The involvement in teaching by HammondCare staff highlights the commitment of our staff to ensure all involved in providing people with needs in the physical, mental, psychological and spiritual domains are well informed and skilled to meet these needs.
Research – are we there yet?

Most researchers can answer this quite easily, at individual project level. Once funding is received, completing the cycle of sending in ethics approval, finding the staff to run the project, gathering the research data, collating results, publicising findings and acquitting the budget, means we can say at the end of each research project, yes, we are there.

In HammondCare, it is equally important for us then to ask of each project, both at planning and at completion – how will this research translate into better care for people? In mainstream practice, translation from research to practice may vary between eight and fifteen years, especially for introducing new medications. Thankfully in HammondCare we can and do compress this somewhat.

Overall, looking back to the start of the formal organising of our learning and research efforts in 2008, we now see careful governance of all research undertaken, within seven defined priority areas. For each project, we test capacity to undertake and project relevance before work starts. All projects are regularly monitored, to ensure steady progress to final completion and reporting, and an integrated database will underpin all this in 2016.

With more than $5 million in government funding, two new Learning & Research Centres have been established at Greenwich and Hammondville, and our research staff has increased in numbers, experience and seniority. In 2008, I was the only HammondCare staff member holding a conjoint academic appointment above the level of Senior Lecturer. As this is being written, we have four staff conjointly appointed at the level of Professor, and six at the level of Associate Professor. We now teach medical, nursing and allied health students across multiple disciplines, from more than a dozen Universities.

Despite increasingly lean times in research funding, HammondCare’s ability to attract new research funding has consistently run at well more than $1 million per annum, and 2015 was no exception. Right at the end of 2015, we received advice of success in significant funding for a landmark project to look at end-of-life care discussions in general practice settings.

Clearly, we shall never arrive at the definitive answer for everything, as there is always room for another set of questions to be asked to improve the care we provide for those in need. As Robert Louis Stephenson once famously observed “to travel hopefully is a better thing than to arrive” and that is certainly true in research.

I commend this report to you, as I now hand oversight of our learning and research portfolio to Professor Chris Poulos, HammondCare’s new Head of Research.
At last: help for people who have suffered chronic pain that would not respond to medication.

The problem.

Around 50% of people with spinal cord injury develop additional pain. It’s a tragic bind. They lose sensation, and are left with no feeling from the waist down, wheel chair bound. But at the same time, they develop significant new pain - nerve pain. And the worst thing is, this pain just doesn’t respond to traditional pain killers like paracetamol, or even morphine. As a result, many people in this position fall between the tracks, and suffer long term, chronic pain.

The research.

The aim of our research grant was to address this problem, to try to find help for people suffering intense and chronic nerve pain as a result of spinal cord injury.

We began by assembling a working team, who would sift through the existing evidence that would help us understand and treat this problem. The team spent two years getting hold of all the raw data and information, and translating it into conclusions that would help people. So eventually, we discovered that there really was hope. That the right medication, exercise, and other support, could actually lead to a reduction in pain levels.

From there, we wanted to do two things.

First - develop some resources.

Our goal was to synthesize that information into some resources that would help those suffering as well as clinicians. And then, we wanted to develop a program that would allow us to deliver the care that would ultimately improve people’s lives.

So we published a book - The Spinal Cord Injury Pain Book, which is now in wide use in many hospitals and clinics throughout Australia.

We also developed a website. So that clinicians such as GPs, will no longer ask - “what do I do? Where do I go for help?” This meant that online, answers were now available for people world wide, and help was able to be found.

Over the last 12 months, we have had around 3,500 users and nearly 33,000 page views - 69% from USA, 14% from Australia, 12% from UK and the other 5% from Japan, Canada, NZ and French and Spanish speaking countries. So we are confident that we have been able to translate our research into practical help for people in need, on a wide basis, and through different channels.

And next, we wanted to develop a program.

This had to be developed specifically around the needs of the people suffering the pain. It had to allow us to deliver the care that would ultimately improve people’s lives. It is a multidisciplinary treatment plan. Doctors are needed to help with medication plans. Physiotherapists are needed to help with things like stretching and exercise, clinical psychologists help with support around relaxation and meditation. All together, it’s a combined approach, targeted to the individual, that really works.

But there was another problem we had to address. The evidence also told us that by definition, accessibility is a big problem for people with spinal cord injury. So we needed a plan specifically tailored to address that. For people with spinal cord injury, the traditional weekly or three week program just won’t work.

So we developed a tele-health model of care that takes the treatment to the person. This has been very effective and people across NSW have received vital care from our team at Greenwich Hospital in Sydney, remaining in the comfort of their own homes.

The outcome.

Overall, it’s been very satisfying to have been able to help a group of people who have suffered greatly, and see a long term change in their lives. And to see that made available extensively.

Case study: Usha’s story

When Usha came to HammondCare for help, he had experienced severe pain for around 2 years. As a result, he had developed a dependence on very large amounts of pain medication. That was on top of the severe spinal cord injury that confined him permanently to a wheel chair.

The team at the Pain Clinic commenced a plan to both reduce his medication and reduce his pain. The program involved a diverse range of treatments, including sports, exercise, meditation, relaxation, distraction therapy and others.

It’s completely changed Usha’s life - he’s been able to almost completely cease all his medication. It’s very satisfying for us to have been able to help Usha and see this remarkable change.
“It’s an area we’ve completely ignored in pain medicine... until now”: pain and spiritual distress.

The problem.

Spiritual distress is what happens when a person is unable to find sources of meaning, hope, love, peace, comfort, strength, and connection in life. Due to the existential distress it causes, it’s well known to contribute to the suffering of people who are dying. And yet, it is an issue that has been almost completely ignored in people experiencing chronic pain. That’s despite many of the issues facing people at the end of life also confronting people with persistent pain.

The research.

HammondCare runs an 8-week group Pain Management Program for people experiencing chronic pain. 17 people with referrals to take part in the Program at Greenwich Hospital were recruited for a research study into spiritual distress by Rebecca McCabe and the team at the HammondCare Pain Clinic.

We wanted to measure the level of spiritual distress in a group of people with chronic pain so that we could work towards building awareness around the issue of spiritual distress and look at further research and treatment options.

Before starting the Pain Management Program, the individuals filled in a questionnaire to assess their pain, as well as a questionnaire to assess their spiritual wellbeing. The same scale that is used to measure spiritual distress among palliative care patients was applied to this group of people.

The scores were then compared to those from people with HIV/AIDS and advanced cancer. The findings were both interesting and disturbing. What we discovered is that people with chronic pain suffer from higher levels of spiritual distress than those with HIV/AIDS and cancer.

People with chronic physical pain often face grief and existential suffering as they lose their meaning and purpose in life. It’s a similar sort of suffering as experienced by those facing end of life.

“Until now, pain medicine has been quite slow to look at these issues even though there has been increasing interest both in the community and the health profession in addressing existential issues as a component of health care,” says Rebecca.

“The plan is to use this research to develop a new course to address these deeper issues as a component of treatment for people living with pain.”

As to why people with chronic pain suffer from higher levels of spiritual or existential distress, we don’t yet know.

The participants from the original study are currently being followed up as part of a qualitative study that forms part two of the research. They will be asked to share more about their experience of spiritual distress so we can better understand what causes their suffering.

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Spiritual distress in chronic pain

Case study: Susan’s story

Susan suffers from full body rheumatoid arthritis that was triggered by trauma at work. As a result she can’t walk for more than 200 metres and is in chronic pain.

Currently, she works as a director of not-for-profit group Dragon Claw, advocating for and supporting individuals suffering from rheumatoid disease and Lupus. Susan recently participated in HammondCare’s Pain Management Program, an 8-week program that addresses different aspects of chronic pain, including spiritually, something she’s very interested in.

Susan had two hip replacements, her marriage has ended, and she has a son with schizophrenia. To say the journey I’ve been on to develop a relationship with myself and a power greater than myself is the journey I’ve been on to develop a relationship with myself and a power greater than myself. What’s a power greater than myself? I don’t know but I do know it’s putting off my ego and having humility.”

Susan says she was pleased the HammondCare Pain Management Program touched on spirituality.

Part of her journey prior to attending HammondCare’s Pain Program had been attending a 12-step program that addresses addiction and pain from a spiritual perspective.

“I needed a program, guidance and support from others who were in the same boat as me, but had reached the other side of the minefield,” she says. “I needed to see the way out from the frozenness, fear and anger, guilt, all the negative emotions, a lack of hope, insensitivity towards others and a lack of tolerance that I was experiencing. I needed to see people on the other side and how they had found happiness.”

Susan says for her, keeping spiritually afloat is crucial to her overall wellbeing.

“It’s been learning to wear my skin like a lovely, loose cashmere coat. That’s spirituality for me. It’s about feeling really warm and good in myself. Spirituality is the journey I’ve been on to develop a relationship with myself and a power greater than myself. What’s a power greater than myself? I don’t know but I do know it’s putting off my ego and having humility.”

Susan says the Serenity Prayer is an anchor for her. God grant me the serenity to accept the things I cannot change; Courage to change the things I can; and wisdom to know the difference. “I cannot change my son from being schizophrenic. I cannot change myself from being in pain with rheumatoid disease. But my spirituality gives me the courage to accept and to change the things I can change and to not worry about things I can’t.”

She says she’s looking forward to participating in any future programs run by HammondCare targeting spiritual distress.
Raising the national standard: creating Australia’s National Cancer Pain Management Guidelines.

The problem.

More than half of people living with cancer experience pain. That increases as their cancer advances, so that up to three quarters of people experience pain, and of those, many experience moderate to severe pain. At the same time, we also know that many cancer patients aren’t given enough medication to treat their pain. It’s a tragedy, because evidence shows almost all cancer pain can be controlled with appropriate analgesia.

The research.

As a Palliative Care Consultant Physician, Associate Professor Melanie Lovell has had a long-term interest in the management of cancer pain.

But it was during the National Pain Summit in Canberra six years ago when she was chairing a working group on Cancer Pain and Palliative Care, that the need for a national guideline for managing cancer pain was identified as a key priority for Australia.

To this end, a group was convened to work towards creating these new national guidelines. A/Prof Lovell took on the role of Chair of the Working Party which developed the Australian Cancer Pain Guidelines.

To create the Guidelines, she and her team carefully assessed all the existing international pain management guidelines, and then adapted them to come up with a draft Cancer Pain Management Guidelines. That document was then open to submissions from health professionals nationally. During the consultation period, the working group received over 1500 submissions to the Guidelines.

Once finalised, the Guidelines were hosted online to equip health professionals to appropriately treat pain in cancer patients in a person-centred, safe and effective manner.

In November 2014 A/Prof Lovell and her team started a very large research project, to find the most effective ways to implement the Guidelines nationally. The research is aimed at developing a national clinical pathway for pain to ensure equitable, cost-effective, evidence-based, person-centred care for people with advanced breast and other cancers.

The outcome.

The pilot study took place at HammondCare’s Greenwich Hospital and the Mater Hospital in Sydney, the results of which are already changing lives. The tools that were developed via that pilot study are in current practise in the Palliative Care Ward at Greenwich Hospital.

Following the pilot study, a large randomised controlled trial was launched at another site, and is currently on track to be completed in 2018.

In the meantime, all patients in the Palliative Care Ward at Greenwich Hospital are treated according to the Cancer Pain Management Guidelines which Dr Lovell’s team developed and which can be accessed online via the Cancer Council Australia website.

Case study: Ann’s story

Ann is 80 years old and lives at home with end stage endometrial cancer.

