nagarajan S, McAllister L, McFarlane L, Hall M, Schmitz C, Roots R, Drynan D, Avery L, Murphy S, Lam, M, *Recommendations for effective telesupervision of allied health students on placements*. Journal of Clinical Practice in Speech Language Pathology, 2018. 20(1), 21-26.

Perry J, Chen A, Kariyawasam V, Collins G, Choong C, Teh W, Mitrev N, **Kohler F**, Leong R, (2018). *Medication non-adherence in inflammatory bowel diseases is associated with disability*. Intestinal research 2018, 16(4): 571-578.

Poulos R, **Gresham M, O'Connor C, Poulos C**, *Bridging the gap: From reablement policy to practice for people with dementia*. Alzheimer's and Dementia: Translational Research and Clinical Interventions. 4, 2018, 508-509.

Poulos R, **Harkin D, Poulos C, Cole A, MacLeod R**, *Can specially trained community care workers effectively support patients and their families in the home setting at the end of life?* Health and Social Care in the Community. Volume26, Issue2, March 2018 Pages e270-e279.

Poulos R, Marwood S, **Harkin D**, Opher S, Clift S, **Cole A**, Rhee J, Beilharz K, **Poulos C**, *Arts on prescription for community dwelling older people with a range of health and wellness needs*. Health and Social Care in the Community. Volume26, Issue2, September 2018. DOI: 10.1111/hsc.12669.

Radhakrishnan S, **Kohler F**, Gutenbrunner C, Jayaraman A, Pieber K, Li J, Schiappacasse C, *Mobility in persons with lower extremity amputations and influencing factors: Using the International Classification of Functioning, Disability and Health to quantify expert views*. Prosthet Orthot Int doi/10.1177/0309364618792714.

Rainsford S, Phillips C, Glasgow N, **MacLeod R**, Wiles R, 2018, *The 'safe death': an ethnographic study exploring the perspectives of rural palliative care patients and their families*. Palliative Medicine 32(10) 1575-1583. doi.org/10.1177/0269216318800613.

Rainsford S, Phillips C, Glasgow N, **MacLeod R**, Wiles R, 2018, *Dying at home in residential aged care: a mixed-methods study in the Snowy Monaro region, Australia*. Health and Social Care in the Community (accepted April 2018).

Rhee J, Teo P, Mitchell G, Senior H, Tan A, **Clayton J**, *General practitioners (GPs) and end-of-life care. A qualitative study of Australian GPs and specialist palliative care clinicians*. BMJ Supportive and Palliative Care (Impact Factor 2.385), 2018 Nov 1. pii: bmjspcare-2018-001531. doi: 10.1136/bmjspcare-2018-001531. [Epub ahead of print] PMID: 30385501

Rogers R, Ormiston W, Heron R, Pontré B, **MacLeod R**, Doyle A, 2018, *Body composition skeletal muscle analysis in cancer cachexia studies: Is there a place for 3T MRI analysis?* Journal of Cachexia, Sarcopenia and Muscle Clinical Reports 3(2), e00059 1-11.

Schnitzler L, Smith S, Shepherd H, Shaw J, **Dong S**, Turner R, Sorensen K, Dhillon H. *What information is communicated by radiation therapists to patients during education sessions on the first day of treatment?* 2018 European Journal of Cancer Care. e12911.10.1111/ecc.12911.

Sellars M, **Clayton J**, Morton R, Luckett T, Silvester W, Spencer L, Pollock C, Walker R, Kerr P, Tong A, *An Interview Study of Patient and Caregiver Perspectives on Advance Care Planning in End-Stage Kidney Disease*. American Journal of Kidney Disease (Impact Factor 6.269), 2018.

Publications

Journal articles



Sellars M, Morton R, **Clayton J**, Tong A, Mawren D, Silvester W, Power D, Ma R, Detering K, *A case-control study of end-of-life treatment preferences and costs following advance care planning for adults with end stage kidney disease*. Nephrology (Impact Factor 1.563) 2018 Feb 1. doi: 10.1111/nep.13230 Epub ahead of print PMID: 29389053.

Sinclair C, Gersbach K, Hogan M, Bucks R, Auret K, **Clayton J**, Agar M, Kurrle S, *How couples with dementia experience healthcare, lifestyle and everyday decision-making*. International Psychogeriatrics (Impact factor 2.423) 2018 Nov; 30(11):1 639-1647. doi: 10.1017/S1041610218000741. Epub 2018 May 25. PMID: 29798741.

Steiner G, Dubois S, Ee C, McBride K, George E, MacMillan F, **Kohler F**, Hohenberg M, *Co-creating a model of care for a new multidisciplinary memory clinic in South Western Sydney*. Australasian Journal on Ageing 2018; 37:77-77. doi:doi:10.1111/ajag.12552.

Stevenson J, Injeti R, *Self-harm: intervening early can save a life*. MedicineToday. August 2018;19:8: 49-51.

Tieck K, McKenzie L, **Lovell M**, (2018) *The lived experience of refractory breathlessness for people living in the community*. British Journal of Occupational Therapy. Epub ahead of print 6 November, 2018. <https://doi.org/10.1177/0308022618804754>.

