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cebparac Comprehensive Evidence Based Palliative Approach in Residential Aged Care

The Comprehensive Evidence Based Palliative Approach in Residential Aged Care Project is funded by the Australian Government Department of Health and Ageing under the Encouraging Best Practice in Residential Aged Care (EBPRAC) program.

Message from Associate Professor Deborah Parker

Welcome to the December 2009 edition of the cebparac newsletter. It has been a very exciting and productive year.

The cebparac project aims to improve the palliative care provided to residents in aged care facilities. This year a major focus of the project has been in developing a facility tool kit and other resources to assist the nursing staff.

The resulting materials link together evidence-based guidelines with the practical aspects of nursing including symptom assessment and management. We have also addressed aged care funding opportunities. This all adds up to better palliative care for the residents.

I would like to take this opportunity to thank our consortium partners in Queensland, South Australia and Western Australia, namely:

- University of Queensland/ Blue Care Research & Practice Development Centre
- Brisbane South Palliative Care Collaborative
- Southern Adelaide Palliative Care Service
- Cancer and Palliative Care Network—Department of Health (Western Australia)
- Blue Care
- Queensland Health
- Padman Health Care
- Boandik Lodge
- Brightwater

We are also grateful to our facility link nurses and project liaisons for their support and enthusiasm this year. Their efforts to champion palliative care in their facilities will guarantee the success of cebparac long-term.

Best wishes for the season

-Deb



Deborah Parker

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Getting guidelines off the shelf and into practice

A key objective of cebparac is to get evidence-based practice guidelines off the shelf and into practice.

Guidelines for a Palliative Approach in Residential Aged Care (2006), developed by the Australian Palliative Residential Aged Care (APRAC) project team, aim to provide support and guidance for the delivery of a palliative approach in the 3,000 residential aged care facilities across Australia. The guidelines are the first of their kind worldwide and incorporate the best scientific evidence available regarding all facets of a palliative approach.

The guidelines are approved by the National Health and Medical Research Council and can be downloaded at the Department of Health and Ageing website: www.health.gov.au/palliative care

This project will translate these guidelines into policy and practice by developing resources that busy facility staff can more readily utilise with their residents to enhance their palliative care practices.



Helen Upton



Penny Munn



Margaret Taylor

Meet 3 of our facility champions!

Helen Upton is a Registered Nurse who has worked in aged care for the past four years and is currently the Deputy Director of Nursing at Blue Care Amaroo in Tweed Heads. Prior to this she had a break away from nursing but had spent many years as a Clinical Nurse Consultant in paediatrics specialising in diabetes.

After the death of her husband from cancer she returned to nursing and enrolled at Central Queensland University, recently graduating with a Bachelor of Health, Nursing. Helen has a strong interest in Palliative Care stimulated by her personal experience and the residential aged care environment where the need for effective Palliative Care was evident.

Since 2007 she has been a member of Blue Care's Palliative Care Advisory Body and implemented an end-of-life care pathway at Amaroo to provide better nursing care for the terminal phase of a resident's life. In 2008 she participated in a Program of Experience in Palliative Approach (PEPA) at St. Vincent's hospital, Lismore and is currently interested in post-graduate studies in Palliative Care.

Penny Munn has worked in aged care for the last 18 years. In 1992 she joined Padman Health Care and currently works in Operation Services. Penny developed a passion for Palliative Care following the passing of her mother in 1989 from cancer.

Each year she has attended workshops, lectures and information sessions externally with a variety of organisations to update her skills and knowledge in Palliative Care. In January 2008 she enrolled and completed a 6 month Certificate in Palliative Care with the Calvary North Adelaide Hospital and also participated in PEPA where great knowledge and experience was gained.

Currently she is participating in the Padman Health Care RTO for Certificate 3 in Aged Care as a trainer in Palliative Care to the new students and will also assist in further training of organisation employees in Palliative Care at a site level as the role further develops.

Margaret Taylor has worked as a Registered Nurse in Aged Care for the past 20 years in the United Kingdom; previous to this she worked on a private ward in a general hospital. Margaret moved to Australia in 2005 with her family for a new challenge in life, firstly living in Tasmania where she worked as a Registered Nurse, Clinical Nurse and Manager of care services in an Aged Care Facility. Margaret moved to Western Australia in 2008, working as a Registered Nurse at Brightwater "The Cove".

Margaret has always been very passionate regarding Palliative Care, especially the terminal care stage and supporting the family. She has been involved in the farewell process in the Aged Care facility in Tasmania, where staff and other residents farewell the deceased resident by making a guard of honour when the resident leaves the facility. She was also involved in implementing the use of a farewell quilt which is put over the resident as they leave. She is involved in implementing this process at "The Cove".

"It is very important that the care we provide to residents and their families have a lasting and positive impact. They are able to remember the good times when their resident lived in our facilities, and that at the end of life, their comfort, privacy, dignity and wishes were met and respected at all times."

Penny Munn



Looking at the evidence

Link nurses and project liaisons have invested in two days of training, to date, to review the latest evidence and recommendations in palliative care in the residential aged care setting.

We thank the nurses for their time and have valued the contribution their wealth of experience brings to the cebparac project.

Facilities also welcomed our specialist palliative nurse consultants for a number of educational seminars addressing terminal care and palliative care case conferencing. Many thanks to the facility staff for their participation.

Future educational sessions, including learning circles, are planned for the facilities in 2010. Another link nurse training day is scheduled for March 2010.