She experiences significant pain as a result of her disease, so the doctors at HammondCare arranged to have her provided with a strong painkiller that’s administered by a patch on the skin. The patches need to be changed every 3 days. But this is a timing that Ann was finding difficult to remember while living at home by herself. Because she wasn’t managing her pain well at home, Ann was recently admitted to hospital. During her stay, Ann has received treatment according to the Cancer Pain Management Guidelines published by HammondCare’s A/Prof Dr Lovell and her team.

During this time, Ann’s pain has been regularly assessed, and she has been put onto a higher strength painkiller, as well as a complementary pain killer, and she has also received breakthrough analgesia when needed.

The Guidelines specify for health professionals the most effective combinations of drugs to effectively treat pain, and also discuss when to use breakthrough analgesia, all of which doctors considered in Ann’s case.

According to the Guidelines, doctors should provide individualised treatment, and avoid taking a one-size-fits-all approach. Because of her problems with some oral pain killers giving her unwanted side effects, Ann had been receiving pain treatment through patches. And to help her with managing the patches at home, Ann’s doctor has come up with a plan to have a community nurse visit her at home when she’s discharged, to change the patches every three days.

Ann says she’s very happy to have been cared for under the Cancer Pain Guidelines at Greenwich Hospital.

“You know that cancer brings pain and that you are going to get weaker, but you’ve got to keep on top of the pain, that’s the answer I’ve discovered. The doctors here have been fantastic, I couldn’t be more happy.”
Now there’s a pathway for caring for loved ones living at home with dementia: Going to Stay At Home.

The problem.
In our society we are seeing the rise of chronic diseases. Navigating the course of chronic disease is often complex. Health services have developed care pathways as guides to know when, where and how to seek help as diseases progress. Dementia can last up to two decades, but unlike other conditions there is often a long gap between diagnosis and the time when professional care is sought. And there is insufficient support for carers.

The research.
We need a program to give people living with dementia and their families a well sign-posted pathway to follow – to support them in caring for loved ones at home as long as possible, and through the many challenges of the dementia experience.

Meredith Gresham, Senior Consultant with the Dementia Centre received funding to update and replicate a successful family-carer training program, originally run in the 1980s. The program was a 7-day residential program for people with dementia and their family carers, specifically designed to enable carers to better understand and navigate the journey ahead of them.

The program, called Going to Stay at Home was designed to enable people to care for the person with dementia at home for longer, by equipping them with the skills and knowledge they needed to care for themselves, as well as the person in their care.

Going to Stay at Home was held in an 8 bedroom residential cottage at HammondCare Miranda. To test the portability of the program, one stream was held in serviced apartments in Tamworth. 19 groups of between 3 and 5 couples participated in the program, involving a total of 180 people.

Carer training sessions during the week were aimed at reducing the psychological impacts of caring, educating carers about the progression of dementia, imparting practical nursing skills, techniques for relating to the person with dementia, and explaining how to access support and plan for the future.

The program was carefully structured. It started with the carer, helping them consider whether they’ve come to terms with the diagnosis, and then aimed to help carers discover they’re not alone, and what communalities they had with the group and to understand that caring for yourself was paramount.

The program then turned to how to care for someone with dementia, commencing with gaining an understanding of the disease and its effects, and other topics such as how to communicate, how to organise your day and your home, and where to apply for professional help and government support, before moving on to more challenging topics such as nursing care, managing incontinence and end of life care.

The pairs that participated in Going to Stay At Home (GTSAH) were followed up over a 12-month period after the course as part of independent evaluation conducted by Professor Henry Bondaty at the Dementia Collaborative Research Centre at UNSW. A number of positive findings emerged that powerfully underline the significance of this program:

1. As dementia progresses, we expect to see an increase in scores on carer burden scales as carers have more to cope with.
2. Before attending GTSAH:
   - 76.7% of carers said they didn’t have adequate information on managing behaviours that challenge. After 12 months, that had dropped to 15.4%.
   - 56.7% of carers said they didn’t have the knowledge they needed to look after the person in their care. After 12 months, that had dropped to 7.8%.
   - 40.3% of carers said they didn’t have the information and instructions on how to carry out practical tasks for the person with dementia. After 12 months, that had dropped to 2.7%.
3. After 12 months, 82% of participants with dementia were still living at home.
4. Compared with a similar group of people who had received usual residential respite care, over the same 12 month period 52.9% of residential respite users at HammondCare had entered permanent care, while only 17.6% of GTSAH participants had been moved out of home and into permanent care.

The outcome.
The research demonstrates that the knowledge, coping skills and capacity of family carers can be significantly increased through a pathway program like this. As a result, there can be less carer stress, and a significantly better provision of care. And best of all, the person living with dementia may be able to stay at home for much longer.

Case study: Brian’s story
Brian Johnson was a much-loved Rugby League player, who began his career with the St George Dragons in the 1980s, before moving to the UK to play for Warrington. Much to the dismay of Brian and his wife Karen, when they returned to Australia, Brian was diagnosed with Younger Onset Dementia at the age of 54, in 2010. Sadly, he passed away from Alzheimer’s Disease in January 2016, age 59.

Three years ago, Karen and Brian took part in Going to Stay At Home as part of a Younger Onset group. Below she shares her experience:

“The main benefit to me from the program is that it existed. It made my role as carer for Brian seem real and recognised as worthwhile, not just the next stage in being his wife. Instead of fumbling through the changes in his personality, abilities and behaviour it showed me what to expect and gave me strategies for dealing with the changes. I particularly liked the practical advice from the nurses and psychologist. I wasn’t aware of what to expect in regards to his diminishing ability to get in and out of bed, chairs, the car – even doors… I thought he would carry on as usual but just forget who I was.

From GTSAH I learnt where to get help, which government department to contact for what. I also learned a great deal from living in for 7 days with other couples in the same position. It was comforting to share our problems, solutions and experiences. It really helped knowing we were not alone and that we could spend very normal happy times with other people, despite coping with challenges.

By the end of the course I felt empowered to take on the challenges of caring for Brian at home. I am sure that if I had not done the course I would have listened to all the people telling me it would be too hard.

I cannot imagine how hard life would have been for both of us if I had placed him in a home, gone back to work and tried to visit him every day. I would have had to sell our house to pay the fees, I would have missed him terribly and he would have been miserable. I feel now that I did everything I could physically and emotionally to look after Brian. I am so grateful for learning that I did not have to place him – that life is easier on the path we chose.”
“Something that could potentially be quite transformative in aged care”.

The problem.
It can be very distressing to have someone else take responsibility for your intimate personal care, particularly if you are living with dementia. It’s also very demanding for family carers and care workers. Assistance with toileting is the most frequently performed intimate personal care activity in aged care, with one Australian study showing toileting comprises 21% of all tasks that staff do during their daily routines.

The research.
HammondCare is supporting research that is examining whether the electronic toilet seat replacement bidet – a ‘washing toilet’ - can give back dignity to older people while promoting other health and wellbeing benefits.

Between 2009 and 2011 Meredith Gresham ran an assistive technology project with family carers of HammondAtHome community clients, matching novel technologies to the needs of the carer for the support of the older person. One stand-out technology was the electronic toilet-top bidet. 16 bidets were installed in people’s homes and almost all were an instant success.

Carers reported that they brought new levels of privacy and dignity in toileting care for people living with dementia and frail older people; a matter of great comfort for both the client, and their carer. Carers also reported additional, unexpected benefits: they required fewer incontinence pads and clients appeared to experience fewer urinary tract infections. These reports were just too consistent to be ignored.

Meredith set about testing these reports in the more controlled setting of residential aged care, asking first if bidets would be feasible in residential aged care and then testing the clinical efficacy of this new way of managing toileting care. Five years later, in what’s become Meredith’s PhD, the research is in its third and final stage.

The project began with a feasibility study to take a closer look at some of these anecdotal findings. As part of this study, we installed 7 bidets in Ashley cottage at HammondCare’s Woy Woy home.

There were a lot of concerns.
How would the residents react? What support would they need to adjust to the new approach? What sort of support would be needed from staff? Contrary to most concerns, we’ve found residents adapted quickly. Some have really embraced it.

For example, at Woy Woy staff told us about an experience with one resident who has significantly reduced communication ability. Experiencing the distressing effects of constipation, this resident looked at her careworker and said with great clarity, “Put the water on!”. She knew the warm water stream from the bidet was comforting and helpful.

We found that it takes a while for staff to adjust care routines to the technology and develop the techniques for using it with individual residents. However, with time the bidet has become ‘business as usual’. Bidets are incorporated in to daily care at Ashley cottage.

In the process, staff have remarked upon a range of positive changes, supporting claims of the family carers that they were using fewer incontinence pads, treating less UTIs and the technology appeared reduced their risk of back injuries.

The learnings of the feasibility study at Woy Woy have now fed into two controlled pilot studies, one in Victoria in 2015 and one in NSW in 2016.

In Victoria we had bidets installed in ensuites of 16 residents and compared with 16 residents who received usual care.

In the NSW pilot study we monitored resident acceptance and staff use of the bidet, measured bacterial load in urine of residents over the study and measured other health and well being changes associate with the new technology.

Because this research is conducted in the real world aged care, all of the difficulties of implementation are being thrown up as we do the research: everything from how do we introduce the bidet and support residents during its use to how we support staff to use the bidet. Rather than a clinical efficacy study, it has turned out to be just as much a study about culture change.

The outcome.
A third stage of the research has begun this year. We are replicating the controlled trial from Victoria, in NSW.
We learned that experience is the greatest teacher. We installed a bidet in the staff toilet to help the staff understand not only operation, but the sensation of using a bidet in order that they confidently support residents. It’s had a profound effect upon how staff respond to using the bidet in their daily work.

“I am really hoping that applying learnings from the first two trials will mean we will get consistency of use of the bidet with residents in the third trial. Even though our numbers of residents involved has been very small, the bidet is something that could be potentially quite transformative in aged care,” says Meredith.
“What we did was basically show that rehabilitating cancer patients works”.

The problem.

As their disease progresses, many cancer patients lose the ability to do everyday tasks independently. From showering, to walking, to getting into cars, to going up and down stairs, to swallowing, cancer patients can develop new and frustrating disabilities. For a long time, cancer patients weren’t offered rehabilitation therapy, because many thought they might not have more than a few years or months to live, making an investment in therapy time and effort not worthwhile. Research has challenged this view.

The research.

In the mid-1990s, HammondCare’s Chief Medical Officer and Rehabilitation Specialist A/Prof Andrew Cole became unsatisfied with the care of cancer patients with disability, while he was working in east Asia.

“One of the ladies I went to see lived in a very small farmhouse. I was there to see her for palliative care after treatment for cancer. But I thought, ‘no, this lady is not yet needing palliative care, she needs rehabilitation’. So I made recommendations about her bedding, bowel and bladder management, wheelchair access to her home, and a few other things – I gave her a basic rehab program.”

A/Prof Cole then looked up what research had been done in the area of cancer rehabilitation, only to find very little. The following year, in 1996, after returning to work in Sydney, A/Prof Cole and other staff began providing rehab for cancer patients at Sydney’s Braeside Hospital, and researching the effectiveness of cancer rehabilitation.

They recruited enough patients with and without cancer to do a case-control study. The outcomes for patients with various types of cancer disability were compared with patients without cancer experiencing similar disabilities. For example, the outcomes of rehabilitation of patients with brain tumours was compared with those of rehabilitation of stroke patients, patients with spinal tumours compared with patients with disc injuries, patients experiencing muscle wasting from chemotherapy and prolonged bed rest were compared with frail aged patients and so on.