Tran M, Grant M, **Clayton J, Rhee J**, *Advance care decision making and planning*. Australian Journal of General Practice (Impact Factor 0.852), 2018 Nov; 47(11): 753 -757 <https://doi.org/10.31128/AJGP-06-18-4613>.

Wrigley P, **Siddall P**, Gustin S, (2018) *New evidence for preserved somatosensory pathways in complete spinal cord injury: a fMRI study*, Human Brain Mapping; 2018 39:588-598. doi: 10.1002/hbm.23868.

Wu J, Faux S, **Poulos C**, Harris I, *Brain injury rehabilitation after road trauma in New South Wales, Australia - insights from a data linkage study*. BMC Health Services Research 18:8 204 23 Mar 2018.

Xu X, Luckett T, Wang A, **Lovell M**, Phillips J, (2018). *Cancer pain management needs and perspectives of patients from Chinese backgrounds: A systematic review of the Chinese and English literature*. Palliative and Supportive Care, 16(6), 785-799. doi:10.1017/S1478951517001171.

Industry and magazine articles



Alford M, Cunningham C, Wallace T, *No longer fearful of the shadows*, Australian Ageing Agenda. January - February 2018. p52.

Christie J, 2018, *The Implications of Living Well with Dementia. Exploring Resilience*. The Elder Magazine. <https://www.elder.org/the-elder/the-implications-of-living-well-with-dementia-exploring-resilience-with-dr-julie-christie/>.

Cunningham C, *Responding better to Unmet Needs*, Australian Ageing Agenda. July - August 2018. p54-55.

Gresham M, Cunningham C, *Thinking Outside the Box*, Australian Ageing Agenda. September - October 2018. p53.

Halovic S, Korner A, McLean L, Chapman C, Haliburn J, **Stevenson J**, Butt D, Graham P, Malloch S, Phillips T, Meares R, *Development of the CoMTAS—Conversational Model Therapy Adherence Scale Psychodynamic*. Psychiatry, 2018. 46(4) 511-536.

Harkin D, Poulos C, Cunningham C, *Frontline: Improving Respite*, Australian Ageing Agenda. May - June 2018. p48-49.

Marshall M, 2018, *No laughing matter*. Accessible toilets for people with dementia. Journal of Dementia Care.

Publications

Industry and magazine articles



Marshall M, Cunningham C, *Future-Proofing Accommodation*, Australian Ageing Agenda. September – October 2018. p52.

Marshall M, Cunningham C, *We need to talk about toilets*, Australian Ageing Agenda. January – February 2018. p53.

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



Christie J, Thompson-Bradley O, 2018, *Dementia Dog Project: Evaluating the impact of an assistance dog program for people living with dementia in Scotland*. Dementia Centre, HammondCare.

Clayton J, Rhee J, Arthurs K, the Advance Project National Advisory Group, *Quick guide for introducing advance care planning in routine consultations or health assessments in General Practice*. New clinician resource released 17 October 2018. Available from www.theadvanceproject.com.au.

Clayton J, Rhee J, Nagarajan S, Arthurs K, the Advance Project National and International Advisory Group, *The Advance Project Toolkit: Better primary health care through team-based initiation of advance care planning and palliative care*. This toolkit has been recognised as an accepted clinical resource by the Royal Australian College of General Practitioners and endorsed by the Australian Primary Health Care Nurses Association. Revised and updated toolkit released on 17 October 2018. Available from www.theadvanceproject.com.au.

Clayton J, Rhee J, Nagarajan S, Arthurs K, the Advance Project National and International Advisory Group, *The Advance Project Guide: a model for initiating palliative care and advance care planning in General Practice*. Revised and updated guide for clinicians released 17 October 2018. Available from www.theadvanceproject.com.au.

Clayton J, Rhee J, Arthurs K, the Advance Project National Advisory Group, *"Preparing for an advance care planning conversation - A guide to help you prepare for a conversation with your family or health care team about your wishes for future health and personal care."* This is a new patient resource released 17 October 2018. Available from www.theadvanceproject.com.au.

Clayton J, Rhee J, Arthurs K, the Advance Project National Advisory Group, *"Who will speak for you if you can't speak for yourself? A guide for choosing a substitute decision maker for healthcare decisions"* This is a new patient resource, released 17 October 2018. Available from www.theadvanceproject.com.au.

Clayton J, Rhee J, Arthurs K, Dixon T, the Advance Project National and International Advisory Group, The Advance Project patient assessment booklet: *'Supporting you to live well with a chronic illness'*. This is a revised and updated patient and clinician resource to assess patients' palliative and supportive care needs. It was released 17 October 2018. Available from www.theadvanceproject.com.au.

Clayton J, Rhee J, Arthurs K, Dixon T, the Advance Project National and International Advisory Group, The Advance Project carer assessment booklet: *'Looking after you while you care for someone with a chronic illness'*. This is a revised and updated carer and clinician resource to assess carers' supportive care needs. It was released 17 October 2018. Available from www.theadvanceproject.com.au.

Clayton J, Nagarajan S, Rhee J, the Advance Project National and International Advisory Group, *The Advance Project website* www.theadvanceproject.com.au The new website for the Advance Project was released 17 October 2018. The Advance Project is led by HammondCare and funded by the Australian government, Department of Health.

