PALLIATIVE & END OF LIFE CARE

making history

PROGRAMME

SYDNEY 2014
PALLIATIVE CARE NSW STATE CONFERENCE
22 – 24 OCTOBER 2014
MENZIES HOTEL SYDNEY
PALLIATIVE & END OF LIFE CARE
making history

ORGANISING COMMITTEE
Linda Hansen, Executive Officer, PCNSW, Chair
Joan Ryan, CNC, Royal Prince Alfred Hospital
Therese Smeal, CNC, South West Sydney Local Health District
Helen Moore, CNC, Calvary Health Care
Jane Connolly, PCOC

SCIENTIFIC COMMITTEE
Peter Cleasby, Chair
Peta McVey
Claudia Giugni
Dr Christine Sanderson

ENQUIRIES
Linda Hansen
Palliative Care NSW
Phone: 02 9206 2094
Email: info@palliativecarensw.org.au

Sarah Masters
CC Conferences and Corporate Events
Phone: 02 9331 1700
Email: sarah@ccconferences.com.au

THANK YOU TO OUR SPONSORS
We would like to thank all of our sponsors without whom this conference would not be possible.

MAJOR SPONSORS

ACI NSW Agency for Clinical Innovation

Silver Chain

Calvary Health Care Sydney

Clinical Excellence Commission

All information contained in this publication is accurate at the time of printing. The Organising Committee reserves the right to make alterations to the program and associated events as circumstances dictate.
WELCOME

On behalf of the Organising Committee I welcome you to the 2014 Biennial State Palliative Care Conference. The theme for this Conference is “Palliative and End of Life Care: Making History”.

For the last several conferences, we have gone out into the regional areas of NSW – Dubbo, Cessnock, Coffs Harbour and Orange, and we have had successful conferences in each area. PCNSW and conference delegates have gained much from our respective travels but it’s time to come back to the city for 2014 and a chance to reflect on our past – examine the present – and take a look into the future as we come to Sydney for the first time in 10 years.

We have gathered speakers from around NSW and Australia to examine the theme that the organising committee has developed this year.

This conference will examine the history of Palliative Care leading up to the present – and what we can imagine for the future. There will be plenty of innovative presentations and new and exciting ideas to consider.

The conference is being held at the wonderful and historic Menzies Hotel Sydney. We are close to Circular Quay and to the Rocks – and to all of the highlights of the city of Sydney.

We look forward to welcoming you Sydney.

Linda Hansen
Chair, Conference Organising Committee
Palliative Care NSW

HIGHLIGHTS

CALVARY WELCOME COCKTAIL RECEPTION

Enjoy the historical piano room at the Menzies Hotel whilst sharing some canapés and cocktails and catching up with colleagues. Thank you once again to Calvary for sponsoring this always popular event.

THE GALA DINNER

As always, the Gala Dinner is a highly anticipated part of the conference and this year you don’t have to travel far to get home! We will have dinner and dancing until late. It’s all part of your conference registration so let your hair down for one night!

KEYNOTE SPEAKERS

We have another great line up of speakers to give their stories – and their opinions on the past, the present – and the future. There are some challenging notions being presented and we hope that you will participate in some vigorous discussion about where we’ve been and where we’re going.

OTHER ATTRACTIONS

You’re in Sydney – near the water – near the ’top end of town’ and right in the heart of shopping heaven. We will have some suggestions for things to do and places to go if you wish to stay on for the weekend.
REGISTRATION
The registration desk is located in the Menzies Hotel and will only be open as follows:
Level 1 Wednesday 4:30pm – 6pm
Level 2 Thursday 8am – 9am & Friday 8am – 9am
The telephone for the registration desk is 02 8235 1807

SPEAKER PREPARATION
There will be a speaker preparation area in The Piano Bar.

TRANSPORT
Transport is the responsibility of individual attendees. From Sydney Airport, the Airport Train will take you to Wynyard which is directly opposite the Menzies Hotel. This will cost you $16.40. Taxis will cost you between $35 and $50 depending on traffic.

TRADE DISPLAY SPONSORS

NSW Nurses & Midwives’ Association
The NSW Nurses & Midwives’ Association (NSWNMA) is the registered union for all nurses and midwives in NSW. It represents industrial and professional interests and services include legal representation, OH&S advice and workers compensation. The Association empowers nurses and midwives to actively participate in shaping every aspect of their professions.

PEPA
Program of Experience in the Palliative Approach EDUCATING.

PCOC
The Palliative Care Outcomes Collaboration (PCOC) is a national program that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care. Participation in PCOC is voluntary and can assist palliative care service providers to improve practice and meet the Palliative Care Australia (PCA) Standards for Providing Quality Palliative Care for all Australians.

GENERAL INFORMATION

TRADE DISPLAY SPONSORS

LINK
LINK Healthcare is a specialist Pharmaceutical and Medical Technology business operating in the regions of Australia, New Zealand, Asia and Southern Africa. At this conference, LINK will be providing product education about a treatment option that is part of the overall patient’s symptom control management. Its efficacy and safety has been assessed and designed for patients with a life-limiting illness receiving palliative care.

Mayne Pharma
Mayne Pharma is an ASX–listed specialty pharmaceutical company that develops and manufactures branded and generic products, which it distributes globally. Mayne Pharma has a 30-year track record of innovation and success in developing new oral drug delivery systems and these technologies have been successfully commercialised in numerous products that have been marketed around the world including Kapanol™ (sustained release morphine used to treat chronic pain).

NSAP
National Standards Assessment Program (NSAP). Improving quality of care at the end of life. NSAP is a quality improvement program, available for all specialist palliative care services across Australia. It is a program that enables services to engage in continuous quality improvement through self assessment against the National Palliative Care Standards, action plan development and implementation, as well as peer mentorship.

SATCHEL INSERTS
PCC4U, Jon Baine Tours, Urban Walkabout, Link, Centre for Palliative Care
KEYNOTE SPEAKERS

NORELLE LICKISS
Norelle Lickiss, AO, Clinical Professor University of Sydney, MD FRACP FRCPE has several decades of experience as consultant physician in clinical practice (especially cancer medicine) and medical education at University of Tasmania, Royal Prince Alfred Hospital and Prince of Wales Hospital group. Education of doctors and the education of other staff in Residential Care Facilities for the Aged in Hobart and Sydney, has included work in most Asian countries, particularly Iran and China. Her work has included interdisciplinary colloquia, focussed on fundamental matters relating to medical practice, with some related academic publications, for example with Professor Jeff Malpas, UTAS (Perspectives on Human Dignity, 2007, Perspectives on Human Suffering 2012, ed Malpas and Lickiss). She continues to learn!

ANTHOULLA MOHAMUDALLY
Anthoulla Mohamudally graduated from the University of London in 1996 and completed basic physician training before moving to Australia in 2001. She undertook basic and advance physician training in Sydney, becoming a specialist in Palliative Medicine in 2009. She went from studying a PhD on “The Impact of the Anorexia–Cachexia Syndrome on the Pharmacokinetics of Opioids” to providing palliative care in the Northern Territory, largely in remote communities. This presentation is a reflection – from the Northern Territory to the Northern Beaches.