Over 10 years, they recruited 180 cancer patients and matched them to “benign” patients, measuring their rehabilitation outcomes.

The research clearly showed that both groups of patients stayed in hospital for about the same length of time, their ability and “functional status” improvements were not significantly different, and about as many people went back home successfully, as needed to go to nursing home care.

The outcome.

20 years on, and Australasia’s first ever specifically dedicated cancer rehabilitation ward, The Jacaranda Ward, has just opened at HammondCare’s Greenwich Hospital.

“What we did was basically show that rehabilitating cancer patients works,” says A/Prof Cole.

He says it’s been immensely satisfying 20 years on, after dreaming of such a thing in 1995. “It feels wonderful to know that there is a need being fulfilled. And to have College trainees in rehabilitation-related disciplines coming up through the ranks actually asking to be allocated to a term that includes work in a ward like Jacaranda, is very exciting.”

Case study: Stephen’s story

Stephen lives on a farm near the Snowy Mountains in NSW. In his late 50s, he was diagnosed with prostate cancer after a routine check-up at the GP.

If that wasn’t enough, soon after his cancer diagnosis, Stephen started to lose function in his legs. “I noticed they were getting weaker and weaker. I just thought my legs were being a bit lazy, and we’d get them going. But they just kept getting worse.”

Stephen was diagnosed with Cauda Equina Syndrome, a condition where the nerve bundle at the base of the spine is damaged, interrupting signals from the brain to the legs. The neurological problem was somehow linked to the cancer. Stephen found it difficult coming to terms with being paralysed from the waist down.

“My legs are what drive me insane. I’ve never been terms with being paralysed from the waist down. And you couldn’t get better. Everything’s here that you were going to do and then we found Jacaranda and about as many people went back home successfully, as needed to go to nursing home care.”

Stephen was the first patient to be admitted to HammondCare’s Jacaranda Ward on the day it opened, September 1, 2015.

While at Jacaranda, every day Stephen was wheeled up to the rehabilitation gym where a physiotherapist had him using a tilt-table to help bring muscle strength back to his legs. And every day he was taken up the road to another hospital for radiation therapy.

As it’s a multi-disciplinary ward, he was also seen by a dietician and other allied health staff, as well as a range of specialist physicians.

A/Prof Cole says accessing rehabilitation has significantly improved Stephen’s quality of life.

“What we were able to do for him was to get him to the point where he was able to get himself on and off his wheelchair, on and off the bed, in and out of the shower and to the point that he could go back to his farm.”

“He went from thinking ‘What am I going to do?’ to being able to live with his disability in his chosen situation. And that is what we aim to achieve.”

Stephen couldn’t be happier.

“It’s a winner. We were stumped about what we were going to do and then we found Jacaranda Ward. I’m very lucky. How could you get better? You couldn’t get better. Everything’s here that you need.”
The value of cottage respite: better care, more choice and major cost benefits.

The problem.

Respite for home-based carers provides vital support. It gives them a much-needed break from their caring role, knowing that the person they care for is being well looked after. But overnight cottage respite is an expensive form of respite, largely funded by the Federal Government. We wanted to know: is it worth the expense? Is it cost effective? Does it prevent or delay permanent residential placement?

The research.

HammondCare provides respite through two purpose-built cottages that can accommodate a maximum of five people each, for up to ten days at a time. Because of the small scale and individual care provided in the cottages, this kind of cottage respite is more expensive than respite in nursing homes.

The Cottage Respite Study, led by Associate Professor Chris Poulos, Hammond Chair of Positive Ageing at the University of NSW, contacted people who had used a HammondCare respite cottage on two or more occasions over a two year period (October 2012 to September 2014). The study sought information from carers on their perceptions of the cottage model of respite care, the value it was to them, and whether it had enabled the person living with dementia they cared for to stay at home for longer.

The study was conducted in 2015.

136 carers were interviewed by phone using a specially designed survey. This represented an excellent response rate of about 80%. Five of these carers also participated in an in-depth telephone interview.

One of the main findings of the study was that, on average, the carers reported that their use of cottage respite delayed placement in residential care by about a year. While that was the average, responses varied greatly, with some carers reporting that it delayed placement by years.

The above savings were based on the current occupancy rate of the two respite cottages of 65%. Strategies that increase the occupancy rate would result in even greater savings to government.

The problem.

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One of the main findings of the study was that, on average, the carers reported that their use of cottage respite delayed placement in residential care by about a year. While that was the average, responses varied greatly, with some carers reporting that it delayed placement by years.

A key insight that emerged was that the people who use this service really like using it. They like the fact that it’s small, and that it delayed placement by years.

The above savings were based on the current occupancy rate of the two respite cottages of 65%. Strategies that increase the occupancy rate would result in even greater savings to government.

The outcome.

"Basically, we found that cottage respite delays placement into permanent care, saves the Government money in the process, and, importantly, people like it and it gives them more choice in the type of care available," says Assoc Prof Poulos.

"And even though cottage respite is an expensive model of care, it seems very effective in helping people to be cared for at home and is still very cost-effective."

Case study: David’s story

Jenny and David are 68-years-old, and live in Sydney’s North. David has younger onset dementia and Jenny cares for him at home. She also works 3 days a week as a music teacher at a primary school, juggling work, caring for David and co-ordinating his care when she can’t be there.

To give herself a break from her caring role, Jenny has been using HammondCare’s Lucinda and Woonona respite cottages since 2014.

“It’s my sanity, and David loves it,” she says. “Most of the time I feel like a rubber band that is completely stretched. Work is great, but stressful, and caring for David is a full-time job in itself. But when he goes to Lucinda Cottage it gives him a lovely environment, he’s happy, and I don’t have to do anything for him, I can fully relax.”

Jenny says having access to cottage respite has enabled her to keep David at home for longer.

“I live from respite to respite. I wouldn’t have cracked long ago had it not been for respite, and I wouldn’t’ve looked for full time care options a lot earlier.”

She says the style and size of HammondCare’s cottage respite is appealing to her and David, as it’s more homely.

“We have a joke actually that it’s nicer than home. We talk about it being David’s motel or his ‘heritage home’. He loves the pool table at Lucinda, because he used to play snooker, and it’s good for him to be standing because he has a catheter and leg bag that make it uncomfortable for him to sit.”

“Last weekend we turned up to drop David off and there were three men sitting around the kitchen bench making jokes, and I thought, this is a much more stimulating environment for David than being at home. He doesn’t get this kind of social life at home.”

“I wish we had 10 Woononas or Lucindas. We need more of them. I know others in my situation and we all rely heavily on it.”

Looking at the economics of cottage respite another way, for a government outlay of $2.5 million dollars on cottage respite, plus community care, the Government saves around $4.0 million in nursing home care, resulting in a net saving to Government of around $1.5 million dollars.

We conducted an economic analysis to try and put a ‘dollar value’ on the benefits of cottage respite.

The cost of permanent nursing home placement to the Government for someone in high care is about $70,000 per year. Taking this figure, and then factoring in the cost of a Commonwealth funded home care package, as well as the cost of cottage respite, our economic analysis showed that the saving to Government is still around $27,000 per respite cottage user.

The research.

HammondCare provides respite through two purpose-built cottages that can accommodate a maximum of five people each, for up to ten days at a time. Because of the small scale and individual care provided in the cottages, this kind of cottage respite is more expensive than respite in nursing homes.

The Cottage Respite Study, led by Associate Professor Chris Poulos, Hammond Chair of Positive Ageing at the University of NSW, contacted people who had used a HammondCare respite cottage on two or more occasions over a two year period (October 2012 to September 2014). The study sought information from carers on their perceptions of the cottage model of respite care, the value it was to them, and whether it had enabled the person living with dementia they cared for to stay at home for longer.

The study was conducted in 2015.

136 carers were interviewed by phone using a specially designed survey. This represented an excellent response rate of about 80%. Five of these carers also participated in an in-depth telephone interview.

One of the main findings of the study was that, on average, the carers reported that their use of cottage respite delayed placement in residential care by about a year. While that was the average, responses varied greatly, with some carers reporting that it delayed placement by years.

A key insight that emerged was that the people who use this service really like using it. They like the fact that it’s small, and that it delayed placement by years.

The above savings were based on the current occupancy rate of the two respite cottages of 65%. Strategies that increase the occupancy rate would result in even greater savings to government.

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Research projects

Palliative Care
Dementia + Mental Health
Ageing, Restorative Care
+ Reablement
Rehabilitation
Pain + Spinal Cord Injury
Advanced Care Planning
Spiritual Dimension
Management of constipation in palliative care Can less be better? study

Multi-Site Clinical Trial

Constipation is a highly prevalent symptom in palliative care and residential aged care, and associated with significant distress for patients and caregivers. It is also a leading cause of avoidable hospital presentations. Better management of constipation will improve quality of life, but will also allow more efficient use of health care resources.

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrnyowsky
Site: Braeside Hospital
Researchers: Associate Professor Melanie Lovell, Ms Alison Hesson & Ms Bronwyn Raymond
Site: Greenwich Hospital
Duration: Nov 12 to Jun 16
Funding Source: Department of Health & Ageing (DoHA)
Project Partners: Palliative Care Clinical Studies Collaborative (PaCCSC)
Status: Closed to recruitment, analysis in progress

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

Multi-Site Clinical Trial

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

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrnyowsky
Site: Braeside Hospital
Duration: Jun 11 to Mar 17
Funding Source: DoHA & PaCCSC
Project Partners: PaCCSC
Status: In Progress

A randomised, double-blind, multi-site, parallel arm controlled trial to assess relief of refractory breathlessness comparing fixed doses of morphine, oxycodone and placebo

Multi-Site Clinical Trial

Refractory breathlessness is one of the most distressing symptoms our patients and caregivers face. It affects the ability to sleep and function independently and is strongly correlated with sensations of panic and anxiety. Sertraline shows some promise as an agent to manage this symptom, where very few treatments are available.

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrnyowsky
Site: Braeside Hospital
Duration: Nov 10 to Jun 17
Funding Source: DOHA/ PaCCSC/ NHMRC
Project Partners: PaCCSC
Status: In Progress

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

Multi-Site Clinical Trial

Delirium occurs in over one third of patients admitted to palliative care, increasing to 80% in the days before death. Delirium causes highly distressing symptoms including loss of cognition, behavioural disturbance and perceptual disturbances. Delirium is also predictive of risk of anxiety disorders in the caregiver who witnesses it in a loved one. There is currently no medication registered for delirium treatment.

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrnyowsky
Site: Braeside Hospital
Duration: May 13 to Jul 17
Funding Source: Cancer Institute NSW, PaCCSC infrastructure support and ImPaCCT
Project Partners: University of Technology Sydney
Status: In Progress

Carers’ perspectives on, and expectations of, the use of long term home oxygen therapy for the treatment of refractory breathlessness

Multi-Site Study

The aim of this study is to understand the prescribing of oxygen for those people who do not qualify for publicly funded home oxygen.

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky
Site: Braeside Hospital
Duration: Jun 11 to Feb 17
Funding Source: DOHA & PaCCSC
Project Partners: PaCCSC
Status: In Progress

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

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrnyowsky
Site: Braeside Hospital
Duration: Jun 11 to Feb 17
Funding Source: DOHA & PaCCSC
Project Partners: PaCCSC
Status: In Progress

Randomised, double blinded placebo controlled pilot phase II trial of oral melatonin for the prevention of delirium in hospital cancer patients

Multi-Site Clinical Trial

Delirium in patients admitted to palliative care is common and distressing.