Publications

Technical and other reports



Clayton J, Rhee J, Stoecker S, Tieman J, **Nagarajan S, Arthurs K**, the Advance Project National Advisory Group, The Advance Project eLearning module for General Practitioners: *Initiating Advance Care Planning and Palliative Care*. This new interactive, self-directed eLearning module has been accredited by the Royal Australasian College of General Practitioners (for four category 2 points) and the Australian College of Rural and Remote Medicine. This was launched in October 2018. Available from www.theadvanceproject.com.au.

Clayton J, Nagarajan S, Rhee J, Stoecker S, Tieman J, **Arthurs K**, the Advance Project National Advisory Group, The Advance Project eLearning module for General Practice Managers – *Module 1: An introduction to advance care planning and palliative and supportive care. A new interactive, self-directed eLearning module*. This was launched in December 2018. Available from www.theadvanceproject.com.au.

Clayton J, Nagarajan S, Rhee J, Stoecker S, Tieman J, **Arthurs K**, the Advance Project National Advisory Group, The Advance Project eLearning module for General Practice Managers – *Module 2: An introduction to the Advance Project and resources. A new interactive, self-directed eLearning module*. This was launched in December 2018. Available from www.theadvanceproject.com.au.

Sinclair C, Field S, Williams K, Blake M, Bucks R, Auret K, **Clayton J**, Kurrle S, (2018). *Supporting decision-making: A guide for people living with dementia, family members and carers*. Sydney: Cognitive Decline Partnership Centre.

Wiese M, Stancliffe R, Wagstaff S, Tieman J, Jelts G, **Clayton J**, (2018). *TEL Talking End of Life* www.caresearch.com.au/TEL/. Australian Government Department of Health under the Public Health and Chronic Disease Grant Program.

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, 13th November 2018.

Agar M, Kerfoot J, Kuwahata L, Davis J, Hauser K, **Lovell M**, Parr C, Williams S, Hosie A, Phillips J, *A phase II cluster randomised controlled trial of a multi-component non-pharmacological intervention to prevent delirium for hospitalised people with advanced cancer: study protocol*, Australian and New Zealand Society of Palliative Medicine Conference 2018, September 06-09, Sydney, Australia (accepted for oral presentation 28 June 2018).

Alford M, Morris T, Robb L, Hall W, Benham J, MacDonald J, Macfarlane S, *Dementia Support Australia Team – A Panel Discussion*. HammondCare International Dementia Conference, Sydney Australia 7th June 2018.

Anand R, Fuggle L, *Architecture and Pain – Incorporating environmental designing as part of the multidisciplinary approach to managing chronic pain*. HammondCare International Dementia Conference, Sydney Australia, 8th June 2018.

Anand R, Siddall P, Ferguson L, Andrews S, **Cunningham C**, *Poster Presentation: Pain in Aged Care Residents Living with Dementia: Baseline Results from the Intervene 2 Study*. IASP 17th World Congress on Pain, Boston USA, September 12-16, 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 Woman's Hospital. Brisbane Australia. 30th November 2018.

Presentations

Academic conference and industry seminars



Arthurs 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.

Arthurs K, Clarke D, *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.

Arthurs 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, Siddall P, Wrigley P, Asghari 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 [awarded best poster in meeting prize].

Barton R, Wiese M, Stancliffe R, Read S, Jelts G, **Clayton J**, *Relationships, rules and resources: Factors that influence discussions about end of life with people with intellectual disability*. Australasian Society of Intellectual Disability Conference, Gold Coast, Australia, 14th-16th November 2018.

Beilharz K, *Music engagement in dementia care and palliative care*. ACOM, SCD and CSU Ageing Conference: Embracing life and gathering wisdom: Theological, pastoral and clinical insights into human flourishing at the end of life. 27 - 28 September, Sydney Australia (2018). 'Ageing well: music and meaning in dementia and de-medicalising palliative care'.

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

Beilharz K, *'Music, Theology and Palliative Care'*. School of Theology, Culture and Public Engagement. Anglican Deaconess Ministries, Sydney, 23 January 2019.

Brassil, M, Noble B, Kurrle S, Cumming A, Caplan G, Chye R, Le B, Ely E, Lawlor P, Bush S, Davis J, **Loveil M**, Brown L, Fazekas B, Cheah S, Edwards L, Agar M, *phase II cluster randomised controlled trial of a multi-component non-pharmacological intervention to prevent delirium for hospitalised people with advanced cancer: study protocol*, Hosie A, Phillips J, Kochovska S, 10th World Research Congress of the European Association for Palliative Care, Bern, Switzerland, June 2018.

Chao S, Gresham M, Cunningham C, Alford M, *Poster Presentation: Getting outside: an underutilised tool for reducing BPSD for people with dementia in residential care?*, NHMRC National Institute for Dementia Research Australian Dementia Forum, Sydney Australia, 4th -5th June 2018.

Christie J, *Design to Realise Resilience*. University of Edinburgh, Scotland Lecture Series, March 2018. Plenary.

Christie J, *Living with Dementia. Is there a place for resilience?* School of Public Health and Community Medicine School Lecture. UNSW, Australia, June 2018.