DAVID ANDERSON
David Anderson is an advanced trainee registrar in Intensive Care Medicine with a strong interest in Palliative Medicine and end of life care in the intensive care setting. He has recently completed a year’s registrar training with the Palliative Care Consult Service at RPA and in patient unit at Greenwich Hospital. David originally trained in Auckland, New Zealand, but mostly in Sydney at Royal Prince Alfred Hospital. He worked as a paramedic before qualifying as a doctor and enjoys travel, fine dining and good west coast IPA.

JANE TOLMAN
Dr Jane Tolman is a geriatrician based in Tasmania. She has a special interest in person centred care, especially with reference to dementia and its impact on families and carers. She is Associate Professor of Aged Care at the Wicking Dementia Research and Education Centre at the University of Tasmania where she is involved in both education and research, and has been heavily involved in their MOOC – Massive Online Open Course which has provided education to 15,000 people from around the world. She has previously worked as a school teacher and counsellor. She regards her biggest professional achievement in recent times as the development of a new staging system for dementia, and it has gained widespread traction among carers, families and health professionals, for its emphasis on dignity and the importance of palliation.

JENNY MCKENZIE
Jenny McKenzie has worked Palliative Care for 15 years, becoming a Nurse Practitioner in Palliative Care in December 2006. She works in the regional centre of Wagga Wagga and is passionate about Palliative Care in rural areas. Clinically she has a special interest in the Management of Dyspnoea and Non Malignant Palliative Care. Jenny is currently an Executive member of the ACI Clinical Network for Palliative and End of Life Care.
PROGRAMME

WEDNESDAY 22 OCTOBER

6:00pm – 8:00pm  Calvary Healthcare Welcome Reception (Menzies Hotel, Parkside & The Piano Bar, Level 1)

DAY 1  THURSDAY 23 OCTOBER

8:00am – 8:45am  Registration (Level 2)

8:45am – 9:00am  Welcome to Country (Plenary Room: Sydney Room, Level 2)

9:00am – 9:10am  Introduction (Plenary Room: Sydney Room, Level 2)
  Carolyn Walsh, President of PCNSW

9:10am – 10:00am  Barbara Leroy Memorial Lecture 'On Personal Care' (Plenary Room: Sydney Room, Level 2)
  Hon Professor Norelle Lickiss

10:00am – 10:40am  Keynote Address: Back to the Future? Palliative Care in the 21st Century
  (Plenary Room: Sydney Room, Level 2)
  Dr David Anderson

10:40am – 11:20am  Morning Tea (Parkside, Level 1)

11:20am – 1:00pm  Workshops topics include:
  » Workshop 1 If you build it they will come! (Brisbane/Adelaide Suites, Level 2)
  » Workshop 2 Palliative Care and Neurological Conditions (Perth/Darwin Suites, Level 2)
  » Workshop 3 Up close and personal (Hobart Room, Lower Ground)
  » Workshop 4 Palliative Care and the Humanities (Launceston Room, Lower Ground)

1:00pm – 2:00pm  Lunch and Posters (Parkside, Level 1)

2:00pm – 3:00pm  Concurrent Sessions

3:00pm – 3:30pm  Afternoon tea (Parkside, Level 1)

3:30pm – 5:00pm  The Plan to Increase Access to Palliative Care 2012–2016: An Update
  (Plenary Room: Sydney Room, Level 2)
  Introduction by Liz Junck, Ministry of Health
  Updates from: Dr John Collins, Westmead, Alex Huntir, Palliative Care NSW Volunteer Support Project, Kath Skinner, SilverChain, Sally Yule and Prof Rod McLeod, Hammond Care and A/Prof Josephine Chow, PEACH.

5:10pm – 5:30pm  PCNSW AGM (Canberra Room, Level 1)

7:00pm – 11:00pm  Dinner at the Menzies. Dancing compulsory! (Sydney Room, Level 2)
PROGRAMME

DAY 2 FRIDAY 24 OCTOBER

8:00am – 9:00am  Registration (Level 2)
9:00am – 9:45am  Pillar Talk
Rob Wilkins from the Agency for Clinical Innovation and Amanda Walker from the Clinical Excellence Commission.

9:45am – 10:30am  Future Nurse Leaders
Jenny McKenzie

10:30am – 11:00am  Morning Tea (Parkside, Level 1)

11:00am – 11:45am  Keynote Address: A staging system for dementia (Sydney Room, Level 2)
A/Prof Jane Tolman

11:45am – 12:30pm  Concurrent Sessions

12:30pm – 1:15pm  Lunch and Posters (Parkside, Level 1)

1:15pm – 2:00pm  Keynote Address: It comes with the Territory (Sydney Room, Level 2)
Dr Anthoulla Mohamudally

2:00pm – 3:00pm  Concurrent Sessions

3:00pm – 3:30pm  Afternoon Tea (Parkside, Level 1)

3:30pm – 4:30pm  The Great Hypothetical 'Dying is everyone's business' (Sydney Room, Level 2)
Hosted by James Valentine. James Valentine, jazz musician and ABC radio personality will be your host for what will be an enthralling session. Panellists include Professor Colleen Cartwright, Director of Aged Services Research, Susan Pearce, NSW Chief Nurse, Mark Buhagier, Manager of Allied Health at Braeside, Dr Frank Brennan, clinician and lawyer, Jenny McKenzie, Rural Nurse Practitioner, Ken Hillman, intensivist, Linda Sheahan, Staff Specialist Calvary and more!

4:30pm – 5:00pm  Wrap up (Sydney Room, Level 2)

WORKSHOPS

Workshop 1 If you build it they will come!
Adolescent and Young Adults (AYA) Workshop exploring a model of care for this patient population. Facilitator: Dr Toni Lindsay is a Clinical Psychologist and leads the AYA team at Chris O’Brien Lifehouse.

Workshop 2 Palliative Care and Neurological Conditions. Clinical Workshop. Palliative Care Australia and Neurological Alliance Australia is in the process of preparing a position statement on Palliative Care and progressive neurological or muscular diseases in Australia. The aim is to improve quality of life for those living with these conditions and funding to support research. This workshop will explore some of the challenges of this future development.

- Motor Neurone Disease. Ms Carman Sanchez
- Neurosciences Update. Kylie Tastula
- Dementia and Delirium. Annie Hepworth
- Cystic Fibrosis. A collaborative approach. Carmel Moriarty

Workshop 3 Up close and personal.
Palliative Care and Inter professional practice. This workshop will explore aspects of end of life care for patients with non-malignant disease and multiple co morbidities.

- Advancing Liver Disease: A changing trajectory for Palliative Care. Barbara Moore
- End of life Heart Failure. Carol Whitfield
- Renal and Supportive Care Model. Elizabeth Josland

Workshop 4 Palliative Care and the Humanities.
Love in our own time by Tom Murray. An Australian documentary on the big things in life – birth, love and death and bearing witness to lives beginning and ending. This documentary along explores the interface between Palliative Care and the humanities and what it is to be human. Madeleine Hetherington, co-producer, will co present with Frank Brennan as the chairperson. Chloe McDonald will also attend and have copies for sale at a special price.

