

Advance Care Planning and End of Life Care Newsletter

Issue 5 – March 2017

Welcome to the quarterly Advance Care Planning and End of Life Newsletter, which is jointly published by the Agency for Clinical Innovation (ACI), Clinical Excellence Commission (CEC) and the NSW Ministry of Health. The newsletter provides updates on ACI, CEC and Ministry Advance Care Planning and End of Life projects and a guest spot for a local health district (LHD), specialty health network (SHN) or pillar to provide information on their initiatives. If you would like to showcase a local initiative in the newsletters please email acp@doh.health.nsw.gov.au.

GUEST ARTICLE: Getting the ACP word out to Aboriginal communities Illawarra Shoalhaven Local Health District

"I stuck a page on my fridge saying: *'I don't want to be resuscitated. I don't want to go to hospital. I want to stay at home til I'm dead'*. I can't make it any clearer than that!" one woman said at an Advance Care Planning Yarn-Up with the Aboriginal community in the Nowra area.

Death and dying are often regarded as taboo subjects, but not so in parts of the south coast of NSW. After a community-wide information day on Advance Care Planning, an Aboriginal Health Liaison Officer at Shoalhaven District Memorial Hospital spoke with organisers to see if the information could be provided in a culturally friendly way to the Aboriginal community.

This became the first joint project for the Palliative Care and Aboriginal Health Building Partnerships Committee. This committee has representation from Illawarra Shoalhaven Local Health District, Grand Pacific Health and numerous Aboriginal specific organisations serving women and families, aged care, Family and Community Services and the local Aboriginal Medical Service.

Stories were told by local members of the community alongside speakers talking about the how and why to have a written directive. There was so much emotion in the room that the next Yarn-Up was born: this time on the topic of Living with Grief.

Grief is a constant state for many Aboriginal people. People experience cumulative grief for the loss of many family members and friends dying through illness, accident or suicide, alongside grief for injustices past and present.

Rather than being a sad day however, the Yarn-Up focussed on the strength of the community to care for each other. It was at this event that the Partnership Committee launched its booklet entitled *'In our care, Into Your Hands – Aboriginal stories about approaching end of life'*. Six local Aboriginal people known to service providers on the Partnership Committee generously told their story about receiving palliative care or caring for someone who had died.



'In our care, Into your hands – Aboriginal stories about approaching the end of life'

Continued over:



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These stories spoke of the importance of talking with your loved ones about what they want at the end of life, and the different ways this can be honoured. They also spoke of this knowledge helping their families to grieve, knowing they had done the best for their loved one. It was a powerful and unifying project to be involved in for all members of the committee – Aboriginal and non-Aboriginal.

This booklet continues to be available at local hospitals, GP surgeries, AMS, as well as in local and State libraries, and on the ACI Innovation Exchange
<https://www.aci.health.nsw.gov.au/projects/aboriginal-stories-about-approaching-the-end-of-life>.

Members of the committee strongly recommend other local communities undertake to do something similar. The benefits go much further than spreading word about Advance Care Planning.

For further information, please contact Kay Cope, Palliative Care Manager, Illawarra Shoalhaven Local Health District on 0421 097 810 or
kay.cope@health.nsw.gov.au.

PS: Since the Yarn-Ups, the Partnership Committee has also held a very well attended joint Reconciliation Day and Palliative Care Week event at Karinya, the Palliative Care Unit at David Berry Hospital.



Pat Seymour, a local Aboriginal elder and Closing the Gap worker with Grand Pacific Health, planting a reconciliation hand at Karinya as part of the Palliative Care and Reconciliation Day event in 2016

Agency for Clinical Innovation (ACI)

The ACI and CEC in consultation with the Ministry of Health will be undertaking a series of localised planning workshops across NSW to assist LHDs to better meet the needs of people approaching and reaching the end of their lives, their families and carers.

The workshops will be co-designed with nominated LHD representatives and draw on local assets, data and planning priorities.

Strengths and opportunities for improvement will be mapped using the 10 Essential Components of Care contained in the Palliative and End of Life Care Blueprint for Improvement.

The ACI and CEC will then work with LHDs to support them in their identified improvement areas. A goal of this series is to work towards building a statewide network for improvement.

For more information contact Rob Wilkins, Manager, ACI Palliative Care Network
T: (02) 9464 4741
E: rob.wilkins@health.nsw.gov.au

Clinical Excellence Commission (CEC)

The End of Life program provides clinicians with the support and tools to ensure safe, quality end of life care for patients in NSW public health organisations.



The AMBER care bundle

The program is available to implement in NSW facilities. Work continues, in collaboration with MOH, ACI and eHealth, to include the AMBER care bundle in the eMR2 Advance Care Plan package which will be released in 2017.

It is planned to 'relaunch' the AMBER care bundle on completion of the eMR2 package.



Last Days of Life Toolkit – caring for patients in the last days of life

The Last Days of Life Toolkit has been piloted between September 2016 and December 2016.

Data analysis and report writing is in progress but initial results are positive.

It is planned to launch the Toolkit in April 2017 and take the opportunity to relaunch the AMBER care bundle at the same time, in collaboration with the MOH in their release of the state Advance Care Plan.

Death Review Program

Facilities continue to use the standardised tool and database – encouraging them to start to review and use the data for local improvement

For more information contact CEC End of Life Program
T: (02) 9269 5596
E: CEC-EOL@health.nsw.gov.au

NSW Ministry of Health

Advance Care Planning Resources

Two important ACP resources are now available in community languages from the NSW Multicultural Health Communication Service website:

- [Advance care planning for end of life for people with mental illness](#)
- [Advance Care Planning: Making your wishes known](#)

For more information contact
T: (02) 9391 9188
E: acp@doh.health.nsw.gov.au