Christie J, *Dependent Independence: A new paradigm in the care and support of people with dementia*. International Dementia Conference, HammondCare. Sydney, Australia. June 2018. Parallel.

Christie J, *Putting the 'We' in Working Together*. International Dementia Conference, HammondCare. Sydney, Australia. June 2018. Parallel.

Christie J, *Resilience in the Context of Dementia. National Mental Health Officer Study Day*. British Association of Social Work. Murrayfield National Stadium, Edinburgh, Scotland. October 2018.

Clayton J, Invited to design and facilitate a 2-day workshop on advance care planning for the 25th 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).

Presentations

Academic conference and industry seminars



Clayton J, Invited session chair, Australian and New Zealand Society of Palliative Medicine conference, 7 September 2018.

Clayton J, Invited workshop facilitator, *Research Workshop - Concept Outline Development (Taking ideas and making them a reality)*, Australian and New Zealand Society of Palliative Medicine conference, 7 September 2018.

Clayton J, Invited presentation on the Advance Project, National Palliative Care Grants Recipients Forum, Canberra, 28 February 2018.

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.

Clayton J, Nagarajan S, Lewis V, Costa D, Tieman J, Halcomb E, Mitchell, Detering K, Phillips J, Morton R, Gavin J, Stokes J, Livingston A, Shaw T, Rhee J, *Evaluation of the Advance Project: Initiating palliative care and advance care planning*. Primary Health Care Research Conference, Melbourne, August 2018.

Clayton J, Nagarajan S, Lewis V, Halcomb E, Rhee J, Mitchell G, Phillips J, Tieman J, Morton R, Gavin J, Stokes J, Shaw T, Detering K, *Evaluation of the Advance Project: Initiating palliative care and advance care planning through training and resources for General Practice Nurses*. APNA (Australian Primary Health Care Nurses Association) conference, Brisbane May 2018.

Cole A, 38th Annual CMDA-CMDE Conference, Marathon, Greece; March 26 - 29 2018. a. *"Multiple Chronic Diseases in Resource-limited Settings"* 28.3.2018; b. *"Appropriate Care at the End of Life"* 29.3.2018.

Cole A, ISPRM Annual Scientific Meeting, Paris, France; July 8 - 12 2018. a. *"Training for Rehabilitation Medicine and Certification in Australasia and the Middle East"* 11.7.2018; b. *"We asked our Patients: What do you need from Cancer Rehabilitation?"* 12.07.2018.

Cole A, American Congress Rehabilitation Medicine, Dallas, USA; Sep 30 - Oct 3 2018. a. *"Normal Ageing, or Disease-induced Changes?"* 3.10.2018.

Cole A, AOSPRM and RMSANZ Annual Scientific Meeting, Auckland; Nov 21 - 24 2018. a. *"Lived Experience of Cancer Rehabilitation Unit Staff - An Australian Experience"* 23.11.2018.

Cunningham C, *Intervene 2: implementing best pain management practice in residential aged care*. Cognitive Decline Partnership Centre Annual Conference, Canberra Australia, 17 October 2018.

Curryer B, Wiese M, Stancliffe R, Wilson N, **Clayton J**, *Multidisciplinary palliative care teams caring for dying people with intellectual disability: Lessons for the disability sector*. Australasian Society of Intellectual Disability, Gold Coast, November 2018.

Detering K, Buck K, Ruseckaite R, Kelly H, Sellars M, Sinclair C, **Clayton J**, Nolte L, *Advance care directive prevalence in Australian health and residential aged care services*. Primary Health Care Research Conference, Melbourne, August 2018.

Ferguson L, Hayes K, **Tichawangana R**, Andrews S, *Poster Presentation: Promoting a pain-vigilant culture for people living with dementia using the COM-B Behaviour Change Wheel*. HammondCare International Dementia Conference, Sydney Australia 7-8 June 2018.

Gresham M, *Going To Stay At Home: An Evaluation of a residential education program for caregivers of people living with dementia*, HammondCare International Dementia Conference, Sydney Australia, 7-8 June 2018.

Gresham M, *Dementia and why design matters*. Industry Webinar. Peddle Thorpe Architects Brisbane Australia 19 July 2018.

Presentations

Academic conference and industry seminars



Gresham M, Clemson L, Low L, *Reducing staff toileting workload in aged care homes using assistive technology*, NHMRC National Institute for Dementia Research Australian Dementia Forum, Sydney Australia, 4th-5th June 2018.

Gresham M, Taylor L, Keyes S, **McIntosh D**, Wilkinson H, *Showing the Way: developing an evaluative framework for signage for people living with dementia*, HammondCare International Dementia Conference, Sydney Australia, 7th-8th June 2018.

Hosie A, Phillips J, Kochovska S, Brassil M, Noble B, Kurrle S, Cumming A, Caplan G, Chye R, Le B, Ely E, Lawlor P, Bush S, Davis J, **Lovell M**, Brown L, Fazekas B, Cheah S, Edwards L, Agar M, *Multicomponent non-pharmacological intervention to prevent delirium for hospitalised people with advanced cancer: a phase II cluster randomised waitlist controlled trial*. Palliative Care Clinical Studies Collaborative Annual Forum Sydney February 2018.