174x332

SYDNEY 2014 PALLIATIVE CARE NSW STATE CONFERENCE
22–24 OCTOBER 2014 THE MENZIES SYDNEY HOTEL
PALLIATIVE & END OF LIFE CARE making history
CONCURRENT SESSIONS

DAY 1: THURSDAY
23 OCTOBER 2.00 – 3.00PM
Stream 1 Brisbane/Adelaide Suites, Level 2
Providing Quality Clinical Placements to Allied Health Students in Palliative Care
Jenny Downes
Food and nutrition for palliative care patients – the past, the present, the future
Jodie Ellis
Occupational engagement at the end-of-life: Occupational therapists’ perceptions
Kathrine Hammill
Stream 2 Perth/Darwin Suites, Level 2
NSW trends in palliative care patient care outcomes. Improvements over time: Where to from here?
Felicity Burns
Understanding How Advance Care Directives are used for Individuals with Dementia living in Residential Accommodation: A literature review
Vivian Masukwedza
The NSW NSAP Results: Quality Improvement Priorities, Actions and Opportunities
Shyla Mills
Stream 3 Hobart Room, Lower Ground
Management of Malignant Ascites at Home – meeting a need
Mary Almer
Where are we now in palliative and end of life care practice and provision?
Peter Cleasby
Community Specialist Palliative Care Nurses Experiences and Attitudes in Caring for Patients with Life Limiting Non-Malignant Chronic Disease
Debbie White
Stream 4 Room4
In the Holding Pen – Palliative Care Service Development in Western NSW
Alison Dawes
ehospice – revolutionising the way we access information about palliative care
Claire Maskell
Where have we been and where to from here?
Sue Hanson

DAY 2: FRIDAY
24 OCTOBER 11.45AM–12.45PM
Aged Care Session
Brisbane/Adelaide Suites, Level 2
Palliative Care: Core Business for Residential Aged Care Providers
Jane Mahoney
An Innovative, Collaborative Learning Pathway: Empowering Aged Care Registered Nurses to provide quality Palliative and End of Life Care (PEoLC)
Chris Lancaster
Stream 2 Perth/Darwin Suites, Level 2
Hydrotherapy, Play and Music in Paediatric Palliative Care – modalities used throughout history to enhance well-being
Marianne McCormick
Ever Changing Landscapes – Joy, Grief, Death & Health Promotion in a Children’s Hospice
Ann-Marie Perry
Life After the Death of a Child: the Experiences of Families
Natasha Samy
Stream 3 Hobart Room, Lower Ground
Responding to the complexity of a nested system of new paradigms to support the emergence of a new palliative care service in New South Wales (Australia) providing last-days-of-life home support primary healthcare.
Kath Skinner
Decision Assist: an Overview
Elizabeth Van Wyk and Karen Conte
The ACDC of Advance Care Planning” It’s a long way to the top...
Coral Marks, Jackie Eckert

POSTERS
Challenges and Barriers for Nurses Caring for people at the End of Life in Emergency Departments
Lyn Campbell
Granting a Dying Man’s Wish Jodie Ellis
Suspected malignant spinal cord compression
Jane Mackintosh
Poetry For Practice, Past, Present and Future
Caroline Short
Presidents of Palliative Care NSW Linda Hansen
Long Service – Palliative Care NSW Linda Hansen
DAY 2: FRIDAY 
24 OCTOBER 2.00 – 3.00PM

Stream 1 Brisbane/Adelaide Suites, Level 2
Impact of Medication Safety In The Home – What Did Carers Say?
Caroline Short
Old Bottle: New Jeanie
Bev Morris
A General Practice Initiated Project to Engage and Support General Practitioners in the Care of their Palliative Care Patients
Dr Alison Vickers

Stream 2 Perth/Darwin Suites, Level 2
Where are we now in palliative and end of life care practice and provision?
Joanne Cooper
Dying in the hospital setting: A systematic review identifying the domains of end-of-life care that patients and their families rank as being most important
Claudia Virdun
Inter–rater reliability and acceptability of the phases of palliative care
Dr Malcolm Masso

Stream 3 Hobart Room, Lower Ground
Pain management can be achieved with commitment and support
Mary–Rose Birch
He won’t last 24 hours at home
Jenny McKenzie
Invitation to participate in ImPaCCT – the New South Wales clinical studies collaborative in palliative care
Melanie Lovell

Stream 4 Launceston Room, Lower Ground
Specialist Palliative Care at Calvary: An Historic Perspective
Naomi McGowan
Palliative Care in the Pub
Julie Flood
Making the Impossible Possible
Dawn Hooper

ABSTRACTS
Listed alphabetically by main author surname

Management of Malignant Ascites at Home – meeting a need
Mary Almer, Clinical Nurse Consultant, Northern Sydney Home Nursing Service
Peta McVey, Clinical Nurse Consultant / Conjoint Lecturer, Learning & Research Centre, Greenwich Hospital, HammondCare

Introduction: Generalist community nurses (GCNs) are essential to the provision of community palliative care services (Walshe & Luker, 2010, p.1197) Included in the current ‘Palliative and End of Life Care’ needs of advanced cancer patients within a northern Sydney Health District, is drainage of malignant ascites via implantable peritoneal portacaths. Palliative care patients prefer to have complex treatments provided at home. GCNs need to expand their scope of practice to provide symptom management for palliative care patients with malignant ascites for drainage of malignant ascites via implantable peritoneal portacath.

Literature Review: A comprehensive literature review finds little evidence of community nursing management for palliative care patients requiring malignant ascites drainage in the home setting.

Objective: The objectives of this study are to explore GCNs’ education needs for expanding their clinical practice in managing home–based malignant ascites drainage procedure. Developing and evaluating effects of computer–assisted video demonstrating malignant ascites drainage at home will enhance accessibility of evidence based learning.

Setting and participants: GCNs working for a northern Sydney community nursing service.

Method:
1. Qualitative – quantitative: focus group of GCNs (n6) (experienced in this procedure) with thematic analysis to inform questionnaire development for survey of GCNs’ learning needs.
1. Quasi–experimental study with a pre-test & post–test design.

Conclusion: Results will reveal key educational elements for extending GCNs’ scope of clinical practice in managing malignant ascites drainage for palliative care patients at home, as well as highlighting the GCN role in provision of community palliative care.
NSW trends in palliative care patient care outcomes. Improvements over time: Where to from here?

Felicity Burns, PCOC Quality Improvement Facilitator (ACT & NSW)

Within a changing health care system it is vital for palliative care services to be able to demonstrate what we do over time. The Palliative Care Outcomes Collaboration (PCOC) has been a key driver in providing evidence based patient care outcomes. This is being achieved through, the use of standardised clinical assessment tools to measure patient outcomes, patient/carer periodic surveys, and benchmarking workshops. Currently in Australia there are 115 palliative care services participating in PCOC, of these, 23 are NSW inpatient services.

