

Extending the Reach and Scope of Palliative Day Services

A Churchill Fellowship to Singapore,
Australia and New Zealand



Kathy Birch - 2018 Churchill Fellow

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Over the six weeks of my Fellowship, I had the opportunity to meet with members of staff, volunteers, patients and caregivers too numerous to mention here. The richness of my experiences and the data I now have are a testament to the time you gave me and the experiences you shared with me. I hope that we will remain colleagues and I will have the opportunity to return the favour one day and welcome you to the UK. Particular thanks, however, go to the people who were my main contacts in each of the organisations and who arranged my time, welcomed and supported me. They went above and beyond the call of duty but I would expect nothing less of palliative healthcare professionals! They include:

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Georgina Miller	Head of Allied Health and Social Support, Totara Hospice, South Auckland
Vanessa Eldridge	Manager Day Services, Mary Potter Hospice, Wellington
Martin Woods	Research Fellow, Mary Potter Hospice, Wellington
Eleanor Barrett	Occupational Therapist, Te Omanga Hospice, Wellington

And finally, to my long-suffering husband **Graham** who is a constant source of encouragement and support. Thank you, once again, for going with and living through this latest adventure.

2. Abbreviations

WCMT	Winston Churchill Memorial Trust
PAH	Princess Alice Hospice
PDS	Palliative Day Services
SAPS	Southern Adelaide Palliative Services
WTE	Whole Time Equivalent
PCOC	Palliative Care Outcome Collaboration
OACC	Outcome Assessment and Complexity Collaborative
SPNDS	Statewide Progressive Neurological Service
OT	Occupational Therapy (Therapists)
AHP	Allied Health Professional
PEPA	Programme of Experience in the Palliative Approach
ANZSPM	Australian and New Zealand Association of Palliative Medicine

3. The Winston Churchill Memorial Trust

The WCMT was established when Sir Winston Churchill died in 1965. Thousands of people, out of respect for the man and in gratitude for his inspired leadership, gave generously so that a living memorial to him could benefit future generations of British people.

As Sir Winston's national memorial, the trust carries forward his legacy by funding UK citizens from all backgrounds to travel overseas in pursuit of new and better ways of tackling a wide range of the current challenges facing the UK. Successful applicants are Churchill Fellows for life and carry the responsibility of building on their learning through implementation of recommendations made as a result of their travelling experiences and supporting future Fellows.

Each year 150 Fellowships are awarded for a wide range of projects. The Fellowships provide a unique opportunity for UK citizens to travel overseas to bring back fresh ideas and new solutions to today's issues for the benefit of others in the UK. This allows them to maximise what they can achieve in their lifetime, both as leaders and role models to inspire others, but also in terms of personal development. These opportunities are offered to people of any age, gender, ethnicity or religion, with or without educational qualifications, and in any occupation or none.

The award of a Fellowship has been seen to have a profound impact on individuals who return with a greater belief in their own abilities, as well as benefiting others through the new ideas brought back to the UK. Often a Fellowship serves as a catalyst that unlocks an individual's potential. It can accelerate their career, developing them as a leader in their field of expertise or as a role model, and continues to be a motivating influence long after they have returned from their travels.

4. Personal Profile



I am a wife, mother, physiotherapist and healthcare manager working at Princess Alice Hospice (PAH) in Surrey. I originally specialised in neuro-rehabilitation before being inspired to use my skills to enable people affected by a life-limiting illness to maximise their quality of life – I wanted to “add life to

days, not days to life.” I joined PAH in October 2001 as a part-time physiotherapist and following the publication of the NICE Guidelines for Supportive and Palliative Care¹ had the opportunity to develop and manage a comprehensive allied health team. I was then asked to lead and redesign the Palliative Day Service (PDS) at the Hospice and most recently have been asked to look at future service provision. As part of this project, I was encouraged to scope PDS locally, nationally and internationally which prompted my application and subsequent award of a 2018 Churchill Fellowship.

5. Executive Summary

The need to stretch the current resource invested in specialist PDS, to ensure more people will have access to it in the future, was the motivating factor in applying for my Churchill Fellowship. I wanted to know if service providers in Singapore, Australia and New Zealand had developed different ways of working that would benefit the UK model.

I had specific aims when I set out but inevitably I learnt considerably more. The objectives I set myself were:

- To explore different models of day hospice and out-patient provision
- To understand how informal caregivers can be supported to provide hands-on and supportive care for their loved ones
- To explore the way in which Allied Health Professionals/therapists work in palliative care ie the rehabilitative palliative care model
- To learn how to better reach minority groups such as groups defined by ethnicity or diagnosis
- To explore how digital technology is being used to increase the reach and influence of service provision
- To understand how services are funded

5.1 Key findings:

- It is necessary for PDS to adapt to meet the needs of the local population and secure funding. Those services that have survived are providing a mixed model with aspects of education, enablement and community outreach but they retain peer and social support through group activities. There continues to be a focus on ensuring the “*person within the patient*” is celebrated.
- The use of outcome measures has been integrated into the clinical setting to support service delivery and manage caseloads.

- Palliative out-patient clinics can be used to support a large number of patients when a resource is limited or to create a critical mass of patients with specialist needs.
- Support for informal caregivers needs to be addressed on a number of different levels. They value both theoretical and practical education on how to support their loved ones, but sessions need to be held either at times when the carer might be free or in conjunction with a service for the patient. Support can also be integrated into out-patient clinics. Peer support for carers is highlighted as beneficial and this can be achieved by delivering a programme in group format over a number of weeks.
- Due to a limited resource within allied health, collaborating with non-specialist AHPs extends the reach.
- Diversifying the professional make-up of the allied health team will benefit patients and caregivers.
- It is necessary to understand the specific needs of minority groups and extend the offer to them in relation to what they want, potentially employing people from within their community or seeking out champions to work alongside. Looking for ways to break down barriers and taboos regarding hospice care is also beneficial.
- Integrating digital technology into service delivery can take many forms but uploading documents and videos supports service delivery and can reach people who are not able to engage in face to face interventions.
- Celebrating cultural, spiritual and personal aspects of an individual's life becomes more meaningful as they approach the end of their lives and can leave a legacy for the future.

5.2 Recommendations:

- To embed outcome measures into clinical practice to inform the pathway of care for patients
- To develop a carer support programme
- To develop and implement a wellbeing programme as part of a mixed model of PDS
- To develop multi-professional out-patient clinics
- To explore the potential of collaborating with local allied health professionals to extend the reach
- To ensure digital resources are uploaded onto the PAH website
- To provide teleconferencing as an alternative to face to face interventions
- To introduce initiatives that enable patients to return to being the people they are and celebrate all that means to them

6. Context

UK Hospices have a reputation for providing high quality care to people with life-limiting illnesses, but receive criticism for only supporting a small proportion of the population who die per annum. Data is forecasting that there will be a significant increase in the number of people dying each year and they will be living, and dying, with multiple co-morbidities², consequently national strategies^{3, 4} have been published to try and respond to the increased demand that will result. This is also being considered at a local level, and PAH has produced an ambitious five year strategy⁵ part of which includes a redesign of its service delivery to increase the number of people who are supported.

My appointment to the post of Programme Lead for Day Services was a direct result of this strategy and I have been tasked with researching and making recommendations for day and out-patient service provision in the future. It was this that prompted my application to the WCMT to travel and learn about PDS provision overseas.

The learning objectives I set for my Fellowship were:

- To explore different models of day hospice and out-patient provision
- To understand how informal caregivers can be supported to provide hands-on and supportive care for their loved ones
- To explore the way in which Allied Health Professionals/therapists work in palliative care ie the rehabilitative palliative care model
- To learn how to better reach minority groups such as groups defined by ethnicity or diagnosis
- To explore how digital technology is being used to increase the reach and influence of service provision
- To understand how services are funded

I acknowledged, however, that given the typical construct of palliative care services it was likely that I would collect information relating to wider palliative and end-of-life services which would be valuable to not only day and out-patient services but also community and in-patient care. These wider findings are not specifically reported on in this document.