Hosie A, Phillips J, Lam L, Kochovska S, Brassil M, Noble B, Kurrle S, Cumming A, Caplan G, Chye R, Le B, Ely E, Lawlor P, Bush S, **Lovell M**, Cheah S, Brown L, Fazekas B, Agar M, *A phase II cluster randomised controlled trial of a multi-component non-pharmacological intervention to prevent delirium for hospitalised people with advanced cancer: study protocol*, 21st Cancer Nurses Society Australia Annual Congress, 2018, June 21-23, Brisbane, Australia (Poster).

Hosie A, Phillips J, Lam L, Kochovska S, Brassil M, Noble B, Kurrle S, Cumming A, Caplan G, Chye R, Le B, Ely E, Lawlor P, Bush S, Davis J, **Lovell M**, Brown L, Cheah S, Edwards L, Agar M, *A phase II cluster randomised controlled trial of a multi-component non-pharmacological intervention to prevent delirium for in-patients with advanced cancer (The PRESERVE pilot study)*, Australasian Delirium Association 4th Biennial Conference 2018, September 06-07, Melbourne, Australia (Oral) Winner of Rotary Club of Eltham Prize for 'Novel delirium research demonstrating improved patient care'.

Hosie A, Phillips J, Lam L, Kochovska S, Brassil M, Noble B, Kurrle S, Cumming A, Caplan G, Chye R, Le B, Ely EW, Lawlor P, Bush S, Davis J, **Lovell M**, Brown L, Cheah S, Edwards L, Agar M, *A phase II cluster randomised controlled trial of a multi-component non-pharmacological intervention to prevent delirium for in-patients with advanced cancer*, European Delirium Association Meeting, 2018, November 1-2, Utrecht, The Netherlands.

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

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

Judd S, **Halton J**, *CDC: Fact or Fantasy*, 2018 International Dementia Conference, Mission Impossible? Truth and lies in the age of choice. Sydney, Australia, 4 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 CDPC in retrospect*, Cognitive Decline Partnership Centre Annual Conference 2018: Evidence For Change, implementing dementia care. Canberra, Australia, 16 October 2018.

Kohler F, *ISPO and the diabetic foot*. D-Foot International Implementation Summit. 16-18 November 2018, Madrid, Spain.

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, *Current ISPO developments*. Central European ISPO Conference. 20-22 September 2018, Portoroz, Slovenia.

Kohler F, *ISPO developments following the Introduction of the WHO Standards in prosthetics and Orthotics*. ISPO Global Educators meeting, 18-20 September 2018, Göttingen, Germany.

Kohler F, *WHO Standards for Prosthetics and Orthotics*. OT World, 15-18 May 2018, Leipzig Germany.

Presentations

Academic conference and industry seminars



Lee J, Currow D, **Lovell M**, Phillips J, McLachlan A, Noble B, Brown L, Fazekas B, Cheah S, McCaffrey N, Chye R, Aggarwal R, Soah D, Sanderson C, Ayoub C, Sheehan C, Aggarwal G, Urban K, Mittal D, Cohan J, Baahattaral P, Linton A, Agar M, *Lidocaine for Neuropathic Cancer Pain – Feasibility Study Protocol*. Palliative Care Clinical Studies Collaborative Annual Forum, Sydney, February 2018.

Lovell M, Phillips J, Agar M, Boyle F, Davidson P, Lockett T, Currow D, Lam L, McCaffrey N, Shaw T, Read A, * *The Stop Cancer PAIN Trial*. Palliative Care Clinical Studies Collaborative Annual Forum, Sydney, Feb 27 2018.

Lovell M, Phillips J, Agar M, Lockett T, Currow D, Boyle F, Davidson P, Lam L, McCaffrey N, Shaw, Read A, (2018) *Strategies to improve routine pain screening in Australian outpatient oncology and palliative care clinics: process data from the Stop Cancer PAIN Trial*. MASCC/ISOO Annual Meeting on Supportive Care in Cancer, Vienna, Austria 28-30 June 2018.

Macfarlane S, *Welcome Address*, RANZCP Faculty of Psychiatry of Old Age and the Asian Society Against Dementia Conference 2018, Melbourne, Australia, 8 November 2018.

Macfarlane S, *Dementia care in Asia Pacific*, RANZCP Faculty of Psychiatry of Old Age and the Asian Society Against Dementia Conference 2018, Melbourne, Australia, 9 November 2018.

Macfarlane S, *DSA: A National Approach to behaviour management*, 2nd Annual Palliative Care And Dementia Forum, Melbourne, Australia, 5 July 2018.

Macfarlane S, *Decoding the Behaviour Myth*, International Dementia Conference, Sydney, Australia, 8 June 2018.

Macfarlane S, *Pharmacological management of BPSD*, Annual Scientific Meeting (ASM) for the Australian and New Zealand Society of Geriatric Medicine (ANZSGM), Newcastle, Australia, 5 May 2018.

Macfarlane S, **Kornhauser M**, **Modini E**, Hampel H, Toutain S, Missling C, *Poster Presentation: A Phase 2b/3, Double-Blind, Randomised, Placebo-Controlled 48-Week Trial of ANAVEX[®]2-73 for the Treatment of Early Alzheimer's Disease Together with Precision Medicine Genetic Biomarkers*, Clinical Trials in Alzheimer's Disease Conference, Barcelona, Spain, 25-27 October 2018.