This presentation will demonstrate trends within NSW palliative care inpatient services, looking at the following benchmarks which were agreed nationally by the sector:

- Date ready for care to first contact
- Patients remaining in the unstable phase for 3 days or less
- Change in pain
- Change in common symptoms experienced by palliative care patients

PCOC provides the evidence for NSW services to celebrate improvements over time within all these benchmarks. The percentage of patients assessed in an unstable phase within three days or less has increased dramatically and the percentage of patients whose change in pain and symptoms is the same as or better than the national average (2008) has also increased.

Finally this presentation will also highlight some of the quality improvement activities and practice changes identified from a survey conducted by PCOC in 2013.
The cost of end of life care at home: A descriptive analysis.

Peter Cleasby, Service Manager, Palliative Care Services, Central Coast Local Health District

The NSW Government plan to increase access to palliative care 2012–2016 includes the undertaking “to help ensure that wherever possible more people can be supported to achieve their wish to die at home with their families and loved ones.” The policies and initiatives that have been generated in part to achieve this intention have been developed without local information on the cost of home based end of life care. This paper reports the findings of a costed audit that provides part of the answer to the question “What does it cost to die at home?”

Through the utilisation of available electronic health records, including progress notes, a convenience sample of all home deaths registered with a specialist palliative care service for a 12 month period was identified. A retrospective audit was completed focussing on the last two months before death. Data was collected relating to health care provider time, equipment and medications. These were costed and an average daily “price” produced. Hospital presentations during the time period were captured so that total time at home could be determined. Supportive time elements such as case discussions were captured, and the infrastructure costs of service provision to the home were also generated. Differences between cancer and non-cancer populations were considered in the analysis.

In presenting this new data the paper also notes the un-costed contribution of family and carers in supporting home based end of life care.

Decision Assist: an Update

Karen Conte, Program Manager for Decision Assist

The presentation will outline the comprehensive components of the substantial investment that is the Decision Assist program. Decision Assist is overseen by a consortium of key participants bringing together a sector cross-section, including Austin Health; Aged and Community Services Australia, Australian and New Zealand Society of Palliative Medicine ; Flinders University ; Leading Age Services Australia; Palliative Care Australia, Queensland University of Technology, and the University of Queensland. Decision Assist is funded by the Australian Government.

Decision Assist has five key components:

» Two telephone advice line, one a 24/7 specialist palliative care advice line, the other a 8am–8pm/7 day advance care planning advice line;

» A comprehensive web site, www.decisionassist.org.au, which contains clinical guidance documents, a national services directory for specialist palliative care services, resource materials for training courses, and it will have a companion Smartphone app;

» Targeted palliative care and advance care planning training workshops for residential and home care providers that are free and CPD eligible;

» A suite of linkages projects designed to bring together different service providers in the sector to synthesise efficient and effective outcomes through collaboration and resource sharing; and

» General Practitioner training for advance care planning, and educational opportunities and resources for palliative care.

This comprehensive and complementary set of products are integrated and interactive and specifically designed and targeted to aged care provider staff and general practitioners operating in the sector. The Decision Assist program was developed to pursue opportunities for better advance care planning and palliative support for older Australians and identifies those two major areas where more activity and support can greatly enhance quality of life.
Patient preferences re – Place of Death Versus Actuality of Location

Joanne Cooper, Palliative Care Clinical Nurse Consultant, NNSWLHD

UK research indicates that some 55% of people with cancer would prefer to die at home, while only around 25% actually do so. Forty percent of people who die in hospital have no medical reason to do so. Patient preference regarding active treatment in the event of terminal disease is contemporarily addressed by Advance Care Planning (ACP) initiatives.

Patient preference regarding place of death is, however, not necessarily focused on in the ACP process. The most appropriate time to ask a patient about end of life care choices such as where they wish to die, is subjective and patient specific.

Certainly it appears true that place of death is a fundamental definer for both patient and family as to whether a ‘good death’ has been achieved. There remains limited study of the reasons why place of death preference is or isn’t adhered to. Research in this area which is specific to rural and regional Australia is very limited.

This qualitative hermeneutic inquiry study seeks to explore the reasons for place of death preference among a sample of newly admitted patients of the palliative care service. Eventual place of death scenarios and carer/patient feedback about this is also tracked qualitatively via a second follow up interview. Reasons for preference change and feedback about the palliative care process as it relates to home vs hospital death is sought at this follow up point.

Preliminary results relating to thematic analysis of the first ten interview transcripts will be presented.

In the Holding Pen – Palliative Care Service Development in Western NSW

Alison Dawes, Palliative Care Clinical Nurse Consultant, Western NSW Local Health District

Historically, Palliative Care services within north western NSW commenced in 1985 with the appointment of a Palliative Care Program Manager. Like much of rural NSW this service began as a nursing led model of care. Historical documents chronicling this region’s service development provides opportunity to reflect on the evolution of the service, its past, present and future direction.

A review of the local historical service literature was conducted and was then supported by some qualitative data provided from key health care providers and community members.

This analysis of historical documentation reveals several features that demonstrate a consistency with contemporary directions of Palliative Care Service development and models of care.

This presentation will focus on three pivotal themes:

» The pioneering support of volunteers across the region

» The importance of education in strengthening the promotion of a palliative care approach

» The development and maintenance of a rural peer support network

While these documents are useful records that give us a sense of our palliative care origins and what has been accomplished, history can also provide us with confidence to adapt to the changes required to meet the needs of our changing palliative care demographic.

In conclusion, these historical documents validate the achievements and challenges in the development of a palliative care service and help us recognise how to adapt to meet the changing palliative care demographic.
Providing Quality Clinical Placements to Allied Health Students in Palliative Care

Jenny Downes, Abdul Shaik, Mark Buhagiar, Braeside Hospital, HammondCare

Education of students is a key element of clinical practice and service provision in end of life care. Students are often reluctant to undertake a palliative care placement due to factors like the high level of grief and loss encountered. Ethics approval was given to undertake a research study to investigate perceptions, attitudes and experiences of allied health students undertaking a placement in palliative care. Eleven students undertaking a palliative care placement were recruited. A mixed method approach was used to evaluate student perceptions and attitudes. Questionnaires were given to student’s pre and post placement, to identify the impact of self-efficacy and outcome expectancies on learning outcomes. Each student also took part in a semi-structured interview at the beginning and end of their placement to get qualitative input regarding their placement experience. The analysis of the results showed that participants approached their placement with varying levels of anxiety and confidence, and that their understanding of palliative care was enhanced by their placement. By reviewing these results, effective approaches and strategies were identified to maximise student’s learning experiences. Post-placement, students acknowledged their changed perception of palliative care and their wide variety of learning experiences. The research data gave useful feedback on parts of the placement which could be altered to maximise the learning experience for future students. Through the pooling of interdisciplinary resources and encouraging education and a culture of support, a placement in palliative care can be made more appealing to students.

The ACDC of Advance Care Planning” It’s a long way to the top...