From web-based research, information from current and ex-colleagues and social media contacts I decided to travel to Australia and New Zealand, with a stopover in Singapore. At my interview, it was suggested a longer period of time might be beneficial in Singapore as a previous Fellow had explored caregiver programmes being delivered there. I was asked on a

number of occasions why I chose these places and why I needed to travel overseas when the UK has been ranked number one in the world for palliative care services⁶. Simply, my reasoning was that Australia and New Zealand rank second and third for palliative and end of life services, I felt that the people residing in these countries would have similar expectations of health and social care provision but there would be differences in service design due to their funding models and differing geographic and demographic constructs. Equally, we can always learn from others and this is the basis of the WCMT travelling Fellowship programme.

“Travel to learn, return to inspire”

7. Methodology

To learn most and understand the way in which services had developed, what had worked well, what hadn't, and fully appreciate the nuances of palliative services in my chosen countries I wanted to visit as many services as realistically possible and build in a variety of different types of services. I had started to make contacts during the application process and continued to develop those links after the award of my Fellowship. I had identified key sites that appeared to be delivering services that supported my learning objectives and two previous Fellows were able to share contacts from their travels in Singapore and New Zealand. It was important, due to the timescales for service development at PAH, that I travelled as soon as possible. This presented some challenges in arranging visits but sites were very accommodating and set up meetings with people within their organisations that would meet some or all of my learning objectives.

I planned to work for approximately three weeks, take a two week holiday when my husband joined me in Australia, then continue with my Fellowship for a further three weeks. Just before I left England I sent out an email to my main contacts advising them of my itinerary and giving them contact details for while I was away. I confirmed all appointments approximately one week before arrival.

During the course of my Fellowship journey I visited three countries, six cities and 13 different organisations (Appendix 1). I had the opportunity to observe programmes, sit in on clinics and meetings, and I interviewed 87 different people including patients, carers and volunteers to senior managers, chief executives and commissioners. I used a notepad and pen to record thoughts, observations and interviews, along with writing a blog (<https://kathybirchblog.wordpress.com>) and gathering many resources that were given to me

from the organisations I visited. It was exhilarating and exhausting in equal measure but provided me with such an amazing opportunity to step out of my own workplace and truly explore how people with life-limiting illnesses are supported on the other side of the world.

My Fellowship provided a unique opportunity to visit numerous organisations, but data remains limited to these experiences. My findings and recommendations could have been different if I had visited other countries or even other services within the Singapore, Australia and New Zealand.

8. Day Hospice and Out-Patient Services

8.1 Singapore: HCA Hospice Care:

My Fellowship journey started in Singapore visiting HCA Hospice Care. They have an island-wide service working out of different locations and I visited two of their Day Care Units. One was based at their headquarters in central Singapore whereas the other was close to the Malay border. Both units were based on the same model:

- They were staffed by a Day Hospice Supervisor with a nursing background and a number of healthcare assistants
- Medical and specialist nurse assessments were available on an appointment basis
- Physiotherapy was provided by a private agency one or two days a week
- There was a significant reliance on volunteers for activities, food provision and preparation and hospitality
- Patients were able to attend every day Monday – Friday
- There was a means-tested charge for the service
- Mornings were focussed on physical wellbeing and afternoons had a cognitive focus
- The day lasted from approximately 10 am – 4 pm with a built-in rest period after lunch
- Minibus transport was made available for everyone



***HCA Hospice Care Day Hospice
Intergenerational Programme***

Patients told me that they enjoyed attending as it got them out of the house and provided cognitive and physical stimulation.

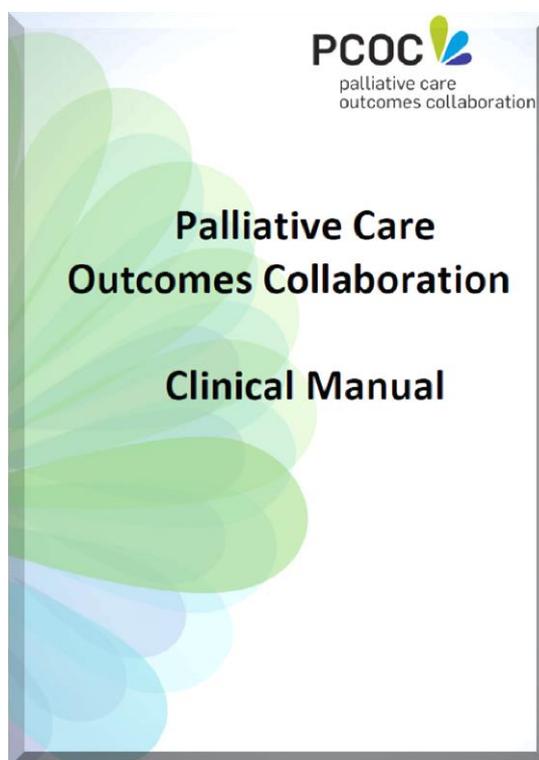
There is a government based intergenerational project which HCA Hospice Care support through visits by local school children and their Young Caregivers Programme. I observed one of the school visits, with children providing entertainment, running quizzes and supporting patients in other activities. Both patients and children were hugely stimulated by this interaction with one patient enjoying serenading his “audience” with traditional songs. It was an uplifting experience and the patients became animated and re-energised by the interaction.

8.2 Australia:

8.2.1 Southern Adelaide Palliative Services (SAPS)

People resources were very limited at SAPS with 6.8 WTE nursing, 3.4 WTE medical, 1.0 WTE Social Worker and 1.0 WTE Caregiver Liaison supporting approximately 500 patients at any one time. To manage this caseload out-patient clinics had been introduced with only the most poorly patients being allocated a community home-based service.

Patients were telephone triaged by the Nurse Consultant using the Palliative Care Outcomes Collaboration (PCOC) Suite of Outcome Measures⁷ which informed their future care within the service. The options included being referred back/discharged, given an appointment for either the nurse-led multi-professional out-patient clinic or medical out-patient clinic or allocation to home-based specialist community nursing care. In the UK the Outcome Assessment and Complexity Collaborative (OACC) Suite of Measures⁸ has been developed based on PCOC and is beginning to be used in many hospices. However, I have not seen it used to inform the patient pathway as it was at SAPS. In Australia these



objective measures have also been fully integrated into other aspects of clinical care, informing discussions at multi—professional meetings and being used to manage caseloads.

8.2.2 Calvary Care, Bethlehem and Caritas Christi Hospice

I visited two Day Hospices in Australia at Calvary Care, Bethlehem and Caritas Christi



Staff and volunteers from Bethlehem Day Centre with a piece of their collaborative artwork

Hospice. Both opened two days a week and were led by Registered Nurses with one unit having a Health-Care Assistant and Activities Co-ordinator and the other an Artist-in-Residence. Additional support was provided by volunteers which including transport to and from the unit. Patients were able to access physiotherapy group sessions and creative therapies. At Calvary Care, one day had a musical focus, with the support of the hospital's music therapist, and an art based activity on the other day. Patients attended from 10 am – 2 pm.

8.2.3 Sacred Heart Hospice

There had been a Day Hospice at Sacred Heart Hospice until just before I visited. I was told it had been closed due to falling numbers of people wanting to access the service and the need to reallocate resource. The Medical Director hypothesised that Day Units were perhaps still viable in the UK because of his perceived sense of community that was more developed in the UK. The closure was still a temporary measure although it seemed unlikely that the decision would be reversed. This had impacted on some of the activities and interventions on offer to patients including physiotherapy exercise groups

The Australian Day Hospice model, from what I observed and was told, appeared not to have changed in recent years and reflecting on what I saw, I wonder if lack of adaptation to changing needs and expectations is the reason why there are so few people accessing the services.

8.2.4 Statewide Progressive Neurological Disease Service

With a background in neuro-rehabilitation earlier in my career and an ongoing interest in how people with progressive neurological diseases are supported, when I heard about SPNDS I decided I had to try and prioritise a visit to their service. The majority of palliative care services in the UK will include a small proportion of people with a progressive neurological disease, most commonly Motor Neurone Disease, Progressive Supranuclear Palsy and Multiple System Atrophy.