All On The Same Page: Lights, Camera, Action…

One of the goals of the cebparac project was to create a training DVD on palliative care case conferencing for residential aged care facility staff. We completed this DVD earlier this year. Its role is to highlight the importance of palliative care case conferences in facilitating advance care planning and establishing clear care plan objectives.

Sincere thanks to Padman Healthcare for allowing us to use Skyline Residential Care Facility for filming. Skyline's Penny Munn (pictured with one of the actors) and Natasha Panazollo, cebparac link nurses, agreed to star in the production and did a brilliant job. General practitioner, Dr John Sniatynskj also volunteered his services for the filming. We thank them for their enthusiasm, professionalism, and fine acting skills.

The thirteen minute production focuses on the story of Alfred and his daughter Sarah. Alfred and Sarah are invited to a palliative care case conference with the palliative care link nurse, Alfred's GP, and a care worker, when it becomes clear that Alfred health is deteriorating.

The palliative care case conference provides an opportunity for Alfred and Sarah to ask questions, express any concerns, and state their treatment preferences. Alfred's current health status is reviewed and plans are put in place and documented concerning future care.

The focus of a palliative case conference is highlighted in the DVD title: *All on the Same Page*



Advance care planning

Advances in medical technology have allowed people to survive longer despite many chronic illnesses. It is good news that many of us will live to a very old age, but people often survive with lots of problems. We now have the technology to keep people alive artificially, where in the past, they may have died naturally.

The tough question is just how much invasive medical attention is a good thing. The best answer is that it is up to everyone as an individual to decide this question.

What constitutes quality of life for you?

What types of invasive medical procedures do you consider to be undesirable?

If you had multiple physical problems, at what point, would you want the doctors to stop trying to prolong your life?

Are you a religious or spiritual person, what are your values and beliefs?

Most people never speak about these issues. When people are critically ill, they are usually unable to participate in these important decisions.

An Advanced Health Directive is a written record of your discussion about these types of issues. It can only be written when you have capacity to do so, but can be changed or updated as often as you like. You do not need to see a lawyer to write an advance care directive. However it is a good idea to show your GP your advance care directive, as your GP is the best person to help you write an advance care directive that makes sense from a medical standpoint.

(Reproduced with permission from authors Helga Merl and Dr Lyndon Bauer: www.planningwhatiwant.com.au)

Promoting advance care planning in residential aged care facilities is a key focus of cebparac.

Most states and territories provide a legal framework for these directives. Most recently Western Australia amended their Guardian and Administration Act, to include: Acts Amendment (Consent to Medical Treatment) Act 2008.

For more information on relevant legislation in your state or territory visit the CareSearch website at: www.caresearch.com.au

"When your time eventually comes, what would constitute a 'good death' for you?"



2010 timelines: 1st quarter

February

Project team management meeting

Reference group meeting

EBPRAC meeting

March

Link nurse training 3

Facility learning circles

April

Link nurse teleconference

We're on the web!

www.caresearch.com.au/caresearch/CEBPARAC.aspx

cebparac Comprehensive Evidence Based Palliative Approach in Residential Aged Care

The cebparac reference group

To further ensure we are producing best-evidence materials of the highest standard we invited a number of palliative care and aged care experts (with specialities including nursing, general practice, speech pathology, counselling, and pharmacy) to review our project materials and advise the project team throughout the duration of the project.

The cebparac project team would like to take this opportunity to thank members of our reference group for sharing their knowledge and expertise with us in 2009. Thanks to:

- Dr Scott Blackwell (Primary Care Network)
- Pam Bridges (Aged Care Qld)
- Bernadette Butler (RSL Care)
- Dr Penny Flett (Brightwater)
- Nancy Gillam (Hospital in the Nursing Home, RBH)
- Tony Hall (Griffith University)
- Kathryn Healy (Southern Adelaide Palliative Services)
- Rhylle Polke (Blue Care)
- A/Prof Chris Toye (Curtin University of Technology)

"Only 25 per cent of Australians have an understanding of palliative care"

(Palliative Care Australia, 2007)

Explaining palliative care: Not just about the last few days

In residential aged care it is important to distinguish between a palliative approach, specialised palliative care service provision and end-of-life (terminal) care.

A **palliative approach** aims to effectively manage the symptoms of a resident's illness, when a cure is no longer possible. Providing active treatment may also still be important and may be provided concurrently with a palliative approach. However, the primary goal is to improve the resident's quality of life: their level of comfort and function, and to address psychological, spiritual and social needs. This period may extend for several months before a resident dies.

Specialised palliative care involves referral to a specialised palliative team or health care practitioner. This does not replace a palliative approach but rather supports it. The goals are assessing and treating complex symptoms experienced by the resident and providing information on complex issues (e.g., ethical dilemmas) to the aged care team.

End-of-life (terminal) care is appropriate when the resident is in the final days or weeks of life and care decisions may need to be reviewed more frequently. Goals are more sharply focused on the resident's physical, emotional and spiritual comfort, and support for the family.

(Adapted from Guidelines for a Palliative Approach in Residential Aged Care)

Did you know?

CareSearch (www.caresearch.com.au) is an online Australian resource of palliative care information and evidence.

CareSearch provides specialised sections for both :

(1) patients (residents) and families, and

(2) professional groups (including nurses, GPs and other allied health).

The website explains what palliative care is and how it is organised in Australia.

There are useful links to organisations, groups and services in Australia.

Links are provided to formal education providers in palliative care; conference details; and web-based learning modules.

Support is provided in finding, appraising and using palliative care evidence and information.