Jacki Eckert, Director Primary Health Services, Hume Medicare Local, Coral Marks Area Palliative Care Program Coordinator, Murrumbidgee Local Health District

The 16 member, multiagency, cross border Hume Regional Advance Care Planning Working Group was established in February 2014. Hume Medicare Local (HML) is the lead agency by consensus and its region covers 40,000sq kms in NSW and Victoria. The purpose of the group is to develop and sustain advance care planning across HML by:

» Building the capacity of health professionals to inform and educate about advance care planning and to share resources

» Raising awareness of advance care planning within the community and promoting the use of consistent language

» Development of sustainable processes around advance care planning by empowering health care providers and the community

Differing ACP language, terminology and documentation between NSW and Victoria adds a level of complexity to the understanding and use of ACPs. To meet objectives 2 & 3, it was decided to utilise volunteers to run a community forum using the Working Group’s promotional acronym of “ACDC” as a basis – Appoint, Communicate, Document, Circulate.

Existing volunteers from Albury Mercy were carefully chosen and supported to arrange the forum. They were chosen due to their existing experience in management, coordination and support and they felt comfortable speaking with community agencies.

Future organisation of similar fora in Albury/Wodonga will be sustained by this core group of volunteers and they will assist other volunteers in different areas to implement the model.

The WG is beginning to research future possibilities re training volunteers to assist community members to undertake advance care planning.
Food and nutrition for palliative care patients – the past, the present, the future

Jodie Ellis, Dr Cynthia Hunter, Dr Pippa Craig, Calvary Health Care Sydney, University of Sydney, University of Notre Dame

Traditionally food and nutrition is often overlooked or thought to be of less importance at the end of life. However one must consider that food holds many more meaning than just the provider of nutrients and for patients and carers this is often an important concept impacting on day to day life.

This paper will report on the results of a large phenomenological study which investigated the lived experience of patients, carers, doctors, nurses and catering staff on food and nutrition at the end of life. The impact food has on relationships and the meanings of food will be discussed.

Each participant group spoke of different issues that were important to them however all groups identified that food was essential for life. The provision of food was an important way of demonstrating love for the patient and the rejection of foods provided was often seen as a rejection of love. Not eating was seen as the start of the end and for carers this was something they fought to stop.

Carers and patients demonstrated a poor understanding of the role of food and nutrition at the end of life with issues around these concepts impacting on the patient and carers personal relationships. Moving forward a proactive approach is required by health professionals to address these issues with patients and carers to assist in maintaining harmonious relationships.

Palliative Care in the Pub

Julie Flood

The baby boomers, those born 1945 – 1964, especially those retired, are talking about two things a lot, their superannuation and what they want for themselves when they die. This is happening at book clubs, at pilates, at tennis and in the pub and this is new.

When you think about it, it makes sense to share information about the questions confronting one, i.e. is there enough money to enjoy the next phase of life and what will happen to me in the end? Implied in both questions is the unique baby boomer paradigm of having control. This translates into accessing information from a wide range of sources, consideration of all options, documentation of choices and making a noise when things aren’t right.

Permission to discuss dying has been reinforced by the increasing focus in social, print and electronic media around death and the dying experience.

Some recent anecdotes which illustrate that death and dying is absolutely on the social agenda ‘in the pub’ include:

» have you done your advance care directive yet, which form did you use and what additional things did you mention?

» can my friend come back to Australia to die?

» how to get specialist palliative in residential care?

» what is a palliative care ‘team’?

These and other stories will both raise questions and provide opportunities for the palliative care world.
**ehospice – revolutionising the way we access information about palliative care**

**Claire Maskell Gibson, National Communications Manager, Palliative Care Australia**

Ehospice is an internationally run news and information resource available online, on mobile and tablet devices, committed to bringing together the expertise and experience of the global palliative care community to deliver the latest news, information, commentary and analysis about palliative care.

Aimed at anyone with a personal or professional interest in palliative care, ehospice is a collaborative venture delivered in partnership by national palliative care organisations across twelve editions and in four languages. Since its launch in October 2012, ehospice has established itself as the leading global website for palliative care, with 40,000 unique visitors per month and a repository of over 4,000 articles.

More than 20 million people require palliative care each year, yet only 10% have their basic human right to access these services met. Ehospice uses the latest technology to share knowledge, experiences, and good practice, and has the ultimate aim of improving patient care. It is creating a global community which reduces the isolation felt by those receiving or delivering care.

This presentation will showcase examples of the contributions ehospice is to palliative care in the present, and the opportunities for it to improve care into the future. It will explain how all health professionals and caregivers can benefit from utilising and provide tips on how to get involved and showcase your own work in palliative care.

---

**Title: Occupational engagement at the end-of-life: Occupational therapists’ perceptions.**

**Kathrine Hammill, Dr Rosalind Bye, Dr Catherine Cook, University of Western Sydney**

Introduction: Occupational therapists provide unique care to meet the diverse needs of people with life-limiting illnesses. However, there is limited evidence as to therapists’ current practices as to which occupations they enable clients to engage in after receiving a life-limiting diagnosis.

Aim: This study aimed to describe occupational therapists’ perceptions of what occupations their clients wished to engage in after receiving a life-limiting diagnosis.

Methods: A national survey of Australian occupational therapists working with people with a life-limiting illness was completed. Recruitment occurred over a one month period in April 2012 using a purposive, snowball sampling technique, leading to 171 survey responses. Qualitative analysis of survey responses was completed using grounded theory methods.

Results: Two inter-related categories and four sub-categories were identified during analysis. The first category, focusing on life has two sub-categories: prioritised engagement and altered engagement. Focusing on life centres on therapists’ perceptions of how clients continue to focus on living post diagnosis by remaining engaged in their chosen occupations. The second category, preparing for death has two sub-categories: practical preparation for death and “facilitating closure”. The category of preparing for death focuses on therapists’ perceptions of what clients do to practically prepare for death and how they find closure as their illness progresses.

Conclusion: Therapists perceive clients’ priorities change from focusing on life, to preparing for death, as their occupational performance level decreases over time.
Chris Lancaster and Bron Heron, Clinical Nurse Consultants Palliative Care, Anglican Retirement Villages

Anglican Retirement Villages (ARV) is a large aged care provider caring for over 2000 residents living in seventeen aged care homes across Sydney. In 2008 ARV employed a Palliative Care CNC who developed an organizational model of PEoLC, a referral and support service and comprehensive education programs engaging all levels of staff. Growing demand saw commencement of a second Palliative Care CNC in 2011.

ARV’s Palliative Care CNC’s consider that RN’s within aged care homes should have the capability to provide PEoLC, but despite a clearly articulated organizational model of care it was evident that without local nursing leadership within each care home gaps in staff’s ability to deliver consistent best practice PEoLC would persist.

In order to address this challenge an innovative solution was conceived. A Palliative Care Clinical Nurse Specialist (CNS) Pathway was developed in collaboration with The International Institute of Palliative and Supportive Studies, Flinders University. This collaborative approach included an interactive workshop aimed at improving participants’ communication skill in Advance Care planning conversations presented by lecturers from the University together with the ARV CNC’s.

In March 2014 a program of learning comprising three key elements commenced with fourteen carefully selected aged care RN’s undertaking:

- An online palliative care nursing course over a six month period accredited by Flinders University
- A PEPA placement within the participant’s Local Health District designed to ensure a robust clinically focused training experience in PEoLC.
- Under the mentorship of the ARV Palliative Care CNC’s participants are completing ten integrated workplace activities designed to further strengthen the impact of the online learning modules.