The [SPNDS](#) at Calvary Care, Bethlehem in Melbourne has developed from a perceived gap in their service 30 years ago. Patients were being admitted onto the ward for terminal care who were unknown to the medical and nursing teams, this made caring for them more difficult. In order to get to know these patients a little earlier and improve their quality of life, an out-patient service was started which is now a specialist statewide service supporting over 1,000 people at any one time and delivering in the region of 1,200 clinical interventions every month. They support people with a range of diagnoses including Huntington's Disease, Motor Neurone Disease, Secondary Progressive Multiple Sclerosis, Muscular Dystrophy, Multiple System Atrophy, Progressive Supranuclear Palsy and Spinocerebellar Ataxias from across Victoria and Tasmania.

The service offers a range of multi-professional assessments, management and advice and people are seen on a regular basis, depending on their need. The specialists in Melbourne then liaise with local healthcare professionals who provide ongoing care and support between appointments. Patients and family members can expect to see between two and four different professionals when they attend the clinic and occasionally people stay overnight if appointments need to be scheduled over consecutive days.

Focusing specialism and expert knowledge in one place, coordinating multiple out-patient appointments and the use of digital technology all contribute to an efficient use of resource and an ability for a large number of people to be supported by experts in the field of progressive neurological diseases. This model should be considered not only for people with neurological diagnoses but also as a way of maximising the use of any limited resource and expertise.

8.3 New Zealand:

The hospice and palliative day care model in New Zealand more closely resembled the UK model. Day Care provision varied with some units having adapted their services to meet the changing needs of their population.

8.3.1 Mercy Hospice

Mercy Hospice run The Manaaki Programme which was based on the Kowhai programme developed by Otago Hospice in South Island. The programme has been developed and is led by an Occupational Therapist (OT) who draws resource from other members of the hospice multi-professional team. It is a twelve week education programme for both patients and carers which is repeated throughout the year. The programme has evolved over time and now includes:

- Introduction to Hospice Services
- Navigating the System
- Breathlessness
- Living with reduced energy
- Nutrition
- Funeral Planning
- Relaxation and sleep
- Pain management
- Having difficult conversations
- Riding the emotional roller-coaster
- Advance Care Planning
- Making memories last

A different topic is covered each week and there is also time to share a meal together resulting in beneficial peer support. Specific individual needs are referred to the most appropriate member of the team for 1:1 intervention. A further development has been the introduction of Manaaki Active, a weekly low impact exercise group for patients and carers with refreshments and peer support.

8.3.2 Totara Hospice

Totara's Day Hospice is staffed by a nurse co-ordinator, healthcare assistants and volunteers and provides a mixed model of palliative day care providing opportunities for education, carer respite, maximising independence and social interaction. The Living Well, ten week education programme, is resourced by members of the multi-professional team and covers a range of topics similar to those of the Manaaki programme. It runs from 10 am – 2 pm one day a week when the day is totally focussed around the topic for that week. People can either attend for the group session or the whole day. The remaining two days of

the week are of a more traditional model with one day being for younger, unstable patients and the other for longer standing stable patients.

At Totara, I also had the opportunity to learn about a nurse-led out-patient clinic that had been used to manage the workload of the community specialist palliative care team. Forty per cent of patients referred to Totara Hospice were seen for an initial assessment in the nurse-led clinic with the additional benefits to staff and patients highlighted as a more consistent approach; increased referrals to allied health; demystification of the hospice environment; and alleviation of pressure on the workload of the community nursing team.

8.3.3 Mary Potter Hospice

Mary Potter Hospice was going through a period of considerable change around the time of my visit. To facilitate change within the day service provision a manager had been appointed



Linda: OT and Day Hospice Co-ordinator, Vanessa: Day Services Manager and me at Kapiti Day Hospice

for Day Services with a remit that was remarkably similar to that of mine at PAH!

Mary Potter has a main hub in central Wellington but given their large geographical catchment area they have other satellite clinics. They run day hospices in three different locations, each opening one day a week. They are led by an OT in two locations and the service manager in the third. There is only one paid member of staff in each location who is supported by volunteers. A creative focus to the day helps people to explore who they are and reflect on their lives and achievements.

The Day Services Manager was working on an outreach programme which mirrors some of the community engagement work that is happening in the UK and moving away from day service provision being held in-house and just being for patients and carers. She is also beginning to incorporate bereavement care as part of the day and out-patient offer.

9. Informal Caregiver Support & Education

Hospice and palliative care is not focussed solely on the person who has been diagnosed with the life-limiting illness it also supports people closest to that person. This support has mainly been offered in the form of psychological support, complementary therapies, respite, carers groups and then extends to bereavement support after the death of their loved one.

Given that there will be increased demand, in the future, on community health and social service provision and following feedback from informal caregivers at PAH⁹, I wanted to explore other ways that services supported caregivers, particularly in the form of practical advice and skills.

9.1 Singapore -Palliative Caregivers Programme:

I had been encouraged to visit HCA Hospice Care and their Palliative Caregivers Programme (<http://hca.org.sg/Palliative-Caregivers>). Most Singaporean families will employ a live-in helper who assists with general household chores. It appeared that when a member of the family becomes unwell their role can be extended to include caring for that person. I heard from the course facilitator that family members will want the helper to receive the training but might be reluctant to attend themselves, however following a persuasive introduction when they arrived seven helpers and five family members attended the session I observed! HCA Hospice Care runs the Caregiver Training Programme every Saturday at one of their community hubs, rotating the venue to improve accessibility. The course is subsidised by the National Council for Social Services and costs S\$10 per family.



I was impressed with the comprehensiveness of the training, pitched at what would be considered an appropriate level for non-specialist health care providers in the UK. The content included what to expect from the hospice service, out of hours support, symptom and drug management, looking after yourself as a carer, trajectory of disease including what

Families and helpers practising manual handling techniques at HCA Bedok Centre

to expect during the dying phase and a significant focus on providing practical and personal care.

About five hours were given to formally taught components, discussion and videos, with an additional two hours of practical skills training.

An experienced nurse facilitated the course and was capable of answering participants' questions and she also added additional value through tips, anecdotes and information about where to source equipment and drugs. She was insistent that everyone took a turn in practicing manual handling techniques despite a significant amount of reluctance.

The families left with a carers manual and signposted to videos on the HCA website (<http://hca.org.sg/Caregivers-Training-Videos>).

9.2 Australia:

9.2.1 Statewide Progressive Neurological Disease Service

Most of SPNDS is delivered in the form of out-patient clinics. Staff supporting people affected by Huntington's Disease, however, realised that there were commonalities in the experiences of male carers of this condition. As a response to this, a male carers group has been set up to provide information, education and peer support.

9.2.2 Centre for Palliative Care

Dr Kristina Thomas is a research fellow at the Centre for Palliative Care attached to St Vincent's Hospital in Melbourne. Working alongside Dr Peter Hudson, Kristina has researched different models of caregiver support, ranging from group to 1:1, face to face and telephone interventions. We talked about the challenge of moving research findings into clinical practice and the barriers there can be for carers accessing support. Tina explained that as a response to these challenges the Centre has uploaded a number of resources and links to services onto their website (<https://www.centreforpallcare.org/page/17/community>). Tina's next piece of work will be exploring the benefit of holding family meetings at entry into palliative care services as a way of managing expectation and preparing for the future.

9.3 New Zealand:

9.3.1 Te Omanga Hospice

The education team at Te Omanga Hospice in Wellington have developed a four-week carer support course, running approximately six times a year – A Map through the Forest. The content is similar to the HCA Hospice Care course with the additional aspect of building peer support among the carers as they meet over a period of a month. The group was co-developed with carers and has been adapted over time following feedback from attendees. Three weeks are focussed on group work exploring different aspects of caring for a loved one and the fourth week is a practical session. To overcome the challenges carers can have in being able to leave their loved one, the course is offered at different times, some during the day and others in the evenings. Attendance has ranged from two to ten people per group.