MacLeod R, *Palliative care and dementia – rethinking how we do it*. The New Zealand Dementia Cooperative, Dementia New Zealand. Wellington, NZ May, 2018.

MacLeod R, *Reflection; developing a career in palliative care*. ANZSPM Aotearoa Annual Education Update. Wellington, June, 2018.

MacLeod R, *Palliative Care*. The Alliance NSW Junior Doctors' Conference, Sydney June 2018.

MacLeod R, *End of Life Choice Bill rebuttal*. Justice Select Committee, Auckland. July, 2018.

MacLeod R, *Opposition to End of Life Choice Bill*. Auckland. July 2018.

MacLeod R, *What is spiritual care and how do we deliver it?* Greenwich Hospital. August, 2018.

MacLeod R, *Physician Assisted Dying*. Palliative Care Grand Rounds, Pallister House, Greenwich Hospital Sydney. August, 2018.

MacLeod R, *Palliative care and dementia: rethinking how we do it*. 2018 Wicking Trust Symposium. Melbourne, October, 2018.

MacLeod R, *Opposition to End of Life Choice Bill (debate)*. Northcote, Auckland November 2018.

McNair D, *Daylight and dementia*. Care and Dementia Environments Conference, Birmingham. March 2018. Plenary.

McNair D, *Velux 'Design a Brighter Future' Event Series*. September 2018, Belfast; October 2018, Birmingham. Plenary.

Marshall M, *The Impact of the Environment*. University of Edinburgh, Scotland, Lecture Series, March 2018. Plenary.

Presentations

Academic conference and industry seminars



Marshall M, *Designing for complexity*. Care and Dementia Environments Conference, Birmingham. March 2018. Plenary.

Marshall M, *Dementia Care in Australia*. Practical Approach to Neurodegenerative Diseases Conference, Brno. March 2018. Plenary.

Marshall M, *Importance of a timely diagnosis with a focus on collaboration*. Practical Approach to Neurodegenerative Diseases Conference, Brno. March 2018. Parallel.

Marshall M, *Let's talk about toilets*. Alzheimer Scotland Conference, Edinburgh. June 2018. Poster.

Mitchell G, **Nagarajan S**, Gavin J, Stokes J, Rhee J, Boyd K, Murray S, Phillips J, Tieman J, Halcomb E, Detering K, Morton R, Lewis V, Livingstone A, Shaw T, **Clayton J**, *The ADVANCE program: equipping and training practice nurses in comprehensive end of life care planning*. Invited plenary session. SPICT International Conference, February, Edinburgh, Scotland, February 2018.

Morris T, Daffas P, *Using AI and smartphone technology to deliver better pain management*, Driving Performance in Aged Care IT, Sydney Australia, 18 April 2018.

Morris T, Barnier A, Harris C, Savage G. *Poster Presentation: Remembering together: Evidence for distributed cognition in long-married elderly couples*. HammondCare International Dementia Conference, Sydney Australia 7–8 June 2018.

Morris T, *Using smartphones to detect pain in people with dementia*, Australian Association of Gerontology 51st Conference, Melbourne Australia, 21 November, 2018.

Morris T, **Gresham M**, **Alford M**, **Cunningham C**, *Poster Presentation: Identifying and modifying factors that lead to severe behaviours in people with dementia*, NHMRC National Institute for Dementia Research Australian Dementia Forum, Sydney Australia, 4 - 5 June 2018.

O'Connor C, *Behavioural Changes: Supporting Quality of Life through the Tailored Activity Program (TAP) and Positive Behavioural Support*. 11th International Conference on Frontotemporal Dementias, Sydney, Australia, 13 November 2018.

O'Connor C, **Gresham M**, Poulos R, Clemson L, McGilton K, Cameron I, Hudson W, Radoslovich H, Jackman J, **Poulos C**, *How do you choose "in the age of choice"? – Dementia reablement guidelines to support function in people with mild to moderate dementia*. International Dementia Conference. Sydney, Australia, 7 June 2018.

Phillips J, **Lovell M**, Agar M, Luckett T, Davidson P, Shaw T, Currow D, McCaffrey N, Lam L, Read A, (2018) *Prevalence of pain in disease-free survivors attending follow-up at two metropolitan outpatient oncology services: A Stop Cancer PAIN Trial secondary analysis*. Cancer Nurses Society of Australia 21st Annual Congress, Brisbane, Australia, 21-23 June 2018.

Phillips J, **Lovell M**, Davidson P, Boyle F, Lam L, McCaffrey N, Honeka N, Shaw T, *A phase 3 wait-listed RCT of a novel targeted inter-professional clinical education intervention to improve cancer patients' reported pain outcomes: Protocol*. Palliative Care Clinical Studies Collaborative Annual Forum, Sydney, February, 2018.

Pollock A, *The Room Outside*. Care and Dementia Environments Conference, Birmingham. March 2018. Plenary.

Pollock A, *Outdoor design considerations*. Care and Dementia Environments Conference, Birmingham. March 2018. Plenary.

Pollock R, *DesignSmart: Products that work for people with dementia*. Care and Dementia Environments Conference, Birmingham. March 2018. Plenary.