Following completion of this learning pathway a vigorous process of evaluation will commence.

ImPaCCT is a collaborative of hospital and university based researchers aimed at developing a NSW program of funded, ethical and rigorous clinical studies that complements national and other state clinical trials programs and includes collaboration with consumers and across disciplines. ImPaCCT infrastructure has been funded by the Cancer Institute NSW since 2009.

Studies underway or in development focus on:

- Improving service delivery and quality of palliative care in hospital, community and aged care settings;
- Improving communication between health professionals and patients/families;
- Improving the assessment and management of common symptoms;
- Better understanding prescribing practices in palliative care.

ImPaCCT welcomes ideas for investigator – and industry-led studies on these and other topics relevant to palliative care.

ImPaCCT will consider studies of any design that inform the development and evaluation of future interventions or will otherwise lead to improvements in palliative care.

Clinical and research staff working in palliative care are invited to:

- Submit ideas for new ImPaCCT studies; and/or
- Involve their hospital, department or service as a study site.
Palliative Care: Core Business for Residential Aged Care Providers

Jane Mahony, Nurse Consultant

As we enter the second decade of this century, an ageing population, living longer with increasing comorbidities is posing new challenges in the provision of palliative care and aged care.

As many older Australians receive end of life care and die in aged care facilities, Palliative Care IS Core business for aged care providers.

This proposes a significant challenge for those of us who work in palliative care and aged care.

The last several years has seen a rise in the number of larger aged care facilities employing palliative care clinical nurse consultants to support their staff, residents and the resident’s family. This new frontier of Palliative care is opening up an additional cohort of people with ever increasing complex needs in much the same way Palliative care, has in the recent past, incorporated non – malignant diseases in their scope of practice.

This paper will explore the challenges presented within aged care facilities and propose workable solutions that are already giving positive outcomes. These solutions build capacity and give confidence of care to residents, families, doctors and all levels of aged care staff by changing the culture of care provision in aged care facilities. In addition, it enables Specialist Palliative Care teams and aged care staff to collaborate in providing an enhanced level of best practice palliative care.

Inter-rater reliability and acceptability of the phases of palliative care

Dr Malcolm Masso, Senior Research Fellow, Centre for Health Service Development, Australian Health Services Research Institute. University of Wollongong

Other authors: Samuel Allingham, Maree Banfield, Claire Johnson, Tanya Pidgeon, Patsy Yates, Kathy Eagar

The concept of palliative care consisting of five distinct, clinically meaningful, phases of care was developed in Australia about 20 years ago and has since become widely used to facilitate clinical communication, improve quality of care and fund services. Only one previous study of the inter-rater reliability of Palliative Care Phase has been published. The definitions for each of the five phases (stable, unstable, deteriorating, terminal, bereaved) were revised in 2011, prompting the need for the current study.

The study was undertaken in 2013 to test the reliability and acceptability of the revised definitions, involving pairs of clinicians independently rating patients according to Palliative Care Phase. Each clinician was also asked to rate (on a scale of 0–4) the ease of assigning a phase and the degree of ‘fit’ between their assessment and the definition for that particular phase. Ten Australian palliative care services participated, including nine from New South Wales.

In total, 595 paired assessments were undertaken by 102 clinicians (medical and nursing). For each pair of assessments, the majority (90.7%) took place within two hours of each other. The overall level of agreement between raters was substantial (Kappa 0.67; 95% confidence interval 0.61 to 0.70), with at least a moderate level of inter-rater reliability at each site. The results indicate that Palliative Care Phase is an acceptable measure, with no significant difficulties assigning patients to a Palliative Care Phase and a good fit between assessment of phase and the definition of that phase. The most difficult phase to distinguish from other phases was the deteriorating phase.
Understanding How Advance Care Directives are used for Individuals with Dementia living in Residential Accommodation: A literature review

Vivian Masukwedza, Victoria Traynor & Elizabeth Halcomb, University of Wollongong, HammondCare

Purpose
The aim of this paper is to present a literature review of the use of Advance Care Directives (ACDs) by individuals with dementia living in residential accommodation.

Overview
There are inconsistencies in the legislation related to the use of ACDs which results in particular difficulties for individuals with dementia who at times have reduced capacity to make life and health decisions. This paper provides insight into best practice about using ACDs with individuals with dementia living in residential accommodation.

Findings
A systematic search of academic and grey literature databases was undertaken to locate international and local studies of the use of ACDs for individuals with dementia living in residential accommodation. The findings were related to the following areas: (i) inconsistencies in legislation; (ii) costs of implementing ACDs; (iii) the positive effects of ACDs on the wishes of individuals with dementia being carried out and (iv) a lack of evidence about the impact of ACDs on family members and care staff.

Conclusion
There was a scarcity of research evaluating the impact of the use of ACDs on family members and care staff and a lack of quantitative research evidence about the effects of ACDs on individuals with dementia. This lack of evidence alongside inconsistencies in legislation results in contentious decisions being made for individuals with dementia. The research team propose developing a decision aid tool to address this need in dementia care.

Hydrotherapy, Play and Music in Paediatric Palliative Care – modalities used throughout history to enhance well-being

Marianne McCormick, Senior Physiotherapist, Sydney Children’s Hospital Randwick, Kirsty Goymour, Senior Play Therapist Sydney Children’s Hospital Randwick

As part of the NSW plan to increase access to palliative care, recent allied health enhancements at Sydney Children’s Hospital and the appointment of dedicated clinicians, have enabled the provision of an additional service with the aim of addressing quality of life goals through hydrotherapy, sensory play and music to children with life limiting conditions.

It is important to understand that often a paediatric palliative care patient is not just sick or dying, they are growing and changing over time. The child needs stimulation and experiences as well as nursing care, medications and feeds. Advocating for early referral to support family’s choices for children living with complex terminal conditions, means that some families are receiving palliative care support for longer periods of time. The model of fortnightly group hydrotherapy, sensory play and music therapy as current palliative care practice sits well with the early referral process and interdisciplinary service provision.

Currently we offer hydrotherapy and play clinic fortnightly to all palliative care patients referred to the multidisciplinary team. This service aims to provide a positive therapeutic opportunity for the patient, siblings and family to experience, in the potentially anxiety provoking hospital environment. We also aim to empower families to engage in therapeutic play, music and hydrotherapy, to promote positivity and a sense of normalcy and well-being, in what is quite often a difficult and stressful daily routine.

Research questions around efficacy and objective well-being measures are required to establish sustainable and accessible services for all children living with life-limiting conditions.
Specialist Palliative Care at Calvary: An Historic Perspective

Naomi McGowan, National Project Manager, Palliative & End of Life Care Strategy, Little Company of Mary Health Care

Calvary has a strong tradition of providing specialist palliative care in NSW. Calvary Health Care Sydney (Kogarah) and Mercy Hospice (Newcastle) began as hospices for the dying. Today they are multidisciplinary specialist palliative care services that care for people approaching and reaching the end of life, and their families and carers.