EDUCATION FOR FAMILY/FRIENDS AS CARERS
A MAP THROUGH THE FOREST

A series of free educational sessions for the family carer on practical issues around caring for your loved one at home.

- Support for the family
- Practical tips
- Challenges
- How to care for a person who cannot get out of bed

FEBRUARY: 7, 14, 21, (28)
(EVENING SESSION 5.30PM - 7PM)

THE SESSIONS FOR THE REMAINDER OF THE YEAR WILL COMMENCE AT 10.30AM - 12.30PM

APRIL: (28 MARCH) & APRIL 4, 11, 18
MAY: 23, 30, & JUNE 6, 13
AUGUST: 1, 8, 15, 22
OCTOBER: 10, 17, 24, 31
NOVEMBER: 21, 28 & 5, 12 DECEMBER

WHERE: PETONE COMMUNITY HOUSE
6 BRITANNIA ST, PETONE, LOWER HUTT

"It was lovely to connect with others going through their own forest. What support was available and information about the act of dying"

To register for a session, please email support.coordinator@teomanga.org.nz or phone 04 566 4535

Te Omanga Hospice
Te Whare Hauāwhiri Tāwhiri

www.teomanga.org.nz

9.3.2 Mercy Hospice – Families as Carers

At Mercy Hospice in Auckland the education team were once again involved in providing educational workshops for carers ([https://www.mercyhospice.org.nz/education/education-for-](https://www.mercyhospice.org.nz/education/education-for-families.asp)

Families as Carers
education workshops

Mercy Hospice Auckland runs free workshops with carers in mind. The workshops are interactive sessions with other carers to discuss the issues you face daily.

These are held on the 3rd Tuesday of each month, 10.30am - 12 noon at Mercy Hospice Auckland, 61 College Hill, Ponsonby.

To register your interest or find out more information, contact the Education Administrator on 361-5966.

You can also discuss with a Mercy Hospice Auckland staff member who visits your home.

Mercy Hospice Auckland

[families.asp](https://www.mercyhospice.org.nz/education/education-for-families.asp)) These ran once a month and although my visit was due to coincide with the group it had been cancelled as no carers had registered for that particular session. This would seem to replicate some of the challenges that we have faced in enabling carers attendance at events and will need to be considered when developing new services.

An alternative is to deliver services that support the patient and carer simultaneously. These were observed during my Fellowship as part of Day Service provision and are included in that section of this report.

Mercy Hospice's community nurses also provide informal education to family members who wish to become more involved in the practical care of their loved one. Supporting family members is common practice in the UK, but in the Auckland District Health Board area the care family members are able to provide extends to the administration of subcutaneous injections and renewing syringe pumps. These devices are pre-filled at the pharmacy, according to the required prescription, and once the family member is assessed as competent, they will be able to administer the drugs without the need for nursing visits.

9.3.3 Other caregiver support:

I observed and learnt about a number of other different initiatives to support family members and carers in supporting their loved ones. Although not directly linked to educating them in how to care, they undoubtedly built up resilience and were able to highlight needs that could be addressed by the health and social care professionals involved in their care.

The multi-professional out-patient model of care adopted by SAPS employs a Caregiver Facilitator who assesses and supports carers. Joint and individual patient and carer appointments are part of the out-patient service and follow up is provided according to the needs of the carer.

The Palliative Care Home Support Programme run by HammondCare in Sydney (<http://www.hammond.com.au/services/palliative-care/palliative-care-home-support-program>) provides 48 hour funded packages of care to directly influence the death at home rate. Primarily aimed at meeting patients' wishes and improving quality at the end of life, carer respite is identified as an additional outcome of the programme.

10. Allied Health Professionals (AHPs)

In the UK the term Allied Health typically applies to therapists and social workers within a multi-professional team. In palliative care, there is a predominance of physiotherapists, occupational therapists (OTs) and social workers in these teams, with a smaller representative, if any, of speech and language therapists, dietitians, art and music therapists. In Australia and New Zealand, I observed that allied health has a wider remit and typically there would be clinical psychologists, counsellors, spiritual and cultural liaison officers and more art and music therapy resource invested in the multi-professional teams.



The multi-professional AHP team at Te Omanga Hospice which includes an OT, counsellor, Māori liaison worker, bereavement support worker, art therapist, music therapist, and social worker

This has given me ideas of how resource could be allocated to maximise the breadth of support given to people affected by a life-limiting illness, but doesn't inform the main focus of this aim which I had envisaged related more to the role of OTs and physiotherapists.

10.1 Singapore:

There was little allied health support to Day Hospices and palliative care services in Singapore. Physiotherapy was outsourced to an agency which provided one or two hourly sessions per week. The patients were assessed based on functional ability and intervention planned based on this (Appendix 2), this resulted in some patients receiving 1:1 treatments while others were allocated to group based exercise class.

10.2 Australia:

I had expected a significant OT and physiotherapy presence in Australian palliative care teams but the reality was somewhat different. I heard that in some services there was no resource allocated to AHPs or that if there had been it had either been reduced or posts not replaced when vacancies arose. I also heard how the specialism of palliative care was not

valued within the physiotherapy profession in Australia and consequently when the resource was available there were challenges recruiting into the posts.

Australian health funding is evidence-based and this could explain the lack of AHP resource in palliative care. I had the opportunity to meet some members of the Australian Allied Health in Palliative Care (AAHPC) committee who were able to explain their long-term strategic aim to gather and submit evidence to national bodies to promote the impact that physiotherapists and OTs can have in supporting people with life-limiting diagnoses. They are aiming to prove that there is an economic benefit to employing therapists in palliative care which will eventually result in more investment in therapeutic and rehabilitative palliative care.

Given the differences I observed I was asked to submit a reflective article for the AAHPC newsletter so that a wider audience could hear about the comparison with the UK and Australian model (Appendix 3). I also hope that it might encourage an Australian AHP to visit the UK on an Australian Churchill Fellowship.

There was non-pharmacological management, such as breathlessness and exercise groups, delivered by physiotherapists attached to in-patient palliative care teams, and I also heard about an innovative multi-professional rapid discharge team for palliative patients in Melbourne which had been set up to address the low home death rate in Victoria.

One exception to the paucity of specialist physiotherapy and OT influence was the model of support adopted by SPNDS which challenged my way of thinking in relation to future service provision in the UK. As a specialist level 5 service, the expertise within the service provides an assessment, advice, liaison and support service which includes specialist physiotherapy, OT, speech and language therapy and dietetics. These therapists have accepted that they cannot be involved in the day to day, week to week care of the patients but that their out-patient interventions must be tailored to influencing the next three, six or even nine months before the patient attends their next out-patient appointment. In-depth assessment, knowledge of disease trajectory and potential future needs, up to date information about equipment and funding and a wealth of disease and intervention-specific information in a variety of forms all contribute to this team being able to influence the care of a large and specialised group of patients. Generalist therapists in the patients' locality are seen as "part of the team" and provide ongoing support between clinic appointments.

10.3 New Zealand:

Although small in number, there were proportionally more OTs and physiotherapists working in palliative care in New Zealand than in Australia and Singapore. Some services employed physiotherapists and no OTs and others OTs and no physiotherapists. Even when both were employed there was a blurring of some professional boundaries to ensure that the needs of the patients and their carers were met and this reflects the UK approach.

From what I was told it appeared that OT was more established and embedded within the palliative care system than physiotherapy, with OTs having a special interest group and annual study day.

Typically, OTs in New Zealand have been employed to lead day hospice services,

acknowledging and reflecting the breadth of their skill set in promoting independence, but also their ability to address occupation and creativity. There was an acceptance that the role of the OTs in the specific hospices had to flex depending on OT services in the surrounding district health boards. Some OTs were focussed mainly on maintaining people's independence within the home environment, others in a supportive and educational capacity and I met one OT who had been employed to set up an out-patient education programme that was now well established so she was looking to develop her role further.

Physiotherapists supported patients as in-patients, out-patients and in the community. They used non-pharmacological management to address symptoms such as breathlessness, oedema, pain and mobility issues, support wellbeing programmes and liaise with local generalist community services.