It is a potential treatment for delirium which has implications not only for palliative care, but also aged care where delirium is also highly prevalent. If delirium can be prevented it also has a huge economic advantage, given it is highly costly to informal caregivers at home, and for Residential Aged Care and health care systems once it occurs.

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrnyowsky
Site: Jacaranda Unit, Hammondville
Duration: May 12 to Dec 15
Funding Source: DoHA
Project Partners: None
Status: Closed

Randomised controlled trial of oral risperidone versus oral haloperidol versus oral placebo with rescue subcutaneous midazolam in the management of delirium in palliative care patients

Multi-Site Clinical Trial

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

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrnyowsky
Site: Braeside Hospital
Duration: May 13 to Jul 17
Funding Source: Cancer Institute NSW, PaCCSC infrastructure support and ImPaCCT
Project Partners: University of Technology Sydney
Status: In Progress

Improving palliative care for people with advanced dementia living in residential aged care

Multi-Site Study

Care for people with advanced dementia requires an evidence-based, multi-disciplinary palliative approach that is targeted to specific issues which occur as dementia progresses and tailored to the needs of each individual and his/her family.

Facilitated case conferencing (FCC) has improved outcomes in other palliative settings but evidence is lacking for Residential Aged Care Residents with advanced dementia. This study aims to gain this evidence so as to be armed with data which can inform funding models and policy.

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrnyowsky
Site: Jacaranda Unit, Hammondville
Duration: May 12 to Dec 15
Funding Source: DoHA
Project Partners: None
Status: Closed

Translational Outcomes:
This project has resulted in national resources to guide case conferences for people with advanced dementia that ensure shared decision making and the best care outcomes for the person with dementia and their families. The resources are free and can be found at: www.caresearch.com.au/ DementiaCaseConferencing

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Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrnyowsky
Site: Jacaranda Unit, Hammondville
Duration: May 12 to Dec 15
Funding Source: DoHA
Project Partners: None
Status: Closed

Translational Outcomes:
This project has resulted in national resources to guide case conferences for people with advanced dementia that ensure shared decision making and the best care outcomes for the person with dementia and their families. The resources are free and can be found at: www.caresearch.com.au/ DementiaCaseConferencing
Palliative care suite evaluation - Lavender Suite
This project was the initial evaluation of the Lavender Suite at HammondCare. HammondCare is committed to evaluating the outcomes of this new model of palliative care delivered in a residential setting to ensure the outcomes expected are delivered and to allow feedback for ongoing improvement.

Project Partners: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrnyowsky
Site: Braeside Hospital
Duration: Jan 13 to Nov 17
Funding Source: Internally Supported
Project Partners: None
Study Status: In Progress

A sustainable and supported clinical pathway for managing anxiety and depression in cancer patients: Developing and evaluating components and testing implementation strategies
Multi-Site Study
This project will inform better and more streamlined psychosocial care of our patients.

Project Partners: Researchers: Professor Phyllis Butow (lead), Associate Professor Josephine Clayton (one of the Chief Investigators)
Site: Greenwich Hospital
Duration: Jun 15 to Jun 20
Funding Source: Funded by Cancer Institute NSW & funds administered by USyd
Project Partners: PaCoG, Sydney Catalyst; Centre for Medical Psychology and Evidence Based Decision Making, University of Sydney
Study Status: In Progress

Exploring the role of clinical psychology in community palliative care: Identifying patients’ psychological needs through ‘real-world’ clinical data
Results of the study will identify the most common patient issues encountered by a clinical psychologist working in community palliative care.

This will be used to clarify the role of clinical psychologists in these services and identify priority areas for professional development.

Researcher: Mr Geoffrey Lyons (University of Wollongong)
Sites: Greenwich & Werrington Hospitals
Duration: Jul 13 to Dec 16
Funding Source: Administered by University of Wollongong
Project Partners: Not Applicable
Study Status: In Progress

Management of nausea in cancer patients - study 1
Multi-Site Clinical Trial
Nausea is a highly prevalent symptom in palliative care which causes poor quality of life and impacts caregivers because the patient does not feel like eating.

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

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrnyowsky
Site: Braeside Hospital
Duration: Mar 09 to May 17
Funding Source: National Health and Medical Research Council (NHMRC) & PaCCSC
Project Partners: None
Study Status: Closed to recruitment, analysis in progress

Project Partners: Queensland University of Technology
Study Status: Closed to recruitment, analysis in progress

Randomised, double blind control of megestrol acetate, dexmethylasone and placebo in the management of anorexia in people with advanced cancer
Multi-Site Clinical Trial
This study is exploring medication to improve appetite in people with advanced illness.

Mestrol acetate is not licensed or subsidised for this indication and if this study is positive, application to the TGA and PBAC will be pursued to ensure treatments to improve appetite are widely available. This study has been particularly important for the culturally and linguistically diverse population in South West Sydney, where great importance is placed on being able to eat and enjoy food by patients and caregivers in these communities.

Researchers: Associate Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrnyowsky
Site: Braeside Hospital
Duration: Jul 12 to May 17
Funding Source: DoHA
Project Partners: PaCCSC
Study Status: Closed to recruitment, analysis in progress

Can death from chronic life-limiting illnesses be predicted in Australian general practice?
Multi-Site Study

This programme 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.

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrnyowsky
Site: Braeside Hospital
Duration: Jun 11 to Jun 19
Funding Source: Associate Professor Melanie Lovell, Dr Bridget Johnson, Ms Alison Hession & Bronwyn Raymond
Site: Greenwich Hospital
Duration: May 11 to Jun 19
Funding Source: PaCCSC Project Partners: PaCCSC
Study Status: In Progress

Improving quality of life at end of life: a randomised control trial of a doctor/nurse/patient intervention
Multi-Site Study

This is a multi-site study of a nurse facilitated intervention to improve end of life care for patients with cancer.

This study will inform our clinical practice for cancer patients and involves collaborations with researchers in the USA as well as across Sydney.

Researchers: Associate Professor Josephine Clayton
Site: Greenwich Hospital
Duration: Jul 09 to Jul 16
Funding Source: Funded by NHMRC administered by USyd
Project Partners: External PhD supervision (Sydney University) & NHMRC grant with various collaborations
Study Status: In Progress

Rapid report of pharmacovigilance program
Multi-Site Study
It is important clinicians monitor patients when they are started on a new medication, both for evidence that the medication is working and for side effects.

This programme 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.

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrnyowsky
Site: Braeside Hospital
Duration: Jun 11 to Jun 19
Funding Source: Associate Professor Melanie Lovell, Dr Bridget Johnson, Ms Alison Hession & Bronwyn Raymond
Site: Greenwich Hospital
Duration: May 11 to Jun 19
Funding Source: PaCCSC Project Partners: PaCCSC
Study Status: In Progress

The experience of dying away from birth country for transnationals
This study will assist in the provision of palliative care to transnationals in the HammondCare service.

Researcher: Professor Roderick MacLeod (PhD Supervision)
Site: Off-Site research
Duration: Aug 11 to Aug 16
Funding Source: Internally Supported
Project Partners: None
Study Status: In Progress

End Of Life in Northern Sydney Local Health District
Multi-Site Study

This study will assist in understanding the provision of end-of-life care in acute settings and any deficiencies.

Researchers: Professor Roderick MacLeod
Site: Greenwich Hospital
Duration: Mar 13 to Feb 16
Funding Source: Funded by NSW Health
Project Partners: None
Study Status: In Progress

ACCeRT Study: Auckland’s Cancer Cachexia evaluating Resistance Training Study - A randomised feasibility study of EPA and Cox-2 inhibitor (Celebrex) versus EPA, Cox-2 inhibitor (Celebrex), Resistance Training followed by ingestion of essential amino acids high in leucine in NSCLC cachectic patients
This study will assist in the planning of clinics at HammondCare for the amelioration of effects of cancer cachexia which is the loss of skeletal muscle mass with or without loss of fat mass.

Researchers: Professor Roderick MacLeod (PhD Supervision)
Site: Off-Site research
Duration: Sept 11 to Mar 16
Funding Source: Internally Supported
Project Partners: None
Study Status: In Progress
Collaborative practice in palliative care

This study will help HammondCare in understanding what collaborative practice actually means.

Researcher: Professor Roderick MacLeod (PhD Supervision)
Site: Off-site research
Duration: Aug 11 to Mar 16
Funding Source: Internally Supported
Project Partners: None
Study Status: In Progress

Understanding Care: The Volunteering experience in the space of Palliative Care

Single-Site Study
This project will aim to increase our understanding of the role of volunteers in enhancing patient quality of care in the palliative care setting.

Researcher: Ms Hoi Birman (UNSW)
Sites: Greenwich, Braeside & Neringah Hospitals
Duration: Jun 14 to Aug 16
Funding Source: Administered by UNSW
Project Partners: Not Applicable
Study Status: In Progress

Evaluating Community Palliative Care Teams

This evaluation will enable estimation of the value of the Community Palliative Care service to patients and families. It will also indicate how HammondCare's contribution to these people in need can be optimised.

Researchers: Associate Professor Roslyn Poulos (UNSW), Professor Rod MacLeod, Associate Professor Christopher Poulos, Associate Professor Andrew Cole, Ms Kristine Apitz & Mr Damian Harkin
Sites: Greenwich Hospital; Local Health Districts: Central Coast, Far Western NSW, Murrumbidgee, Northern Sydney, South East Sydney, Southern NSW, Western NSW
Duration: Oct 14 to Jun 16

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

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

Researchers: Ms Katherine Kelly and Ms Kerry Gilson
Site: Braeside Hospital
Duration: Jul 15 to Jun 16
Funding Source: Internally Supported
Project Partners: None
Study Status: In Progress

An exploration of patient experiences of multiple symptoms in palliative care

Multi-Site Study
It is well recognised that patients receiving palliative care often have multiple symptom patterns which may interact in a multiplicative rather than additive fashion.

This study aimed to understand the patient experience of multiple symptoms in order to lead to better assessment, management and care.

Researchers: Associate Professor Melanie Lovell, Ms Skye Dong and Professor Phyllis Butow
Site: Greenwich Hospital
Duration: Dec 14 to Jul 15
Funding Source: Internally Supported
Project Partners: University of Sydney
Study Status: Completed

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

Multi-Site Study
This study aims to assess the clinical benefit of PAX 1 on pain intensity, and also ensure it isn’t associated with adverse effects that outweigh its potential benefit.

A phase III trial would then be undertaken to confirm these results, to allow the agent to be available more widely in clinical practice. This project provides our clients’ access to a novel agent for cancer pain. The management of cancer pain is core business for our palliative care services, and this project ensures the evaluation of new treatments which might allow us to better manage more complex cancer pain.

Researchers: Professor Meera Agar, Ms Julie Wilcock & Ms Natalie Ohrynowsky
Site: Braeside Hospital
Duration: Jun 15 to Dec 16
Funding Source: Flinders University Project Partners: Bio and Gene University
Study Status: In Progress

Decision Assist Training Program

This education project will aim to improve palliative care skills and advice by staff in aged care facilities, and advance care planning.

Team Members: Ms Margaret Brown, Ms Pauline Luttrill, Ms Cheryl Johnson & Associate Professor Josephine Clayton
Sites: Various
Duration: Sept 14 to Dec 15
Funding Source: DoHa (Austin Health)
Project Partners: Respecting Patient Choices Program (Austin Health)
Status: Completed
Training Outcomes: The level of promotion and marketing of workshops led to a smaller number of participants than expected, and cancellation of some workshops. This was evidenced most strongly in the community sector and the ability of Residential Aged Care Facilities and Community Service Providers to release sufficient staff to attend the workshops was problematic.