Calvary Health Care Sydney (CHCS) was built on land bequeathed to Cardinal Norman Gilroy from the estate of Miss Sarah Fitzgerald. It was opened by the Sisters of the Little Company of Mary in 1966 with the specific purpose of caring for the terminally ill. In the early years, locals referred to CHCS as “the death house on the hill”, however the Calvary of today – a 100-bed subacute hospital with inpatient and community specialist palliative care and rehabilitation services – is much more focused on living than dying.

The Mater Newcastle was founded by the Sisters of Mercy in 1921. Palliative care at the Mater began with the establishment of a community outreach service in 1983, closely linked to oncology services. With assistance from a community telethon, Mercy Hospice opened in 1993, with 20 beds and approximately 100 staff, including 40 volunteers. The Day Hospice Life Enhancement Program commenced in 1995. In 2006, the hospital was entrusted to the Sisters of the Little Company of Mary and renamed Calvary Mater Newcastle. Today, Mercy Hospice has 17 inpatient beds and a community outreach service. In its 20th year of operation, more than 800 people used Mercy hospice’s services.

He Won’t Last 24 Hours at Home...

Jenny McKenzie, Nurse Practitioner, Palliative Care; Dr Helen Boland, Senior Medical Registrar, Calvary Healthcare Riverina

This case study offers an opportunity for reflection of how a small specialist palliative care community nursing team has evolved. From being a single discipline nursing focussed team to co-opting a large multidisciplinary team, to achieve a patient’s goal of dying at home.

Denis was a 67y.o gentleman. Until 2013 he experienced good health. That year he presented to a range of medical professionals with an eclectic range of symptoms. Late December he presented to hospital, hyponatremic, and experienced a respiratory arrest. As a consequence he was ventilated and had a tracheostomy formed. Post ventilation he was diagnosed with Bulbar Motor Neurone Disease.

Post diagnosis he languished in Intensive Care Unit for 3 ½ months. His primary goal was to go home.

After a number of well-intentioned false starts, Palliative Care became the lead agency and successfully facilitated his discharge.

Denis died at home 7 weeks later. He had one brief trip into the acute setting for a tracheostomy change and brief medical ‘once over’.

In keeping Denis at home a large committed team of health professionals from across sectors worked together. The team consisted of community based speech pathologist and dietician, private occupational therapist, ICU CNC, inpatient physiotherapist, MND support worker, care assistants from a NGO, private hospital senior medical registrar, physicians, General Practitioner, community palliative care nurses and the paediatric outreach team.

Roles of team members and communication between health professionals and the family will be discussed, and lessons learned from such an intense episode of care.
The NSW NSAP Results: Quality Improvement Priorities, Actions and Opportunities

Shyla Mills, National Program Manager and Mari Lo, Helen Vaz, Enyonam Glover, National Standards Assessment Program (NSAP)

Background
National Standards Assessment Program (NSAP) is a quality improvement program available for all specialist palliative care services in Australia. It is a resource that enables services to engage in continuous quality improvement through self assessment against the national palliative care standards, action plan development and implementation, as well as peer mentorship.

Method
Over 70% of NSW Specialist Palliative Care Services are participating in NSAP, the majority of them in their second NSAP cycle.

Improvement priorities and improvement actions were identified by Services through the process of self-assessment. Improvement priorities are aggregated into a state picture and improvement actions were analysed firstly through a thematic analysis of the improvement actions then into key improvement areas.

Conclusion
The NSW NSAP results up to 30 June 2014 identify opportunities for services, funding bodies, policy makers, education providers, researchers and/or national initiatives to recognise and support collaborative efforts. The improvement actions provide specific focus towards collaborative efforts, directly involving services and opportunities for sharing ideas and minimising duplication of effort.

Funding Acknowledgement:
NSAP is funded by the Department of Health

Old Bottle; New Jeanie

Bev Morris, Palliative Care CNC; Mid North Coast LHD Coffs Harbour Health Campus, Jacquie Page, Clinical Consultant Manager for regional mid North Coast, NSW, Silver Chain, Scott Handsaker, Palliative Care CNC, Mid North LHD Coffs Harbour Health Campus

It has always been the intention of community based palliative care services to provide a 24 hour service for clients and families at end of life. The Australian average death at home rate is 16%, even though 70% of patients express a preference to die at home (Agar; 2008). The NSW Ministry of Health (2012) and Agar (2008) have identified several reasons to why this may be, including, inadequate after hours support and access to medical staff, medication and equipment (especially in rural areas), inadequate symptom management, and poor communication between health professionals.

A collaborative approach and partnership between Silverchain and local health district mid North Coast, Coffs Harbour Palliative Care services has commenced to directly address the identified concerns of client and family by providing a 24 hour support framework to minimize their burden. This framework incorporates case management from Palliative Care team, evening Registered Nurse, daily personal care and respite, and overnight Registered Nurse on call via video link support. The aim is to improve access to palliative care services and the goal is to facilitate choice for the client and family facilitating preferred place of end of life care.
Ever Changing Landscapes – Joy, Grief, Death & Health Promotion in a Children’s Hospice

Ann-Marie Perry, (CNS); Sue Bartolini (CNS)

Past: Bear Cottage is one of only two Children’s Hospices in Australia. It was an initiative of The Children’s Hospital at Westmead. In the past, the first steps towards offering services to families included respite & end of life care. The initial forays into family support services saw the establishment of Camps for boys with Duchene’s Muscular Dystrophy and a yearly “Remembrance Day”.

In Paediatric Palliative Care the emphasis is very much family-centred and in order to support children with life-limiting illness, we needed to support the entire family unit. Often Mothers are particularly isolated and carry much of the burden of care for their child.

Thus, in time we added; Mum’s Camps, this was followed by Dad’s Camps & Sibling Camps.

Present: In recent times we have added a “Ski-Camp” for siblings, a Bereaved Families Camp and “Boot Camp” for Mum’s. The importance of supporting each family member is at the core of each service we offer.

This ever-changing landscape has seen our staff expand to include allied health, in the form of Social Workers, Child Life Therapists, an Art Therapist & a Music Therapist.

Future: The future holds exciting possibilities as we strive to incorporate Social Media, Tele-Health & Video-Links as a means to collaborate with other health care providers & embrace families far and wide. We also aspire to provide a service which sees nursing care extend into the home, with the goal of striving towards excellence in the emerging speciality of Paediatric Palliative Care.

Impact of Medication Safety In The Home – What Did Carers Say?

Caroline Short, Clinical Nurse Consultant, Cessnock Kurri Kurri Singleton Palliative Care

Improving Medication Safety for Clients and their Carers in the Palliative Care Home Setting commenced in 2008 in response to clinicians identifying that no formalised process existed within NSW for carer medication administration despite a widespread practice of carers administering subcutaneous medications at home, especially in the last few days of life. It was recognised that formalised protocols and standardised training for carers were required to ensure patient safety.

The need to respect patient and carer choices is emphasised throughout care while providing effective symptom control in the palliative care home setting. The project consisted of evaluating a carer’s preparedness to administer subcutaneous medications and provided education and structured support to the carer to administer medications. A culture of medication safety emerged that was welcomed and embraced by patients, carers and families, the clinicians, and endorsed by General Practitioners. A legal and ethical framework was developed on which to base these standardised practices.