At Totara Hospice there is a physiotherapist in a strategic management position and they are beginning to implement a strategy to reach out further into the community to include wellbeing, enablement and rehabilitative models of care.



Pippa and Cherie: Mercy Hospice's Physiotherapy and OT team

11. Minority Groups

A significant strategic aim of hospice services in the UK is to improve the access for people in minority groups, defined by ethnicity, race, diagnosis or social circumstances^{10, 11}. I wanted to understand what processes, services and initiatives had been used to reach out to minority groups in Singapore, Australia and New Zealand.

Most of the experiences I had during my Fellowship journey related to minority groups due to ethnicity but I believe learning could be applied to any minority group.

11.1 Cancer Support Group at The British Club:

The Cancer Support Group at The British Club is open to ex-pats of any nationality affected by cancer. They meet once a month and also have a private Facebook page that connects them to others who are no longer part of the community in Singapore. Listening to the experiences of this group there were a number of themes:

- Whether and when to tell family and friends back at home
- Navigating the healthcare system
- A lack of broader information relating to living with cancer
- Differing cultural expectations and norms.

The physical group is fluid with people coming and going depending on personal circumstances, but the closed Facebook group provides ongoing support. I heard that previous members continue to contribute to this group and having people living in other parts of the world facilitated additional support and provision of resources.

11.2 Australia:

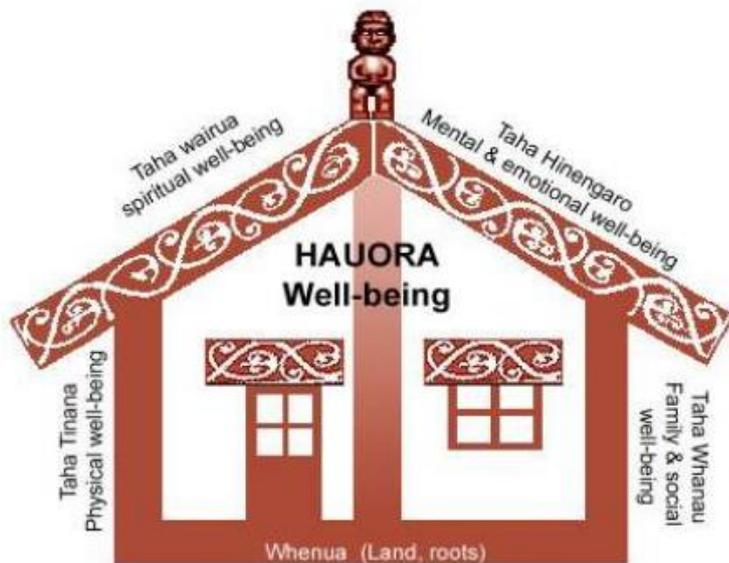
On a visit to Palliative Care South Australia, I met John McMahon who is the Programme Lead for the [Programme of Experience in the Palliative Approach](#) (PEPA). PEPA is a government-funded nationwide education programme aimed at empowering healthcare professionals to deliver quality end of life care. The programme consists of free healthcare placements within palliative care services and workshops on the palliative approach for non-specialists healthcare professionals. There is a specific arm of PEPA focusing on the healthcare needs of the Aboriginal and Torres Strait Islander population¹². My discussions with John, however, gave me an insight into the greater challenges in supporting the needs

of these peoples. John explained that although 2% of the South Australian population identifies themselves as Aboriginal, the caseload of palliative care services includes only 0.5% of patients with this heritage.

I was also challenged to consider my own inherent and subconscious biases based on personal, professional and institutional experiences and upbringing. Cultural Safety Training is being offered to healthcare professionals in South Australia as an alternative to Cultural Awareness Training to improve the care and experience of minority groups. Some practical steps have also been taken to improve engagement with the Aboriginal population through the implementation of joint working. Clinics which would traditionally have been held in hospitals are now being held at the Aboriginal Health Centres. Hospital liaison services are also encouraging translators and Aboriginal Healthcare Workers to advocate for people admitted to hospital.

11.3 New Zealand:

Cultural liaison and awareness are firmly embedded into healthcare education and provision in New Zealand. Te Whare Tapa Whā is a Māori model of care developed by Professor



Mason Durie¹³ which compares a person's total wellbeing to the four cornerstones of a house. When one of the cornerstones becomes damaged or is missing the model suggests that the person will be unwell or unbalanced. This approach has now been embedded within Te Ara Whakapiri (Principles and Guidance for the Last Days of Life)¹⁴

Historically Māori and Pasifika populations have been the main minority groups in New Zealand although in more recent years there has been a significant increase in the Chinese population. Māori and Pasifika liaison workers are employed to reach out and support the needs of their populations, working as part of the multi-professional team and one hospice has recently appointed a Chinese liaison worker to address the needs of the growing Chinese population in Auckland. I found it was normal to include Māori and Pasifika cultural practices as part of everyday hospice life. I was

welcomed with a Māori blessing at Mercy Hospice and with a Samoan welcoming ceremony at Totara Hospice, something I learned was afforded to most new members of staff. I also heard how people would be “sung out” of the hospice when they died.

Speaking to the liaison workers gave me valuable insight into their approach which was driven by the desire to ensure their communities received culturally sensitive support and that there were as few barriers as possible to them accessing palliative and end of life care. I heard that it could take many years to develop significant relationships and progress the work but that it was important to wait for an invitation to get involved and move at the pace and with the particular needs of the specific community.



Georgina: AHP Lead, Aran: Spiritual Lead, Marleen: Māori and Pasifika Liaison and me following the Samoan welcome at Totara Hospice

Despite the diversity of needs among the different cultural groups, there were a number of themes that emerged:

- **Language:** not only that English would be a second language or not spoken but that there might not be words for “palliative care” or “hospice” and other similar terms in the vocabulary of the group.
- **Culture:** for some death is accepted as part of life and all the community would be involved in supporting the person and their family and Whānau, whereas with other groups a forthcoming death is not acknowledged at all.
- **Community engagement:** this appeared to be the best solution for offering the groups the opportunity to engage with hospice services. Some of the workers also spoke about how people who had received hospice care became “champions” within their communities. Groups had taken place within the communities, workers attended community events and hospices had broadened their offer and opened up their facilities to other services that were needed within the community.

- **Rituals:** the ability to respect and enable cultural rituals to take place was of utmost importance. But also being able to communicate that this was possible was needed to encourage people to engage with hospice care.

During my time in New Zealand, I came to realise that embedding cultural practices within healthcare not only improved the quality of care for the patients and their families but also improved resilience and wellbeing of the staff employed to provide the care. The holistic approach of Te Whare Tapa Whā has also challenged my thinking about the way in which palliative care has developed in the UK. Having the opportunity to step back from my day to day work made me more objective and my personal opinion is that the UK model has become very focused on clinical care potentially to the detriment of true holistic care.

12. Digital Technology

As the world becomes an increasingly digital and connected place I wanted to know how palliative care services were using this technology to improve efficiency, reach more people and improve the patient experience. My assumption was that given the remoteness of some areas of Australia and New Zealand that they would be using technology to support services.

12.1 Websites:

I accessed websites as part of my research into where to visit, trying to find out specifics of the services they provided and contact details of key personnel. The information provided and ease of navigation varied. Some services had uploaded videos, programme details and provided the opportunity to self-refer or book on to groups through the website. Others were less informative just giving details of departments without further explanation of what was specifically available. Increasingly a website will be the first, or maybe the only, point of contact many people will have with an organisation. It is important to maximise the value of a website, not only as its digital window into the organisation but to provide information and signpost people to other forms of support.

12.2 Video and teleconferencing:

I saw most use of this at SPNDS in Melbourne. Given that patients are supported from across the whole of Victoria and Tasmania, and that they have a progressive diagnosis that can impact on mobility it would seem obvious to use video conferencing to manage the

workload and improve the patient experience. It had been a gradual process, but I heard that it was becoming more commonplace for follow-up multi-professional appointments to be offered as a video call, and occasionally a first assessment is offered in this format when the patient is referred late and unable to travel.