Decision Assist Training

This study aimed to understand the experience of multiple symptoms in order to lead to better assessment, management and care.

Researchers: Associate Professor Melanie Lovell, Ms Skye Dong and Professor Phyllis Butow
Site: Greenwich Hospital
Duration: Dec 14 to Jul 15
Funding Source: Internally Supported
Project Partners: University of Sydney
Study Status: Completed

Transitional Outcome: This research sheds light into the multiple symptom experience for patients and health professionals managing them, which will hopefully improve symptom management pathways and integrated, co-ordinated care. Clinical implications in the assessment and management of both symptom clusters and psychosocial issues are outlined in our papers.

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

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

Researchers: Professor Roderick MacLeod, Dr Matra Robertson, ProfessorCantidad Duggleby and Ms Jenny Broadbent
Site: Greenwich Hospital; Neringah Hospitals; Northern Sydney Local Health District; University of Sydney
Duration: Dec 15 to Aug 17
Funding Source: University Of Notre Dame
Project Partners: Calvary Health Care Kogarah; Department of Forensic Medicine, Sydney
Study Status: In Progress

Stop Cancer Pain

Multi-Site Study
Improved pain outcomes for patients and improved staff satisfaction and improved international and national profile for HammondCare.

Researchers: Associate Professor Melanie Lovell, Ms Bronwyn Raymond, Ms Jane Phillips & Mr Tim Luckett UTSC; Professor Fran Boyle USyd
Site: Off-site research
Duration: Nov 14 to Nov 18
Funding Source: National Breast Cancer Foundation
Project Partners: University of Technology Sydney and Sydney University
Study Status: In Progress

This study will assist in leading to further knowledge in the area of Cannabis use in advanced cancer patients and lead to evidence based practice in patients suffering with weight loss, appetite and taste loss.

Data will be added to a larger sample from other sites and analysed. Findings will at this stage lead to a larger study that will answer questions about the usefulness of cannabis in the proposed setting.

Researchers: Associate Professor Melanie Lovell, Ms Bronwyn Raymond, Dr Bridget Johnson, Professor Jane Phillips UTSC; Dr Caitlin Sheehan Calvary Hospital; Dr Rajeesh Aggarwal Liverpool Hospital; A/Prof Meera Agar Braeside Hospital; Dr David Allsop University of Sydney
Site: Greenwich Hospital
Duration: Aug 15 to Jun 16
Funding Source: Internally Supported Project Partners: ImPACT & PaCCSG
Study Status: Closed to recruitment, analysis in progress

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

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

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

Researchers: Dr Hilary Stel, Associate Professor Josephine Clayton and Dr Ben Foster
Site: Off-site research
Duration: Aug 15 to Jun 16
Funding Source: Internally Supported
Project Partners: None
Study Status: In Progress
26 Dementia+Mental Health Projects

A health economic model for the development and evaluation of innovations in aged care: an application to consumer directed care

Firstly, the project aims to develop health economics modelling about the cost of the new Consumer Directed Care (CDC) model, which is being rolled out as national policy.

Secondly, in order to build these models, the researchers are conducting in-depth workshops (including with HammondAtHome clients) on the priorities of clients. Finally, the research is also interested in the relevant administrators within the Department of Social Services and the benefits the industry through a cooperative research partnership with the researchers in the research with Catholic Community Services, Helping Hand Aged Care and ACH Group.

HammondCare Liaison: Rebecca Forbes, with Researchers based at Flinders University Site: HammondAtHome Central Coast & Hunter & South West Sydney. Duration: Apr 12 to Jun 16

Funding Source: Australian Government Department of Social Services. Project Partners: HammondCare Collaborative Research Centre (Assessment and Better Care) University of NSW. Study Status: In Progress

The nature of grief in family and professional caregivers of people with dementia

This study will inform HammondCare about aspects of grief in carers in dementia units.

Researchers: Professor Roderick MacLeod (PhD Supervision) Site: Off-Site research Duration: Aug 11 to Jun 16

Funding Source: Internally Supported Project Partners: None Study Status: Suspended

Going to stay at home

This project is providing a 6 day intensive, comprehensive, residential carer education and support program designed to provide family carers with the tools to manage their journey with a family member with dementia.

The program provides a working example of an innovative way of utilizing capital resources such as residential cottages, respite cottages now and in the future. This model could be adopted as part of Consumer Directed Care offerings. The going-to-stay-at-home model has significant potential to form a basis for management of long-term chronic conditions in the community.

This program is being replicated as a Randomised Controlled Trial in Rotterdam, The Netherlands led by Dr Betty Birkinhager, an elder care physician from Laurentius. Dr Birkinhager and psychologist Jannet van Kauften spent time in Australia speaking with staff and former participants of the program to support their trial commencing in May 2016.

Researchers: Ms Meredith Gresham, Mr Jason Li, Ms Deborah Moore, Ms Rebecca Forbes, Professor Henry Brodaty, Ms Megan Heffernan & Ms Ruby Tsang Site: Now at evaluation stage Duration: Aug 12 to Jun 19

Funding Source: Australian Government Department of Social Services. Project Partners: Dementia Collaborative Research Centre (Assessment and Better Care) University of NSW. Study Status: In Progress

Exploring the value of overnight cottage respite

To explore the cost effectiveness of Cottage respite to carers (primary caregivers of people with dementia), including the value of Cottage Respite in preventing or delaying permanent residential placement.

Researchers: Associate Professor Chris Poulos & Ms Mary-Rose Birch Site: Lucinda Cottage & Woonaon Cottage Duration: May 15 to Jun 16 Funding Source: Internally Supported Project Partners: None Study Status: In Progress

Functional & symptomatic outcomes of psychogeriatric patients in Riverglen inpatient unit

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

Researchers: Associate Professor Janine Stevenson Sites: Greenwich Hospital Duration: Apr 14 to Apr 17

Funding Source: Internally Supported Project Partners: None Study Status: In Progress

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

Stage 1 (completed): Incorporating consumer opinions into dementia care in residential age care service configurations: what is important to people with dementia and their family members. This project will benefit HammondCare by providing an opportunity to develop an understanding of the key determinants of a good residential aged care experience from the perspective of people with dementia and their family members, which will both benefit those providing and designing services at HammondCare, as well as providing this information for use across the sector. In addition, this will provide an opportunity for staff at HammondCare to participate in research and gain capacity in conducting research, an important benefit given the need for research in the future to improve the care of those with dementia.

Stage 2 & 3 (in progress): This project aims to determine the outcomes (specifically quality of life, quality of care, and utilization of healthcare resources) and the costs to operate alternative ways of providing residential aged care for people with cognitive impairment and dementia. This will provide HammondCare with information on the outcomes provided by alternative ways of providing residential care for people with dementia.

Stage 4 (completed) decision of facility level costs. This project will benefit HammondCare by providing an opportunity to develop an understanding of the key determinants of a good residential aged care experience from the perspective of people with dementia and their family members, which will both benefit those providing and designing services at HammondCare, as well as providing this information for use across the sector. In addition, this will provide an opportunity for staff at HammondCare to participate in research and gain capacity in conducting research, an important benefit given the need for research in the future to improve the care of those with dementia.
The effects of regulation on aged care services for people with cognitive decline

This project will lead to greater understanding on how regulations such as rules, standards, guidelines, conventions and norms, influence and shape dementia care in different settings.

It is expected the outcomes will enhance the effective delivery of care, and prioritise the needs, desires and rights of people with dementia. A series of policy recommendations on aged and dementia care regulations will also result from this research.

Lead Investigator: Professor Susan Kurrle, University of Sydney
Designated System Based Investigator: Associate Professor Colm Cunningham, Dr Catriona Lorang & Ms Rebecca Forbes
Sites: Not applicable
Duration: Jul 13 to Jun 16
Study Status: In Progress

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

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

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

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

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

Lead Investigators: Professor Sarah Hilmer, University of Sydney and Associate Professor Simon Bell, Monash University
Designated System Based Investigator: Associate Professor Colm Cunningham, Ms Rebecca Forbes & Ms Catriona Lorang
Sites: Various HammondCare care homes.
Duration: Stage 1: Jun 14 to Aug 14 and Stage 2: Sept 14 to Dec 16
Study Status: Stage 1: Completed and Stage 2: In Progress

Improving quality of residential dementia care and promoting change by supporting and caring for staff

Literature review. This project is examining the relationships between variables involving staff and the quality of care delivered in aged care homes.

Lead Investigator: Dr Mike Bird, University of Bangor, Wales
Designated System Based Investigator: Ms Meredith Gresham
Sites: Not Applicable
Duration: Mar 14 to Dec 18
Project Partners: Flinders University
Study Status: In Progress

Opportunities for improvement in aged care service delivery by Information & Communication Technology (ICT)

This study aims to identify opportunities for improvement in residential aged care service delivery by ICT.

This research study fits in an ongoing program at HammondCare that aims to streamline clinical and financial processes with an ICT solution.

Researchers: Professor Christopher Poulos & Ms Anne Loupis
Sites: Bond House, The Meadows, The Pines, Southwood (Hammondville); Leighton House; Princess Juliana Lodge and Waldegrave House (North Turramurra); HammondCare Woy Woy; HammondCare Hornsby
Duration: Jun 12 to Mar 15
Funding Source: Commonwealth Department of Health and Ageing
Project Partners: School of Public Health and Community Medicine, UNSW
Study Status: Completed

Translational Outcome:
At HammondCare, information and communication technologies have been identified as a possibility for residential aged care facilities to streamline clinical and financial processes. To initiate any organisational innovation, it is critical to identify challenges in present practices or circumstances or significant enhancement opportunities. In this project, participant observations and interviews were conducted with key stakeholders to identify the challenges and opportunities in 8 areas such as care coordination and medication management. With the project findings, business and stakeholders requirements will be elected and specified in a near future for a new residential care management system.

Real Cases, Real Time (TRACS): Teaching and Research Aged Care Services

This study introduced a new teaching model for staff in Residential Aged Care Homes and HammondCare Home settings, using distance education and case method teaching methods.

The outcome is that there will be a direct benefit to HammondCare staff learning and their residents. TRACS is a ten session education project run in two streams. Stream 1 is for professionally registered staff and Stream 2 is for the care worker staff. The project, using case studies, provides education, which constantly reminds staff to consider the patient and/or client in the context as a whole person.

Researchers: Associate Professor Andrew Cole, Professor Christopher Poulos & Ms Anne Loupis
Sites: Bond House, The Meadows, The Pines, Southwood (Hammondville); Leighton House; Princess Juliana Lodge and Waldegrave House (North Turramurra); HammondCare Woy Woy; HammondCare Hornsby
Duration: Jun 12 to Mar 15
Funding Source: Commonwealth Department of Health and Ageing
Project Partners: School of Public Health and Community Medicine, UNSW
Study Status: Completed

Improving carer wellness

Helping carers focus on their own wellness needs. This is a guide for carers to help them understand their own wellness needs, how being a carer can adversely impact on wellness, and strategies for carers to take positive steps towards improved wellness.