The outcomes demonstrated that carers were trained to safely administer subcutaneous medication in a timely manner in response to pain and other symptoms. In an effort to ensure that these practices ‘do no harm’, and in response to some concerns raised in the literature regarding administration of the ‘the last dose’ a carer survey was conducted.

This presentation will report the outcomes of the telephone interviews conducted six months or longer after the death of the client, with palliative unpaid carers who participated in the administration of subcutaneous medications in the last few days of life.
Responding to the complexity of a nested system of new paradigms to support the emergence of a new palliative care service in New South Wales (Australia) providing last-days-of-life home support primary healthcare.

Skinner, Kath. A., Benvie, E., Silver Chain Group

In December 2013, Silver Chain Group (SCG) commenced a new palliative care service in NSW focusing entirely on the last-days-of-life aimed specifically at increasing the death at home rate for those who desire this outcome.

The service is funded by the NSW Ministry of Health and incorporates a nested system of new paradigms: a new paradigm for healthcare in NSW in that it involves contracting and sub-contracting arrangements to outsource clinical service delivery to a not-for-profit (NFP) organization; a new paradigm for eight public health care providers to embrace a shared-care service model; and a new paradigm for SCG, a NFP organization with over 120 years of experience providing healthcare and wellbeing programs primarily across Western Australia and South Australia, now heavily engaged in developing a national mindset requiring new skills to operate effectively in new geographies with new partners and in new political landscapes whilst at the same time investing heavily in technology based service delivery enablers in support of its strategic goal to extend organizational reach.

This paper shares a short video narrative documenting the establishment of the service in regional NSW, and proposes that the key to successes to date have been as a result of approaching the challenges with an increasing appreciation for working effectively in complex adaptive systems. This approach included:

» Tranched approach to start up applying reflexis and incorporating iterative learnings

» Unorthodox approach to recruitment and selection of emotionally intelligent managers and front line staff

» Facilitated ‘dialogue’ to fast track the development of a group social identity and establish an authentic and inspiring organizational sub-culture

» Novel approaches to up–skilling front line staff to manage the dissonance encountered working within the new paradigms and focused entirely on end–of–life care

» Overt attention to effective self–care enablers in order to build a responsive and resilient workforce

» Developing new corporate strengths to respond effectively to the technological and political challenges of new geographies, working with multiple partners and within complex variations of medical and funding governance structures.

A General Practice Initiated Project to Engage and Support General Practitioners in the Care of their Palliative Care Patients

Dr Alison Vickers, Dr Philip Moore, Dr Sharyn Wilkins, (GP) Dr Jan Maree Davis, Dr Suharsha Kanathigoda, Caroline Belfanti, Dr Margaret Rainbird, (Calvary) Andrew Coe, Amanda Rattray, Raelene Elliott (SE Sydney Medicare Local)

Will GPs be part of the palliative and end of life care landscape in the future?

If a general practice presence is to be maintained it is essential that GPs have a voice in outlining the barriers and resources they need to continue their involvement.

A focus group of GPs identified the important role and barriers to GP involvement in palliative care. Barriers identified were episodic nature of palliative care, difficulty of maintaining confidence, and clear pathways for working as a team with the local palliative care service – Calvary Healthcare Sydney.

Based on GP feedback and in partnership with the clinicians at Calvary and the South Eastern Sydney Medicare local, a four page, easily accessible clinical resource has been developed for GPs reflecting the practices of the Calvary clinicians and including pathways for enhanced communications through face to face meetings, fax, mobile and in future secure messaging. The project will be evaluated, reviewed and updated regularly to reflect changes to clinical practices and feedback. GPs face very real challenges and barriers to involvement in palliative care. Responding to GPs and creating resources and communication pathways to assist them will facilitate their involvement and if successful, have application in other geographic areas.
Dying in the hospital setting: A systematic review identifying the domains of end-of-life care that patients and their families rank as being most important

Claudia Virdun, University of Technology, Sydney, Tim Luckett (ImPaCCT), Jane Phillips, Professor Palliative Nursing, University of Technology, Sydney

Background
Although most people state their preferred place of death is in the community, the majority (52%) of palliative care deaths in Australia occur in hospitals. Recent evidence outlines that optimal end-of-life care within hospitals is yet to be realised. Focusing on improvements within this setting is fundamental to inform optimal palliative care.

Research question
To better understand the care elements that are important to patients with palliative care needs and their families in relation to end-of-life care in hospital.

Methods
A systematic search of health journal databases, desktop searching of the internet and hand searching was completed. Elements of care ranked as the top five most important in each included article were tabulated, analysed and grouped into domains.

Results
Data were synthesised from 3,117 families and 1,141 patients. There were four domains in common across patient and family reports: i) effective communication and shared decision making; ii) expert care; iii) respectful and compassionate care; and iv) trust and confidence in staff. Patients noted an additional two domains: i) adequate environment for care and ii) minimising burden. Families noted one additional domain: i) financial affairs.

Conclusion
The message from patients with palliative care needs and their caregivers about what domains of care are most important at the end-of-life in the hospital setting, is clear and has remained consistent for over two decades. Evidence is also available about the fact we are not currently providing this in the hospital setting. How to enact improvements to enable universal access to optimal care is an important question for ongoing focus.

Community Specialist Palliative Care Nurses Experiences and Attitudes in Caring for Patients with Life Limiting Non-Malignant Chronic Disease

Debbie White, Nurse Practitioner Palliative Care, Port Macquarie Community Health Campus

The palliative care movement arose in the 1980s in Australia, with the first federal funding for palliative care allocated in the 1988–89 federal budget. Similar to the United Kingdom model, palliative care was primarily delivered to patients with a cancer diagnosis. Over the past ten to fifteen years there has been a shift to advocate that all people who are dying should have access to quality palliative care services. As a result, patients with life-limiting non-malignant chronic disease are increasingly being referred to palliative care services.

The literature suggests that the principles of symptom management and end of life care for patients with a cancer illness trajectory are transferable to patients with life-limiting non-malignant chronic disease despite the differences in illness trajectory between the two groups. Whilst palliative care services are endeavouring to embrace this additional patient demographic, little is known about the phenomenon of caring for this patient group.

This paper will describe the early stages of a qualitative study aimed at exploring the lived experience and attitudes of community specialist palliative care nurses from the Mid North Coast of NSW in caring for patients with life-limiting non-malignant chronic disease.

This study will examine current palliative care practice and the impact of caring for patients with life-limiting non-malignant chronic disease for nurses. The outcomes of this research may impact future palliative care service provision by highlighting education needs for palliative care nurses, illuminating possible collaborative care opportunities and provide an initial foundation for further research that may inform palliative care service development.

This study is supported by the Health Education Training Institute (HETI) as part of the Rural Research Capacity Building Program.
PALLIATIVE & END OF LIFE CARE
making history

SYDNEY 2014
PALLIATIVE CARE NSW STATE CONFERENCE
22 – 24 OCTOBER 2014

Palliative Care NSW
PO Box 487 Strawberry Hills NSW 2012
Fax 02 9281 0157