Pollock A, *The Room Outside*. University of Edinburgh, Scotland. March 2018. Plenary.

Pollock A, *Care plans – Why going outside should be included*. Scottish Caring and Dementia Congress, Edinburgh. April 2018. Parallel.

Presentations

Academic conference and industry seminars



Poulos C, *The development of reablement programs – Translational challenges*. Cognitive Decline Partnership Centre (CDPC) Annual Conference, Canberra Australia, October 15-16, 2018.

Poulos C, *Rehabilitation, Restorative Care and Reablement in Dementia – What is there to offer?* International Dementia Conference, Sydney Australia, June 7-8, 2018.

Poulos R, **Harkin D**, Beattie E, **Cunningham C**, **Poulos C**, *Home delivered participatory art to support wellness in dementia caregiver and care recipient dyads*. International Dementia Conference, Sydney Australia, June 7-8, 2018.

Rainsford S, Glasgow, N, Phillips C, **MacLeod R**, Wiles R, *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. September 2018.

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

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

Razmovski-Naumovski V, Agar M, Medical Cannabis Investigator Team (**Lovell M**), *Designing Medicinal Trials in Palliative Care*. Palliative Care Clinical Studies Collaborative Annual Forum, Sydney February 2018.

Rhee J, Zwar Z, **Clayton J**, Meller A, Hermiz O, Miller H, Tan J, Bonakdar M, *Pilot study of a primary care nurse led model of Advance Care Planning*. Primary Health Care Research Conference, Melbourne, August 2018.

Siddall P, *Opioid prescription misuse: The issues, solutions and way forward*, NSW Agency for Clinical Innovation Forum, Sydney, 15 March 2018.

Siddall P, *Pharmacological management of neuropathic pain: an update*, Australian Pain Society Annual Scientific Meeting, Sydney, Australia, 8 April 2018.

Siddall P, *Opioid safety: The NSW experience*, Queensland Clinical Senate Symposium; Managing the Pain of Opioids, Brisbane, 19 July 2018.

Siddall P, *Spiritual well-being and its relationship with pain, depression and life satisfaction*, International Spinal Cord Society Annual Scientific Meeting, Sydney, Australia, 13 Sept 2018.

Siddall P, *Developing new models of care for managing SCI pain* International Spinal Cord Society Annual Scientific Meeting, Sydney, Australia, 15 Sept 2018.

Smith-Uffen M, Johnson M, Tattersall M, Stockler M, Butow P, Bell M, Detering K, **Clayton J**, Silvester W, Clarke S, Vaccaro L, Beale P, Kiely B, *Estimating survival time in advanced cancer: a comparison of estimates may by oncologists and patients*. Clinical Oncology Society of Australia conference, Perth, Nov 2018.

Stancliffe R, Wiese M, Read S, Jeltos G, **Clayton J**, Barton R, *Do no harm: Anxiety, depression and fear of death when discussing end of life with people with intellectual disability*. Australasian Society of Intellectual Disability, Gold Coast, November 2018.

Stevenson J, *Healthy Ageing*, Chickendocs Conference, Shanghai, China, April, 2018.

Stevenson J, *Psychotherapeutic Management of Personality Disorders*, Chickendocs Conference, Shanghai, China, April, 2018.

Stevenson J, *Trauma, Dissociation and Personality Disorders*, RANZCP Annual Congress, Auckland, NZ, May 2018.

Tichawangana R, **Chao S**, *Pain management in residential aged care: an overview of the Intervene Phase 2 Project*, Australian Physiotherapy Association, North Ryde. 23rd October 2018.

Presentations

Academic conference and industry seminars



Tieck K, McKenzie L, **Lovell M**, *The lived experience of refractory breathlessness*. International Conference of Palliative Care, Montreal, October 2018.

Wiese M, Curryer B, Stancliffe R, Wilson N, **Clayton J**, *Multidisciplinary palliative care teams – the experience of caring for people with intellectual disability who are dying*. NSW Palliative Care Conference, November 2018.

Wiese M, Curryer B, Stancliffe R, Wilson N, **Clayton J**, *Multidisciplinary palliative care teams caring for dying people with intellectual disability: lessons for caregivers*. Australasian Society of Intellectual Disability, Gold Coast, November 2018.

Wiese M, Stancliffe R, Read S, Jeltos G, Barton R, **Clayton J**, *Relationships, rules and resources: Factors that influence discussions about end of life with people with intellectual disability*. Australasian Society of Intellectual Disability, Gold Coast, November 2018.

Wiese M, Stancliffe R, Wagstaff S, Teiman J, Jeltos G, **Clayton J**, *Teaching people with intellectual disability about end of life*. Australasian Society of Intellectual Disability, Gold Coast, November 2018.

Xu X, **Lovell M**, Lockett T, Phillips J, *Pain management experiences and needs of Chinese migrant cancer patients*. International Society of Nurses in Cancer Care, 2018.