As a statewide service they work collaboratively with health and social care professionals in the patient's local geographical area and to assist in communication at multi-professional meetings will include teleconferencing to include these other key workers. Videoconferencing is also used to enable the staff to virtually attend case conferences and family meetings.

I heard that the main challenges with using this technology are the connectivity and accessibility but that through persistence and perseverance it has become a valuable tool to support people when otherwise they might not be able to access the service.

Some services also used video calls for out of hours on-call services to provide support for patients and carers overnight.

12.3 Electronic patient records:

Most organisations I visited were either already using or moving towards using electronic patient records. What varied, however, was the breadth of accessibility. Some services were fully integrated into records across all healthcare providers, whereas others could only access their own records.

12.4 Use of laptops and tablets:

Many community-based teams had been issued with laptops or tablets so they had access to information while on the road and could update records contemporaneously. Laptops were brought to meetings to enable individuals to be able to access records of their own interventions rather than being reliant on one main screen and to avoid unnecessary use of paper resources.

12.5 Quality and Health and Safety:

At Totara Hospice, South Auckland, there were a number of iPads placed in key positions around the building that were used for feedback and patient information.

In Singapore volunteers and visitors used an electronic check in and out system that enabled the organisation to know who was onsite should an evacuation be necessary and also gave them a record of who had supported the service. Analysing this data provides valuable information about the level of support an organisation gets from volunteers but also provides the volunteer with a quantitative record of their service.

There were other examples of where digital innovation was beginning to be considered. I heard about the Second Ears app in Melbourne to record the content of an out-patient appointment so that patients can listen back and share it with family and friends. At one service in New Zealand, they are considering videoing their in-service training programmes so that people who are not able to attend will be able to access the programme electronically.

Digital technology is going to provide many opportunities to develop and expand services, improving user experience and staff efficiency but without exception, the main concerns I came across were accessibility and acceptance. I am sure this will change in the very near future as we all become more comfortable with what is available and consequently adjust our working practices.

13. Funding

Specialist palliative care services (hospices) in the UK are typically funded from a number of different sources. The average government contribution across the sector is 30%, with Princess Alice Hospice receiving 23% of funding from NHS sources in 2017/18. The shortfall is met through local charitable fundraising, trust funding, legacies and income from retail sources such as charity shops. The low level of central funding can present challenges but it also creates an element of freedom in how services are developed to meet the needs of the local population. This has resulted in no standardised service specification, although elements of similarity exist and national documents provide guidance on core aspects of care.

I wanted to explore how different funding models impact service delivery in other countries.

13.1 Singapore:

HCA Hospice Care is a charity which relies on charitable giving from individuals and corporate foundations as well as grants from the Ministry of Health and National Council of

Social Services. Nominal, means-tested, amounts are charged for attendance at Day Hospice and the Caregiver Training programme. This equates closely to the funding model in the UK and although Princess Alice Hospice currently offers all services free of charge some UK hospices do ask for contributions to cover costs such as meals and transport when people are attending PDS.

I wasn't made aware of any restrictions placed on how central funding was spent although some of this money is generated directly from patient and carer activity which would replicate commissioned services in the UK.

13.2 Australia:

Federal government funding for health is devolved down to state governments, with decisions about allocations of these funds being made at a local level. This results in differing amounts of money being made available for palliative care in different states.

State funding can come with specific criteria, for example, funding for in-patient nursing care is calculated against a set number of nursing hours per patient per day. This does not, however, account for dependency and without fail the nursing managers stated that they would overstaff their wards if dependency necessitated this.

Some palliative care providers are charities or have their foundation through religious orders, such as HammondCare and Calvary Care, and they deliver their services based on income from a number of different sources including government grants and "bulk-billing" relating to activity.

There is little charitable income generated to supplement state funding although I did learn that in some states additional monies are generated for health from philanthropic giving. Services are delivered based on specific funding criteria with less ability to provide any "value added" services to meet the needs of a local community.

Specific amounts of federal funding are made available, however, to fund projects based on nationally identified objectives and the specialist palliative care providers seemed well placed to respond to these opportunities, allowing them to develop new services and share their expertise. These projects included improving home death rates, increasing awareness of advance care planning, developing the knowledge and expertise of non-specialist healthcare workers and reaching out to marginalised groups such as the aboriginal population. Time will tell if any long-term funding will follow from these projects and increase the amount invested in palliative care services.

13.3 New Zealand:

The funding model in New Zealand more closely represented the UK model although with a higher proportion of government funding in each of the hospices I visited. Typically hospices would expect to receive 50 – 60% of their funding from the District Health Boards and then supplement their funds through charitable sources. It is not surprising therefore that there was a broader and more varied offer of services in each of the locations I visited which again replicates how services have developed in the UK.

Hospices were accessing specific funding that has been made available from the government to explore improvements and there was a significant focus on upskilling generalist healthcare providers on how to support people with life-limiting illnesses. Some of these projects had led to a number of hospices working together to develop resources that would support their local healthcare models.

In Wellington, I was able to meet with the Service Development Manager for Hutt Valley District Health Board who explained how she is working with palliative care providers, including Te Omanga Hospice, and GP practices to explore different ways of working, which in time it is hoped will improve efficiency and reach more people. It was interesting to hear about strategic planning of funding models to address some of the same challenges that are being predicted in the UK ie increasing numbers of people with multiple co-morbidities needing support relating to end of life issues.

14. Conclusions

My Churchill Fellowship enabled me to travel to Singapore, Australia and New Zealand to explore how PDS, hospices and other palliative care providers have developed their services based on each of their funding models, demographics and local needs.

Services in Singapore and New Zealand were remarkably similar to those in the UK, but I was already aware of new developments in New Zealand. Having seen them in practice, being able to meet people who have developed them, and talk to patients and carers who have experienced them has encouraged me to push forward with introducing them at PAH.

I had hoped that differing funding models and the large geographical areas in Australia would provide me with experiences of services that would be helpful in extending the reach in the UK. The use of digital technology, PCOC, out-patient clinics and specialists supporting

generalists healthcare professionals have all contributed to the recommendations I am making.

I have always had a fascination with culture and its impact on day to day life. Being exposed to the Aboriginal, Māori and Pasifika cultures, hearing about the way in which healthcare providers are developing services to meet their needs, and focusing on people and what is important to them rather than seeing them solely as patients will be another area of focus as I move forward. I will be able to consider implementing some of the activities I observed but also draw on others that are relevant to UK culture.

The Churchill Fellowship also allowed me to step out of my regular place of work for a prolonged period of time. Naively, I was not expecting to develop the level of objectivity in relation to the service I am part of at PAH, nor the impact this would have on my professional life when I returned to the UK. I have decided to step back from full-time working to allow space to implement some recommendations that might not be possible in my place of work.

15. Recommendations

➤ **To embed outcome measures into clinical practice to inform the pathway of care for patients**

OACC has already been introduced into clinical areas at PAH but isn't currently being used to inform the direction of travel of the patients. To ensure resources are used effectively OACC should be introduced into both the triage and review processes, enabling the patient to be offered a more tailored package of care. Using the patient reported problems as a referral tool will enable those issues of importance to the patient to be addressed by the most appropriate member of the multi-professional team.

One of the measures, Phase of Illness, could be used to help to balance caseloads and ensure a more equal division of workload.

➤ **To develop a carer support programme**

Before I set off on my Fellowship journey some work had started on ways in which carers could be supported to care for their loved ones, and when I returned a Families and Carers' Lead had been appointed. Based on additional information collected during my travels, and encouraged by what I saw and heard, a carers' course has now been planned and will be piloted in January 2019 (Appendix 4). Feedback from the first cohort

will be used to adapt the content to fully meet the needs of the people who attend. The last session will include time to allow the group to explore ways that they can continue to support each other.

Other ways of supporting carers will also be considered such as introducing a multi-professional approach to the current nurse-led out-patient clinics.