Researchers: Professor Christopher Poulos, Dr Damian Harkin & Ms Mary-Rose Birch
Site: Not applicable
Duration: Aug 15 to Jul 17
Funding Source: Department of Social Services
Project Partners: None
Study Status: In Progress

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Site: Not applicable
Duration: Aug 15 to Jul 17
Funding Source: Department of Social Services
Project Partners: None
Study Status: In Progress
Is inpatient rehabilitation necessary after knee replacement? (HIHO study) which includes sub-study:- Determining clinically relevant change in 6-minute walk test (6MWT) following a total knee arthroplasty (TKA)

Main study
If inpatient rehabilitation is shown not to benefit patients following joint replacement, the resources could be redistributed to other patients.

Sub-study: Exploring patient important improvement thresholds for the six minute walk test in a knee arthroplasty cohort

Researcher: Mr Mark Buhagiar
Site: Braeside Hospital
Duration: Jun 12 to Dec 16
Funding Source: HCF Foundation (sub study is internally supported)
Project Partners: South West Sydney (SWSS) LHD, Ingham Institute UNSW
Study Status: In Progress

Validation and confirmation of reliability and sensitivity of the ICF brief core set in stroke patients as an outcome tool in sub-acute setting

The HammondCare unit, where this new assessment tool is tested, is at the leading edge of developing stroke assessment rehabilitation in the world. This study will influence how stroke rehabilitation will be developed throughout the world. ICF is open access and does not cost. Use of the FIM incurs significant costs.

Researchers: Associate Professor Friedbert Kohler
Site: Braeside Hospital
Duration: Jan 12 to Dec 16
Funding Source: In researcher’s own time
Project Partners: None
Study Status: In Progress

Sub-acute tools project. The development of an internationally valid ICF mobility outcome measure

Multi-Site Study
Developing, testing and validating an ICF based mobility assessment tool.

Researchers: Associate Professor Friedbert Kohler
Site: Braeside Hospital
Duration: Dec 14 to Jun 16
Funding Source: Otto Bock Healthcare Foundation
Project Partners: Multiple
Study Status: In Progress

Understanding consumer and clinician preferences for inpatient rehabilitation after joint replacement

Together with the findings of the related RCT, it is expected that this study will contribute to the redesign of the delivery of rehabilitation for total knee arthroplasty (TKA) recipients in particular, and especially in the private sector.

Researchers: Associate Professor Friedbert Kohler
Site: Braeside Hospital
Duration: Dec 12 to Jun 16
Funding Source: Otto Bock Healthcare Foundation
Project Partners: Multiple
Study Status: In Progress

Exercise self-management to improve long-term functioning & prevent falls after hip or pelvic fracture

The results of this study will be directly relevant to the care of older people recovering from fall related fractures. We have designed a program that aims to enhance mobility and prevent falls in this high risk population.

The program involves home visits from a physiotherapist to teach a home exercise program as well as fall prevention strategies. This self-management approach has the potential to have a lasting impact on mobility and falls. If the intervention is found to be effective we will make program resources freely available so they can be implemented broadly.

We will also undertake an economic evaluation so healthcare providers can decide whether any additional benefits from the program warrant the additional cost of providing it.

Researchers: Ms Constance Vogler
Site: Greenwich Hospital
Duration: Jan 09 to Dec 15
Funding Source: Administered by The George Institute for Global Health Australia
Project Partners: Not Applicable
Study Status: Paper submitted

Using the ICF to explore mobility and the factors influencing mobility of individuals with an amputation from the perspective of the professional.

Sub-study of a multi-site study

It is essential to explore and understand the perspective of the professional who treat individuals with an amputation and the differences between the perspectives of professionals and individuals with an amputation.

Exploring this in a multinational setting is the basis for a broad understanding of relevant concepts in the functioning of individuals with an amputation to facilitate the development of the ICF mobility outcome measure.

Researchers: Associate Professor Friedbert Kohler
Site: Braeside Hospital
Duration: Dec 12 to Jun16
Funding Source: Otto Bock Healthcare products and Osseur
Project Partners: Multiple
Study Status: Paper being finalised for submission

Redundancy of transfer items in the Functional Independence Measure (FIM)

The FIM is an outcome measure used in inpatient rehabilitation practice and as part of the funding classification in rehabilitation.

Using the ICF to explore mobility and the factors influencing mobility from the perspective of persons with an amputation.

Sub-study of a multi-site study

It is essential to explore and understand the perspective of the individual with an amputation in provision of quality individualised care.

Exploring this perspective from an international sample facilitates incorporation of relevant and important cultural and geographical aspects of functioning in the development of the ICF mobility outcome measure.

Researchers: Associate Professor Friedbert Kohler
Site: Braeside Hospital
Duration: Dec 12 to Jun 16
Funding Source: Otto Bock Healthcare products and Osseur
Project Partners: Multiple
Study Status: Paper submitted
Thalamic neuroplasticity and pain following spinal cord injury

This project is at the forefront of research investigating the underlying mechanisms of pain following spinal cord injury. Pain following spinal cord injury is common, debilitating and resistant to currently available treatments.

Researchers: Professor Philip Siddall Site: Off-Site research Duration: Jun 12 to May 17
Funding Source: Internally Supported Project Partners: None Study Status: Completed Translational Outcome: Better understanding of the mechanisms underlying this condition, drawing on promising new insights from neuroplasticity research, is leading to exploration of innovative new methods of treatment that target brain plasticity as a novel and potentially effective new approach to treating this type of pain (also refer to publications listing).

Developing a community of practice for knowledge translation and practice improvement in spinal cord injury (SCI) and traumatic brain injury (TBI)

This project builds on the grant looking at a state-wide model of care by a wider project that takes it further to examine implementation and evaluation and brings in interstate and international contributors.

This increases the national and international exposure of the state wide model of care that we are developing and therefore the role of HammondCare in this area of service provision. It also means that we may have a role in delivering a model of care at a national and possibly international level.

Researchers: Professor Philip Siddall Site: Off-Site research Duration: Jun 13 to Dec 16

Outpatient pain self-management program

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

This is essential in disseminating the results of our program and establishing the value of the program, particularly as it takes a new approach. The very positive outcomes we have been achieving have already been noted by the Northern Sydney Local Health District and the NSW Agency for Clinical Innovation with Philip Siddall invited to present the data at a state wide meeting in November 2014. The results are crucial in validating our program.

Researchers: Professor Philip Siddall & Ms Rebecca McCabe Site: Greenwich Hospital Duration: May 11 to Dec 19
Funding Source: Internally Supported Project Partners: None Study Status: In Progress

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

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

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

Researchers: Professor Philip Siddall, Ms Mandy Corbett & Dr Phil Austin Site: Greenwich Hospital Duration: Feb 14 to Dec 17
Funding Source: Australian & NZ College of Anaesthetists Project Partners: University of Sydney Study Status: In Progress

The SCI Pain Course: Examining a low-intensity self-management program for chronic pain and emotional wellbeing among adults with spinal cord injuries

This project involves key researchers in the field of pain management at Macquarie University and Sydney University and aims to develop an on-line pain management program for people with pain following spinal cord injuries.

This project will have important implications for the treatment of people with pain following spinal cord injury, and complements the resources that are also being developed as part of our state wide service at Greenwich Hospital.

Researchers: Professor Philip Siddall Site: Off-site research Duration: May 14 to Dec 16
Funding Source: Lifetime Care and Support Authority Project Partners: Macquarie University, University Sydney, NSW Agency for Clinical Innovation Study Status: In Progress

A clinically relevant tool for assessing pain modulatory pathways

This project will help us understand the contribution of several different mechanisms.

On completion of our research it is hoped we can provide a new and simple technique for the assessment of persistent pain. By doing so, it will enable us to identify potential targets for treatment.

Researchers: Professor Philip Siddall & Dr Phil Austin Site: Greenwich Hospital Duration: Feb 14 to Dec 17
Funding Source: Australian & NZ College of Anaesthetists Project Partners: University of Sydney Study Status: In Progress

Changing the culture of pain management: Addressing the problem of pain for older Australians and people living with dementia (INTERVENE)

Intervene is a research project investigating pain experience and pain management practices in residential aged care (RAC) in Australia.

It has involved data collection across 8 RAC sites in NSW, HC and non HC, retrospective audit of resident notes, resident interviews, staff focus groups, staff knowledge questionnaires and monitoring DBMAS data. Findings show that pain assessment and management for older people fails short of best practice guidelines and is limiting quality of life. Intervene stage 2 is currently seeking funding to improve organisational culture, knowledge and skills in residential aged care.

Researchers: A/Prof Colm Cunningham, Dr William McClean, Prof Philip Siddall, Ms Juliet Kelly Site: Residential and HammondAtHome Duration: Stage 1 Apr 2014 to Sept 2015, Stage 2 June 2016 to June 2018
Funding Source: John T Reid Trust & HammondCare Foundation Project Partners: None Study Status: In Progress
Food waste, dietary intake and nutritional status at Alfred Health: is there a link?

**Single-Site Study**
This project is investigating the wastage of food and fluid in order to assist in developing strategies to help improve dietary intake of inpatients across Alfred Health.

Researchers: Ms Sarah Ryan & Ms Indi Swan, Ms Kudzai Norah Nyamundoro
Site: Caulfield Residential Facility, Melbourne
Duration: Jun 15 to Jun 16
Funding Source: In researchers own time
Study Status: In Progress

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

**Multi-Site Study**
This project will inform better end of life care and education about dying for people with intellectual disability and their caregivers. It will strengthen ties with care providers in ID settings. This in turn will inform our palliative care services caring for people with ID. This project involves international collaborations with an expert in palliative care for people with ID from the UK.

Researchers: Professor Roger Stancliffe (lead), Associate Professor Josephine Clayton (one of the Chief Investigators)
Site: Greenwich Hospital
Duration: Oct 13 to Jun 17
Funding Source: Funded by ARC administered by USyd
Project Partners: Department of Disability and Community, Faculty of Health Sciences, University of Sydney; Sunshine; Keele University, UK
Study Status: In Progress

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

**Multi-Site Randomised Clinical Trial**
This multi-centre project will evaluate an advance care planning intervention for people with incurable cancer. This could in turn help people with incurable cancer to be better prepared for their deaths, be able to participate in decisions about their care, enable their wishes for end of life care to be respected and reduce decision making burden for their loved ones. This will be a landmark study and involves collaborations with key researchers in this area across the country.

Researchers: Professor Martin Tattersall (lead), Associate Professor Josephine Clayton (one of the chief investigators)
Site: Greenwich Hospital
Duration: Jul 13 to Jun 17
Funding Source: Funded by NHMRC administered by USyd
Project Partners: Multiple including: Department of Cancer Medicine; USyd; Respecting Patient Choices Program, Austin Hospital Victoria; CUMPEP USyd
Study Status: In Progress

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Advance Care Planning: Ensuring your wishes are known and honoured

**Multi-Site Study**
This research will help to increase the awareness and knowledge of Advance Care Planning for elderly people in a primary care setting. This will enable elderly people in the community to discuss their wishes for future medical care should they ever become too unwell to participate in decisions. We hypothesise that this will help normalise end of life discussions in the community and improve end of life care for elderly Australians, including people who are served by HammondCare.

Researchers: Associate Professor Josephine Clayton, Dr Abigail Franklin & Dr Joel Rhee
Site: Off-site research
Duration: Jan 15 to Jan 17
Funding Source: Internally Supported
Project Partners: Cremorne Medical Practise, Seaforth Medical Practice, GP Cremorne, Lynwood Medical & Natural Health Centre
Study Status: In Progress

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The Spiritual Dimension

**Projects**

**Spirituality and spiritual care in practice**
To understand what staff think and know about spirituality and spiritual care in order that we can provide more effective care and also to have a basis for professional development in this area.