Service locations

Where and how we care

RESIDENTIAL CARE

- Erina **NSW**
- Horsley **NSW**
- Hammondville **NSW**
- Miranda **NSW**
- Newcastle **NSW**
- North Turrumurra **NSW**
- Scone **NSW**
- Wahroonga **NSW**
- Woy Woy **NSW**
- Caulfield **VIC**

HEALTH

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

HAMMONDCARE AT HOME

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

RESEARCH AND EDUCATION

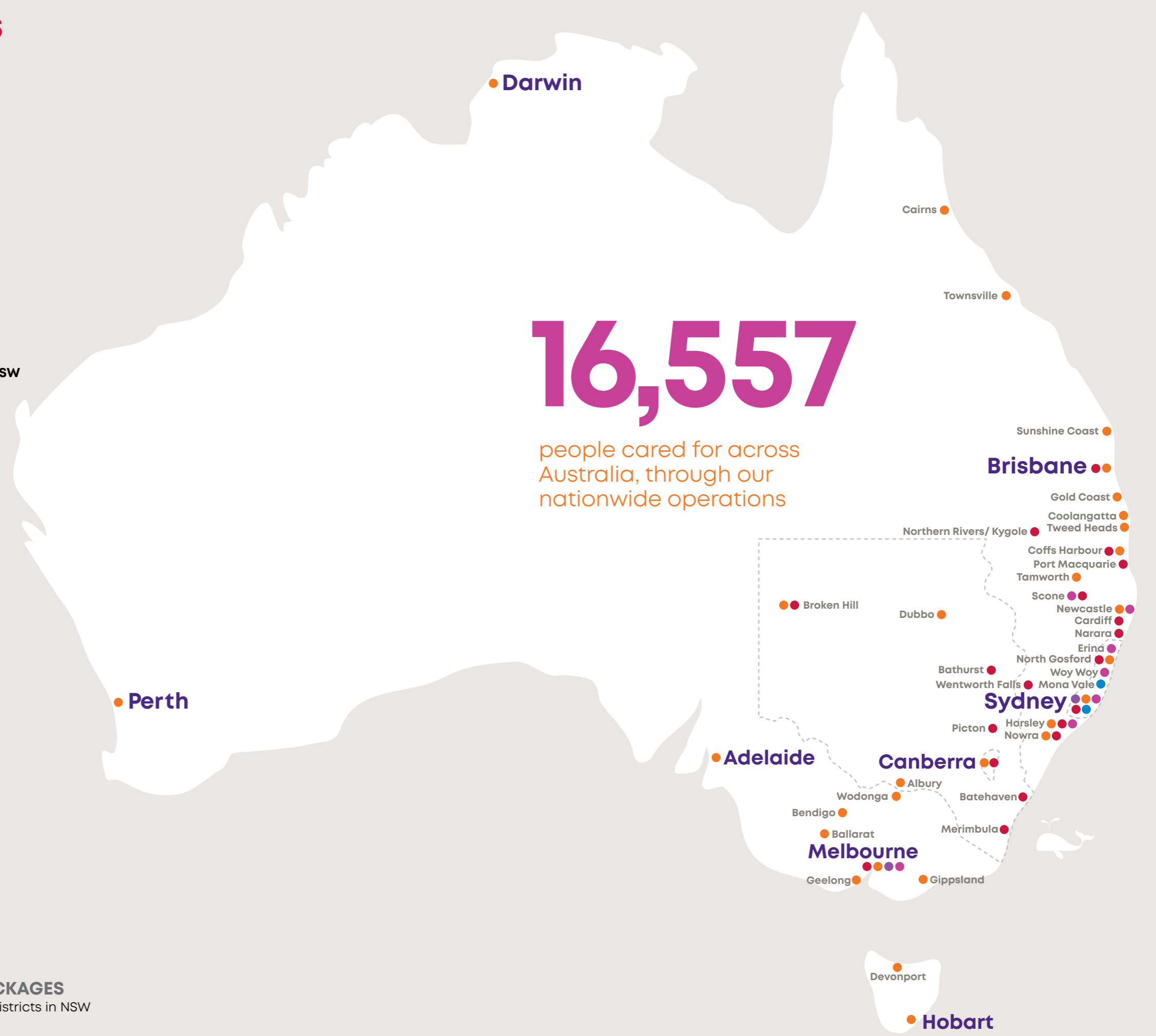
- Braeside **NSW**
- Greenwich **NSW**
- Hammondville **NSW**
- Malvern **VIC**

DEMENTIA SUPPORT AUSTRALIA (DSA)

- Albury **NSW**
- Broken Hill **NSW**
- Coffs Harbour **NSW**
- Dubbo **NSW**
- Greenwich **NSW**
- Hammondville **NSW**
- Horsley **NSW**
- Newcastle **NSW**
- North Gosford **NSW**
- North Turrumurra **NSW**
- Nowra **NSW**
- St Leonards **NSW**
- St Marys **NSW**
- Tamworth **NSW**
- Tweed Heads **NSW**
- Brisbane **QLD**
- Cairns **QLD**
- Coolangatta **QLD**
- Gold Coast **QLD**
- Sunshine Coast **QLD**
- Townsville **QLD**
- Ballarat **VIC**
- Bendigo **VIC**
- Geelong **VIC**
- Gippsland **VIC**
- Malvern **VIC**
- Wodonga **VIC**
- Canberra **ACT**
- Devonport **TAS**
- Hobart **TAS**
- Dulwich **SA**
- Wembley **WA**
- 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



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