➤ **To develop and implement a wellbeing programme as part of a mixed model of PDS**

A one size fits all programme of activities in PDS does not meet the needs of all people who could benefit from support. A wellbeing/education programme will not only reach a different cohort of people but will also empower attendees to take control of the time they have left to them. A programme has been developed (Appendix 5) in draft format and implementation is now being considered. It will be necessary to promote this to ensure people are referred earlier in their palliative journey. It will be run at different times of the day to attract people who may still be working.

➤ **To develop multi-professional out-patient clinics**

Nurse-led out-patient clinics have recently been introduced but the model of multi-professional interventions offering additional support should be considered to include social and family support. Focusing expertise in one place would also maximise the use of resource and expertise for people diagnosed with rarer conditions.

➤ **To explore the potential of collaborating with local allied health professionals to extend the reach**

This recommendation could be challenging due to the different funding models and existing practices in the UK. However, developing links with non-specialist providers or even specialists in other fields must be possible and beneficial to both parties even if not to the extent that I observed during my Fellowship journey.

➤ **To ensure digital resources are uploaded onto the PAH website**

A consistent approach to uploading patient information leaflets and videos of practical aspects of care will, in the future, be adopted to ensure the PAH website is used to maximise its potential but also to offer follow up support to those people who receive face to face support. Sharing these links with local and national organisations will again extend the reach.

➤ **To provide teleconferencing as an alternative to face to face interventions**

Teleconferencing will be used for patient interventions and multi-professional meetings but also to facilitate carers attending the carers' support programme if they are not able to leave their loved one at home.

➤ **To introduce initiatives that enable patients to return to being the people they are and celebrate all that means to them**

At the end of their lives people need to have clinical interventions to manage symptoms, however, it is of as much if not more importance that they are supported to be people. I want to explore ways that will help them celebrate who they are and have been, along with enabling them to maximise the use of the time remaining to them. Some initiatives, such as Life Stories and cultural practices have been inspired by my Fellowship, but others might be gleaned from other sources.

This recommendation might need to be achieved outside of the healthcare environment but there should be some opportunities to address personal aspirations through interventions provided at PAH.

Some of these recommendations are already beginning to be implemented, others are for the future and yet others are aspirational. The current financial climate, the need to challenge cultural norms, and the ability (or inability) to influence change could all be barriers to success. However, I end with this quote from Sir Winston:

“Every day you may make progress. Every step may be fruitful. Yet there will stretch out before you an ever-lengthening, ever-ascending, ever-improving path. You know you will never get to the end of the journey. But this, so far from discouraging, only adds to the joy and glory of the climb.”

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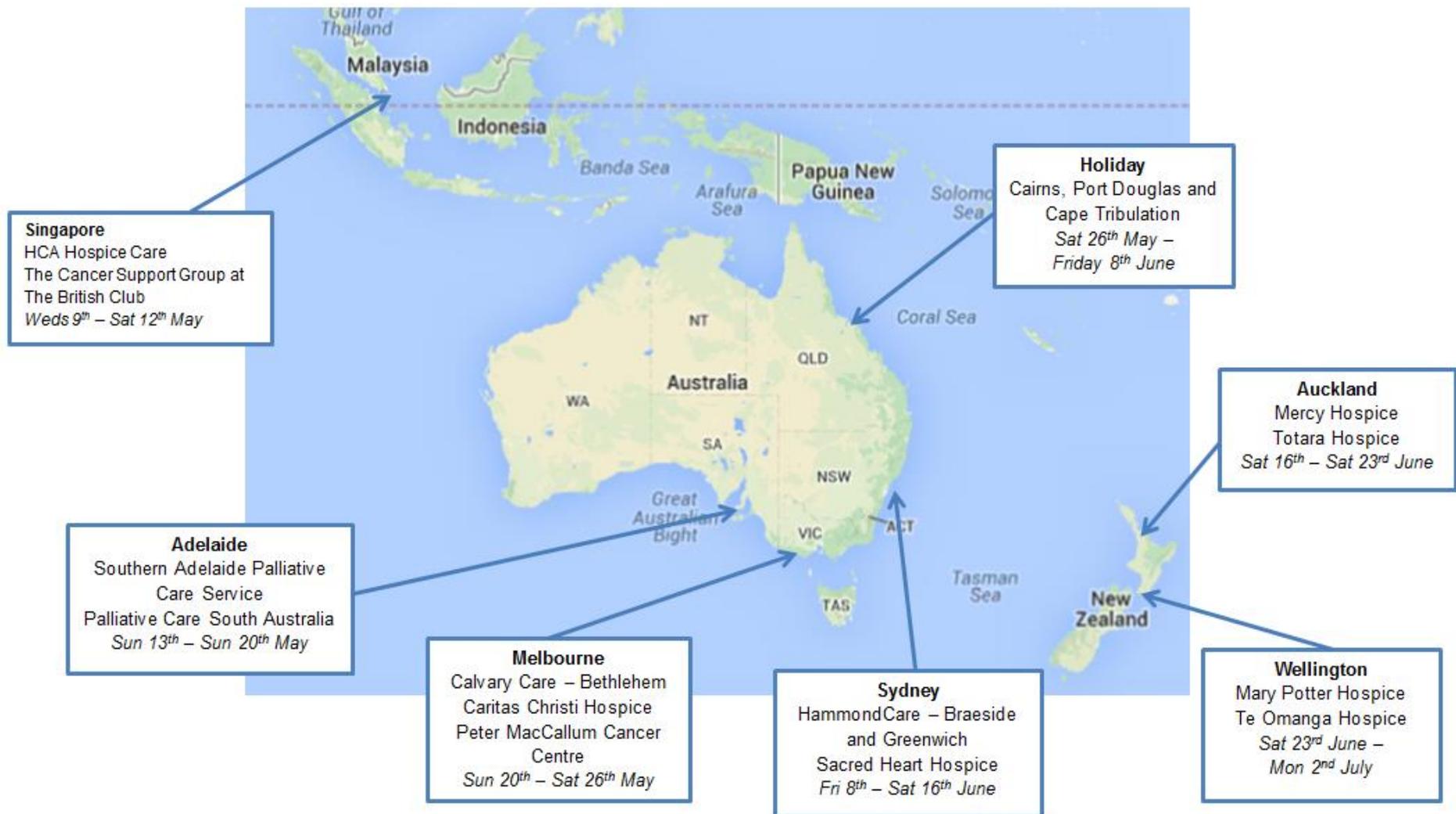
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17. Appendices

Appendix 1: Itinerary

		Purpose/Experiences/Main contacts
8 th /9 th May	Travel to Singapore	
10 th /12 th May	HCA Hospice Care Cancer Support Group at The British Club	Day Hospice and Palliative Care Giver Programme Angela Tan, Director of Nursing Ex-pat experience of living with a significant illness Jackie Green
12 th /13 th May	Travel to Adelaide	
14 th /15 th and 17 th May	Southern Adelaide Palliative Care Service	Medical and multi-professional palliative out-patient clinics Jo Wells, Nurse Consultant Triage
16 th May	Palliative Care South Australia	Supporting minority groups Extending the reach through education John McMahon, PEPA Manager
17 th May	Australian Allied Health in Palliative Care	Allied Health in Australia and Research Deidre Morgan, Lecturer Palliative Care, Flinders University
20 th May	Travel to Melbourne	
21 st /22 nd May	Calvary Care Bethlehem Statewide Progressive Neurological Service	Neurological out-patient service Anna Smith, Deputy Manager
23 rd May	Calvary Care Bethlehem	Day Hospice Janine Kekich, Day Hospice Co-ordinator
24 th /25 th May	Caritas Christi Hospice Peter MacCullum Cancer Centre	Day Hospice and Allied Health provision Rebekah Boffa, Senior Occupational Therapist Allied Health provision in the acute sector Celia Marston, Occupational Therapy Clinical Lead
26 th May – 8 th June	North Queensland	Holiday
8 th June	Travel to Sydney	