Researchers: Professor Roderick MacLeod & Dr Phil Austin
Site: Greenwich Hospital
Duration: Mar 14 to Jun 16
Funding Source: Friends of Greenwich
Project Partners: None
Study Status: In Progress

**Levels and associations of existential distress in people with persistent pain**
This project is examining levels of spiritual wellbeing in people with chronic pain.

The aim of the project around issues of spirituality in end of life care at HammondCare, is an innovative approach to pain management. The different emphasis on spirituality that is emerging from this research has gained interest and positive support from pain consumer groups.

Researchers: Professor Philip Siddall, Dr Mandy Corbett & Associate Professor Melanie Lovell (Spiritual wellbeing in chronic and cancer pain), Ms Bromwyn Raymond & Ms Joan McClelland
Site: Greenwich Hospital
Duration: May 13 to Dec 16
Funding Source: Australian & NZ College of Anaesthetists
Project Partners: University of Sydney
Study Status: In Progress
Education, presentations, publications

Teaching+ Academic
Professional Activities
Higher Research Degrees
Academic Degree Supervision
Books+ Chapters
Journal Articles
Technical+ Other Reports
Industry+ Magazine Articles
Academic Conference+ Industry Seminars
Teaching+Academic Professional Activities

Professor Roderick MacLeod
As well as being a Senior Staff Specialist with HammondCare Rod is Conjoint Professor in Palliative Care with the University of Sydney. He is committed to teaching and learning about palliative and end of life care and to this end he is involved with teaching medical students at all stages of their career. He has also taught care workers across New South Wales and delivered teaching to GPs. He supervises research students many of whom will complete their PhD studies this year. He continues to be closely involved with the Palliative Care Bridge which provides easy access to professionals and the public to education on many aspects of end of life care - HYPERLINK "http://www.palliativecarebridge.com" www.palliativecarebridge.com He also published an anthology The Unknown Sea (Steele Roberts Publishing, Wellington, NZ in 2015.

Rod continued to review manuscripts for many medical publications and collaborates with international research partners on a number of projects. He continues as International Advisor to Hospice New Zealand. He was appointed a Member of the New Zealand Order of Merit by HM Queen in the NZ Queen’s Birthday Honours in 2015.

Professor Christopher Poulos
As Foundation Hammon Chair of Positive Ageing and Care, UNSW Chris has had a number of teaching roles during 2015, including undergraduate teaching within the UNSW Medical Faculty and postgraduate teaching in the Master of Public Health / Master of Health Management programs and Health Policy course. Chris was also invited to teach on ambulatory rehabilitation models and the rehabilitation patient journey at the Hong Kong Hospital Authority Annual Convention in May 2015.

In 2015 Chris was invited to chair an international working party on reablement in dementia for the International Federation on Ageing and DaniaAge. This involved two meetings in Copenhagen (the Global Think Tank on Ageing) and will culminate in a further meeting, the Copenhagen Summit, in April 2016. It is hoped that this collaboration with firmly place reablement strategies for older people, and those with chronic disease, on the global policy agenda.

Through a large arts in health grant for the Commonwealth government Chris has also taught artists on the role of the arts in improving the health and wellbeing of older people, as well as providing community education on ageing and dementia. Chris is a Visiting Principal Fellow, Australian Health Services Research Institute, University of Wollongong and during 2015 continued in the role of Immediate Past President of the Australasian Faculty of Rehabilitation Medicine, Royal Australasian College of Physicians.

Associate Professor Andrew Cole
As well as Andrew’s substantive roles with HammondCare as Chief Medical Officer and Head of Research, he is a Conjoint Associate Professor at the University of New South Wales in the School of Public Health & Community Medicine. He convenes the Aged Care & Rehabilitation teaching block in Phase 2 of the UNSW MD program, with regular teaching of medical students at Kensington, St George and Hornimondale campuses.

During 2015, he also presented lectures to doctors, nurses and allied health practitioners in general practice, anaesthesia, pain medicine, palliative care and rehabilitation.

In 2015, Phil served as a member of a number of local, national and international committees including co-chair of the NSW Agency for Clinical Innovation Pain Management Network, research committees of the Australian & New Zealand College of Anaesthetists and several committees of the International Association for the Study of Pain and the Court of Examiners for the Faculty of Pain Medicine of the Australian & New Zealand College of Anaesthetists.

Professor Meera Agar
As a clinical academic at University of Technology Sydney, University of NSW and Rinehers University, Meera holds a combination of teaching and supervisory roles including: lecturing, coordinating, tutoring and examining undergraduate and postgraduate medical students.

In 2014/15 Meera served as a Member of a number of committees: Guidelines Adaptation Committee Australian National Clinical Guidelines for Dementia NHMRC Partnership Centre for Cognitive Decline; Scientific Advisory Committee Psycho-oncology Cooperative Research Group (PaCOCR); Ingham Cancer Research Steering Committee of the Ingham Institute of Applied Medical Research; and Cooperative trials group Neuro-oncology (COGNo) Scientific Advisory Committee, and Management Executive.

In an ongoing capacity Meera also chairs the NSW Palliative Care Clinical Studies Collaborative for Improving Palliative Care through Clinical Trials (IMPACCT). Meera is the Lead Fellow (Assessment) of the Palliative Medicine Education Committee Royal Australasian College of Physicians. She also contributes to her profession as a member of various committees; Palliative care clinical trials collaborative (PaC SSC) Risperidone trial management committee; Choosing Wisely Australia Advisory Committee; and is a Board Member of the European Delirium Association.

Associate Professor Josephine Clayton
Josephine coordinates palliative care teaching for medical students during the oncology block and for pre-interns at the Northern Clinical School, University of Sydney and contributes to teaching various health professionals about palliative care and advance care planning (ACP) locally, nationally and internationally. She has a strong interest in teaching end-of-life (EOL) communication skills.

Examples of Josephine’s professional contributions in 2015 include serving on: NSW Ministry of Health reference group to develop a training framework to support health professionals across public health facilities in ACP/EOL conversations; NSW Health Education and Training Institute subject matter expert group for the blended learning solution called “SHARE End of life conversations” (an elearning module and workshop for clinicians), National Decision Assist project (to improve palliative care and ACP in aged care) evaluation advisory group; and the NHMRC Cognitive Decline Partnership Centre advisory committee to implement a national approach to dementia specific ACP. In 2015 Josephine was the Clinical Lead for the Clinical Excellence Commission’s Communication Group for the Last days of Life Toolkit. She chaired the patient resources working group and was a member of the steering committee for Cancer Institute NSW’s ADAPT (Anxiety and Depression Pathways) Program. She chaired the expert advisory group for Australian Research Council funded “enabling people with intellectual disability to understand dying” project and was a facilitator for the Australasian Chapter of Palliative Medicine Communication Skills training workshop. She is a Pillar lead for Sydney Vital Translational Cancer Research Centre’s pillar 4: Supportive care, end-stage tumours and end-of-life management, a member of the management committee for InhPaCCT (improving palliative care through clinical trials) and was a member of the Scientific Committee for the National ACP & EOL Care Conference held in Melbourne in November 2015. She was an invited speaker and workshop Chair at the International ACP & EOL Care conference held in Germany in September 2015 and an invited speaker and guest at the Cechy Saunders Institute, Kings College London in September 2015.
Teaching + Academic Professional Activities

**Associate Professor Melanie Lovell**
Melanie holds a clinical academic appointment at University of Sydney and as an affiliate at University of Technology Sydney. Her teaching roles include lectures and small group teaching for medical students and health science students in pain, symptom management and spirituality. She supervises 2 PhD students at University, and physician trainees through the College of Physicians.

Melanie’s professional contributions include committee membership of the ImPaCCT (NSW Palliative Care Trials group) Management Advisory Committee, Palliative Care Clinical Studies Collaborative Trials (PaCCST) Management Committee and Publications Subcommittees, Caresearch Knowledge Network Management Committee. She continues to chair the Australian Cancer Pain Guideline Working Party which developed and updates the guideline on the Cancer Council Australia wiki platform.

She is a member of the ADAPT Measurement working group for implementation of the Anxiety and Depression Pathway for oncology patients nationally and the Cannabis Trials group.

She is involved in research into psychotherapy and outcome of personality disordered adults across the age range, with treatment-resistant depression; the management of behavioral problems in dementia and effects on length of stay of psychiatry inpatients.

She has published articles on Borderline personality disorders and on differentiating bipolar disorder from borderline disorder as well as the psychotherapeutic management of treatment-resistant depression.

Janine has presented her research findings at international conferences in Australia, China and the USA.

**Dr Kirsty Beilharz**
At the University of Edinburgh UK, and the University of Salford UK, Kirsty presented public lectures and seminars on music engagement in dementia care. Kirsty is a Visiting Fellow (Music) at the University of Edinburgh. At UNSW Art and Design, Kirsty (on behalf of the HammondCare Dementia Centre) with academic staff of the Master of Interaction Design Degree collaborated on the design instruction of specialist age-appropriate musical instruments and interfaces for people living with dementia. HammondCare provided training in perceptual and interactive experiences of people with dementia, language for developing dementia design, and residents of Leighton Lodge North Turramurra participated in the user-centred design process. This teaching activity contributes to our understanding of active and creative music making, which is part of the music engagement pilot project.

**Dr Matra Robertson**
As well as being a Clinical Senior Lecturer at the University of Sydney, Matra is the Allied Health Academic, for HammondCare. She is dedicated to research in end of life care addressing the social, spiritual and psychological factors that support vulnerable people and also research on the use of the arts to promote health and healthy ageing. During 2015 she lectured Medical students, Advanced Studies Nursing students and contributed to the Death, Dying and Mourning program for Masters Social Work students. Matra continued in 2015 to support Postgraduate students individually and promote professional activities.

Matra’s academic professional activities include serving her professional peers internationally through consultation, collaboration and Life membership of the Social Work and Hospice and Palliative Care Network of the United States of America. During 2015 Matra was Chair of the Palliative Care Education Committee, HammondCare. She continued to review of manuscripts for local and international academic publications.

**Ms Meredith Gresham**
Meredith Gresham is a Designated Systems Based investigator of the NHMRC Partnership Centre for Cognitive and Related Function Decline in Older People and was the inaugural Chair of this Enabling Sub Unit of the Centre.

She is an Associate Editor of the journal International Psychogeriatrics and edits the occupational therapy section of the International Psychogeriatric Association Newsletter. She is a member of the Australian Association of Occupational Therapists and the Australian Association of Gerontology.
### Higher Research Degrees

<table>
<thead>
<tr>
<th>Student Name</th>
<th>Degree: PhD candidate</th>
<th>University:</th>
<th>Supervisors:</th>
<th>Thesis Title:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Phil Austin</td>
<td>PhD completed 2015</td>
<td>University of Edinburgh</td>
<td>Dr Gordon Drummond and Dr Sarah Henderson</td>
<td>Investigating elements of post-operative rehabilitation for total knee replacement (TKR)</td>
</tr>
<tr>
<td>Mr Mark Buhagiar</td>
<td>PhD candidate</td>
<td>University of New South Wales</td>
<td>Professor Phyllis Butow and Professor Ian Oliver</td>
<td>Theses Title: The spiritual needs of cancer patients and the role of the doctor in meeting them</td>
</tr>
<tr>
<td>Ms Meredith Gresham</td>
<td>PhD candidate</td>
<td>University of Sydney, Medical Faculty</td>
<td>Professor Anne Cusick (primary at UoW) &amp; Associate Professor Natasha Lannin (secondary at LaTrobe University)</td>
<td>Thesis Title: Physical Therapy as an adjunct to Botulinum toxin-A for treatment of spasticity in adults with neurological impairment</td>
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<tr>
<td>Ms Bianca Kinnear</td>
<td>PhD candidate</td>
<td>University of Wollongong</td>
<td>Professor Lindy Clemson and Associate Professor Lee-Fay Low.</td>
<td>Thesis Title: Junior hospital medical officers’ experience of making clinical decisions regarding patients with advanced, irreversible, progressive and life-limiting medical conditions when on-call after hours.</td>
</tr>
<tr>
<td>Dr Michael Darragh</td>
<td>PhD candidate</td>
<td>University of Wollongong</td>
<td>Professor Anne Cusick</td>
<td>Thesis Title: Effective approaches to leadership skill development</td>
</tr>
<tr>
<td>Ms Meredith Darragh</td>
<td>PhD candidate</td>
<td>University of Sydney</td>
<td>Professor Anne Cusick</td>
<td>Thesis Title: An investigation of the clinical utility of the electronic bidet for Australian nursing home residents and staff</td>
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### Academic Degree Supervision

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<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>Megan Jeon</td>
<td>PhD candidate</td>
<td>University of Sydney</td>
<td>Adam Walcock, PhD</td>
<td>Improving quality of life at the end-of-life of University of Sydney.</td>
</tr>
<tr>
<td>Marcus Selars</td>
<td>PhD candidate</td>
<td>University of Sydney</td>
<td>Marcus Selars, PhD</td>
<td>commencement part-time candidature in 2009</td>
</tr>
<tr>
<td>Skye Dong</td>
<td>PhD candidate</td>
<td>University of Sydney</td>
<td>Skye Dong, PhD</td>
<td>PhD Thesis: Symptom clusters in cancer patients, University of Sydney.</td>
</tr>
<tr>
<td>Christine McDonald</td>
<td>PhD candidate</td>
<td>University of Sydney</td>
<td>Christine McDonald, PhD</td>
<td>PhD Thesis: Collaborative practice in the New Zealand palliative care environment. AUT University, Auckland, 2011</td>
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<td>Elaine Rogers</td>
<td>PhD candidate</td>
<td>University of Sydney</td>
<td>Elaine Rogers, PhD</td>
<td>Does a multi-targeted approach of supportive care improve the cancer cachexia status in lung cancer patients?, University of Auckland, Auckland. 2008-16</td>
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<tr>
<td>Sue Jacob</td>
<td>PhD candidate</td>
<td>University of Sydney</td>
<td>Sue Jacob, PhD</td>
<td>PhD Thesis: The nature of grief in family and professional carers of people with dementia, University of Auckland, Auckland. 2011-16</td>
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<tr>
<td>Dr Jane Wu</td>
<td>PhD candidate</td>
<td>University of Sydney</td>
<td>Skye Dong, PhD</td>
<td>PhD Thesis: Early Rehabilitation in Trauma and Critical Illness. Faculty of Medicine, The University of NSW.</td>
</tr>
<tr>
<td>Rosemary Chakiath</td>
<td>PhD candidate</td>
<td>University of Sydney</td>
<td>Rosemary Chakiath, Doctoral Thesis: Central sensitisation in visceral and somatic pain, University of Sydney, Sydney, 2013-2017</td>
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### Awards

- **Professor Roderick Duncan MacLeod**, Member of the New Zealand Order of Merit, Her Majesty the Queen
- **Professor Philip Siddall**, ANZCA/Pfizer Research Award, Australian & New Zealand College of Anaesthetists

### Best Poster Presentation

Dementia Collaborative Research Centre - Assessment and Better Care. The University of NSW, 2015


Dementia with advanced dementia in aged care – development of the palliative care planning coordinator role. Oral presentation 13th Australian Palliative Care Conference, Melbourne, September 1-4, 2015


17. Buhagiar M, The HIIHC RCT, UNSW Dean’s Seminar, Sydney Australia, 25 February 2015


Buhagiar M, Naylor J, Kohler F, Harris IA, Simpson G. Understanding consumer and clinician preferences for inpatient rehabilitation after joint arthroplasty. 23rd ASM, AFRM, 14-16 September 2015, Brisbane Australia, 11 October 2015.


Buhagiar M, Naylor J, Harris I, Kohler F, Xuan W, Wright R. Hospital inpatient versus home-based rehabilitation post total knee arthroplasty (the HIHO study): a randomised controlled trial, Ingham Institute Research Showcase. Sydney Australia, 27 November 2015.


Clayton JM (invited keynote speaker), Advance Care Planning in Chronic Kidney Disease – results of recent research. Chronic Kidney Disease New Zealand nephrology setting: a national survey, 5th International Conference on Advance Care Planning and End-of-Life Care (ACPEL), Munich, Germany, 11 September 2015.


Clayton JM (invited researcher-workshop chair and facilitator) Houben CHM, Gismen J, van der Heide A, Tattersall MHN. The challenge of conducting randomised controlled trials to study ACP effectiveness. Practical insights from 4 current RCTs. 5th International Conference on Advance Care Planning and End-of-Life Care (ACPEL), Munich, 9th September 2015.

Clayton JM (invited poster session chair), Poster Group 2 Session, 5th International Conference on Advance Care Planning and End-of-Life Care (ACPEL), Munich, 11th September 2015.

Clayton JM (invited speaker), Advance care planning in Chronic Kidney Disease – results of recent research, Renal Supportive Care Symposium, St George Hospital, Sydney, Australia, 21st August 2015.

Clayton JM (invited speaker), Advance care planning in Chronic Kidney Disease – results of recent research, Renal Supportive Care Symposium, St George Hospital, Sydney, Australia, 21st August 2015.

Clayton JM, Communication about advance care planning in general practice, Advance Care Planning workshop for General Practice Nurses, University of New South Wales, Sydney, Australia, 18th July 2015.

Clayton JM, Meier A. Advance Care Planning. End of life and people with intellectual disability seminar, University of Sydney, Sydney, Australia, 30th June 2015.


Cunningham C, Dementia Friendly Design, Palliative Care Lecture Series 2015, Hospice New Zealand, Webinar, 5 March 2015.

Cunningham C, Exploring palliative care for people with dementia, NICON 2015 Conference & Exhibition, Belfast, Ireland, 22-23 April 2015.

Cunningham C, Hearing and engaging people with dementia, Rolley College Later Life Pastoral Seminar, Melbourne, Australia, 4 May 2015.

Cunningham C, Sex, drugs & rock’n roll – addressing the negative perceptions around dementia in aged care, Changing Minds 2015 Conference, Te Oraongia Hospice, Wellington, New Zealand, 4 September 2015.

Cunningham C, Less race and more grace, 10th Annual Conference on Dementia and End of Life Care, The National Council for Palliative Care, London, United Kingdom, 1 December 2015.


Gresham M.D., Geaves M. Dementia Care in Australia. Sanghaiama Regional Dementia Care Conference, Sanghaiama Japan, 13 October 2015.

Gresham M.D., Pitfalls and Problems – the tale of a PhD project in an aged care facility. Aging Work and Health Research Unit. The University of Sydney. Sydney, Australia 19 November 2015.


Lobb E, Movd J, Lars L, Lacey J, Chiochorov H, Kelly S, Agar M, Links M, Kearsey JH, Brock C, and Liauw W. An exploratory study of an intervention for couples to facilitate...
105. Siddall PJ, Greenwich Hospital Spinal Cord Injury Pain Program, Australian Pain Society Annual Scientific Meeting, Brisbane Australia, 16 March 2015

106. Siddall PJ, Let’s talk about values, National Pain Week Conference, 24 July 2015


108. Siddall PJ, Pain and neuroplasticity: what does it mean for physiotherapy? Australian Physiotherapy Association Annual Conference, Gold Coast, Australia, 4 October 2015

109. Siddall PJ, The lesser known consequences of spinal cord injury, Australian Physiotherapy Association Annual Conference, Gold Coast, Australia, 4 October 2015


114. Yule SA, MacLeod RD, Johnson C. A good enough death? (P1-233), 14th European Association for Palliative Care Congress, Copenhagen, Denmark. May 2015. Poster
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Projects by Area of Research

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HammondCare provide inpatient units, outpatient clinics and a day hospital at Braeside Hospital and Greenwich Hospital. Greenwich Hospital is also the centre of HammondCare's Pain Clinic, specialising in helping people manage chronic pain. Greenwich Hospital is a base for providing home-based rehabilitation services. HammondCare is participating in a number of research projects focusing on stroke recovery, functional independence, pain management, and spinal cord injury pain.

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HammondCare provide inpatient units, outpatient clinics and a day hospital at Braeside Hospital and Greenwich Hospital. Greenwich Hospital is also the centre of HammondCare's Pain Clinic, specialising in helping people manage chronic pain. Greenwich Hospital is a base for providing home-based rehabilitation services. HammondCare is participating in a number of research projects focusing on stroke recovery, functional independence, pain management, and spinal cord injury pain.

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Successful Grant Applications

**Agar M.** Perpetual Foundation. Phase II randomised non-comparative placebo-controlled double blind trial of Acetazolamide plus Dexamethasone versus dexamethasone alone for management of cerebral oedema in recurrent and/or progressive High Grade Glioma. Awarded $100,000 for 2015.


Alexander Smith, Jason Karlawieth, Sel Lee, Patricia Moran, Josephine Clayton (Consultant), Rebecca Suidore (Consultant), USA National Palliative Care Research Center Grant (This project is based within the Department of Geriatrics, Palliative, and Extended Care, University of California, San Francisco (UCSF) Division of Geriatrics, Department of Medicine). Enhancing Prognosis Communication with Disabled Elders. Awarded $140,000 from July 2015 for 2 years.


Lovell MR (C), Ms Bronwyn Raymond, Ms Jane Phillips & Mr Tim Luckett UTS, Ms Fran Boyle USyd. Ritchie Foundation Grant. Stop Cancer Pain, (ongoing funding).

Mowfi L, Sandersons C, Lobb L, Macleod R, Robertson M, Duffuor J, Cahill J, Fitzpatrick C. Title: “Mapping Grief” Australian Government Collaborative Research Network CRN funding. A mixed method longitudinal study to investigate and compare a group of palliative care and coronial deaths with regard to family members’ experiences of their care, of the death, and their adjustment/recovery, and to be correlated with their grief and trauma outcomes over the first 25 months post loss. Awarded $720,000 for 2015.


Poulos CJ, Poulos RG, Cunningham C, Beatie E. Arts on Prescription @ Home. Dementia Collaborative Research Centre (DCRC) – Carers and Consumers (NHMRC). $22,000. Extends the Arts on Prescription model to a home-based program for people with dementia and their carers.

Poulos CJ, McLeod RD. Quantitative evaluation of a state-wide Community Palliative Care Service. HammondCare internal grant. $19,600. Quantitative evaluation of HammondCare’s new community palliative care home support service.

Poulos CJ, Harkin D, Gresham M, Beatie E. Helping carers focus on their own wellness needs – translational project. Dementia Collaborative Research Centre (DCRC) – Carers and Consumers (NHMRC). $8,800. Developing a consumer resource to assist carers of people with dementia.

Poulos RG, McLeod RD, Poulos CJ, Cole AMD, Harkin D. Quantitative evaluation of a state-wide Community Palliative Care Service. HammondCare internal grant. $110,000. In-depth qualitative evaluation of HammondCare’s new community palliative care home support service.


Grants+Statistics

**Statistics**

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