12 th June	HammondCare Braeside	In-patient palliative care model Allied Health provision Rose Estrada, Clinical Nurse Educator
13 th June	HammondCare Greenwich	Government-funded pilot services Breathlessness group Bereavement In-reach to nursing homes Felicity Burns, Director of Community Palliative Care North
14 th /15 th June	Sacred Heart Hospice	Changing picture of palliative care provision Allied Health provision Prof Richard Chye, Medical Director
16 th June	<i>Travel to Auckland</i>	
18 th /20 th June	Mercy Hospice	Development of hospice movement in New Zealand Allied Health provision Manaaki Programme Maori, Pasifika and Chinese support Life Stories Volunteer Support Extending the reach through education Collette Par-Owens, Clinical Director
21 st /22 nd June	Totara Hospice	Maori and Pasifika Support Day Hospice and Wellbeing model Nurse-led out-patient clinics Funding models in New Zealand Poi – Extending the reach through education and mentoring Georgina Miller, Head of Allied Health and Social Support
23 rd June	<i>Travel to Wellington</i>	<i>Northern Explorer Train</i>
25 th June	Mary Potter Hospice	Day Hospice provision Extending the reach through community engagement Martin Woods, Research Fellow Vanessa Eldridge, Manager Day Services
28 th June	Te Omanga Hospice Hutt Valley District Health Board	Carer Education Allied Health provision Eleanor Barrett, Occupational Therapist Exploring new funding models Jazz Heer, Service Development Manager
30 th June	ANZSPM Conference	Right to Die debate
2nd/3 rd July	<i>Travel home</i>	



Appendix 2:

Functional Assessment and Physiotherapy Intervention, HCA Hospice Care

EATING	4	Eating independently and comfortably
	3	Requires supervision
	2	Needs assistance
	1	Totally dependent
BATHING	4	Can perform the activity independently and comfortably
	3	Can perform the activity with supervision
	2	Needs assistance while bathing
	1	Totally dependent
DRESSING	4	Independent
	3	Needs supervision
	2	Requires assistance to carry out the activity
	1	Totally dependent
TOILETING	4	Independent
	3	Needs supervision
	2	Requires assistance
	1	Totally dependent
TRANSFERRING	4	Independent
	3	Requires supervision
	2	Requires assistance of 1
	1	Totally dependent
MOBILITY	4	Walking independently with or without a walking aid and is community ambulant
	3	Walking under supervision and is not community ambulant
	2	Walking with assistance of 1
	1	Walking with assistance of 2
	0	Unable to walk

SCORE	CATEGORY	PERFORMANCE STATUS	FREQUENCY OF TREATMENT
<9	R3	Fully active without restriction Symptom- free Continue with activities to promote quality of life	Twice a week
9 – 18	R2	Minimal symptoms noted Able to participate with activities Able to perform rehabilitation with minimal or no supervision	Once a week
19 and above	R1	Symptomatic management Requires therapist to address specific symptoms and plan appropriate treatment	Once in two weeks

Appendix 3:

Reflections of a UK Churchill Fellow

Kathy Birch, Programme Lead Day Services, Princess Alice Hospice, Esher, Surrey

In February I was awarded a 2018 UK Churchill Fellowship to explore how palliative day services could be used to reach more people affected by a life-limiting illness. As a physiotherapist and palliative day care leader in a large UK hospice, I was also interested in understanding how allied health professionals are utilised in palliative services.

My Fellowship journey took place in May, June and early July and I travelled to Singapore, Australia and New Zealand. During the research into where I might visit, I came across the AAHPC and that led to a request for this reflection of my time in Australia.

Before we go any further though I have to include a disclaimer – I was only able to visit a limited number of services and these are my personal reflections which could be “off the mark” but here goes!

I have always been encouraged by the research that comes out of Australia and the way in which Australian healthcare encourages the use of outcome measures – much better and more integrated into clinical practice than in the UK. I had assumed, therefore, that palliative care services would be overrun with allied health professionals, specifically physiotherapists and occupational therapists. I soon realised this is generally not the case, which greatly saddened me because I know the benefit that therapeutic interventions can be for people in the last weeks/months/years of life.

I heard about posts having been cut and even when funding was available difficulty recruiting into posts which ultimately results in that funding being lost. It was suggested on more than one occasion that, specifically in relation to physiotherapy, palliative care as a speciality wasn't valued by the profession. I met a number of physiotherapists passionate about how their skills can be used but frustrated that their work can be undervalued and limited by decisions that are taken over which they have little or no control.

But on a positive note, I met with a number of the AAHPC committee who described how they are trying to influence the future. Deidre Morgan is doing this through her research work at Flinders University and clearly explained her thinking about gathering evidence to prove the value of functional training and the impact this has on patient wellbeing, experience and reducing carer burden. She is aiming to prove that investment in this will be of value to health economics.

In Melbourne, I spent time with Rebekah Boffa who explained how the Victorian OT Association Special Interest Group has worked to influence state and federal government on the role of OT, undergraduate education and the post-grad education sessions they provide. At Peter MacCallum Cancer Centre I met with Celia Marston and a couple of her colleagues and heard about the innovative rapid response team at the Royal Melbourne Hospital, that has been set up to address the low numbers of people who die at home, and the research being done by the Victorian Comprehensive Cancer Centre.

Another encouragement for me was the wider remit that Allied Health has in Australia with the inclusion of psychology, pastoral care and bereavement. There are very few psychologists working in palliative care in the UK and pastoral care and bereavement would generally not be included in allied health. This appeared to provide opportunities for inter professional working that wouldn't be possible in the UK.

So, all in all, I was left wishing it was possible for there to be a mix of the Australian and UK models. The UK has lots to learn from Australia in relation to research and use of outcome measures but Australian healthcare providers might be encouraged to consider additional resource for allied health if they knew more about how allied health professionals are working as part of palliative care services in the UK.

Anyone fancy applying for an Australian Churchill Fellowship to explore this?

If you are interested in reading more about my reflections during the time I was travelling check out the blog I wrote: <https://kathybirchblog.wordpress.com/> and I can be contacted at kathybirch@hotmail.com if anyone would like to know more about the UK model.

Appendix 4:

Your hospice, your charity

pah.org.uk

Course for Carers

Princess Alice
Hospice 

Tuesday evenings 7.00-9.00pm- Jan-Feb 2019

Princess Alice Hospice, Large Teaching Room

Meet other carers and learn more from experts. We will be talking about a number of subjects including what it is like to be a carer, the financial implications, looking after yourself, moving and handling, how illness progresses and nutrition for you and your loved one. This is an interactive course with opportunities to ask questions and talk about anything that affects your life as a carer.



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Email Rosienoble@PAH.org.uk or call 01372 468 811 and ask for Rosie Noble or Megan Andrews

Appendix 5:

Wellbeing Group Programme

WEEK	SUBJECT
1	Who's who at the Hospice An explanation of what the hospice is, the healthcare professionals you are likely to meet and how the hospice can support you and your family and friends
2	A Life Changing Event The impact of illness on the individual/family relationships both physical and emotional Coming to terms and adjusting to illness Moving Towards Acceptance Looking at strategies for coping with the impact of illness, focusing on developing resourcefulness
3	Planning for the future An overview of making a will and lasting power of attorney Discussion on PPD/PPC and advance directives
4	Spirituality What does it mean to you Mindfulness, Complementary Therapies and other strategies to help you become more resilient, including sleep hygiene
5	Fatigue General introduction to the fatigue programme; causes and impact of fatigue. Making lifestyle changes, the 3P's – pacing, prioritisation and planning Hand out – fatigue diaries
6	Anxiety and strategies to help
7	Coping with the symptom of breathlessness
8	Managing other symptoms Pain Nausea and vomiting Constipation and diarrhoea
11	Medicines Management How to keep on top of all those drugs and potential side effects
10	Dietary Advice Dealing with altered appetite, difficulty eating and nutrition
11	Keeping Active Appropriate exercise, maintaining independence and equipment that is available and how it can help
12	Open session and reflection on the programme An opportunity to talk about anything else that might be relevant eg travelling abroad, taking part in clinical research etc There will also be the opportunity to reflect on the programme and decide on goals for the future.