

# NSW State-wide Approach to Excellence in End of Life Care

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Clinical Director, CEC

Cervantes Institute Forum

26<sup>th</sup> May, 2016

# Acknowledgement of Country & Elders

I would like to acknowledge the Gadigal people of the Eora Nation who are the traditional owners of the land on which we are meeting today and remind all present that we are meeting on Aboriginal land.

I also pay my respects to elders past and present.



Bienvenido a Nueva Gales del Sur!

Benvingut a Nova Galles del Sud!



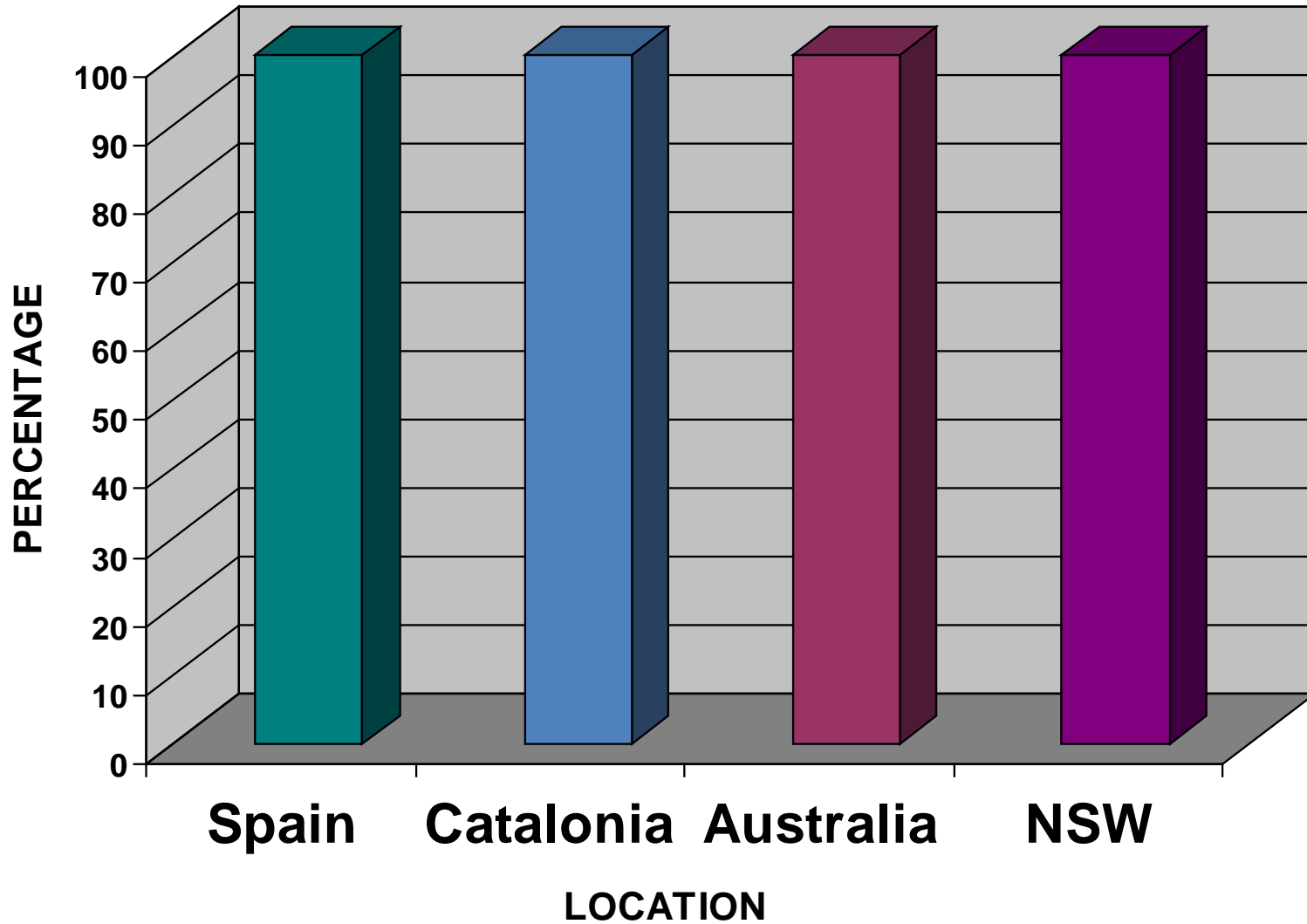
# New South Wales



- 810,000 km<sup>2</sup> vs 505,000 km<sup>2</sup>
- Population 7.5 million  
(Australia = 23 million)  
vs 48 million / 7.3 million
- 264 public hospitals (6-800 beds)
- Universal health coverage  
(+ Private options)



# MORTALITY RATES







# NSW data 2012

- In NSW ~ 50% die in Acute Care Facilities
- 24,446 patients died in NSW Acute Care Facilities
- These patients experienced on average >3 admissions of >10 days each admission in the 12 months prior to death.
- 733,380 bed days occupied by those approaching death last year
- ~ 30% of these deaths are referred to Palliative Care Services
- Of these 70-80% are cancer-related

# Further Background

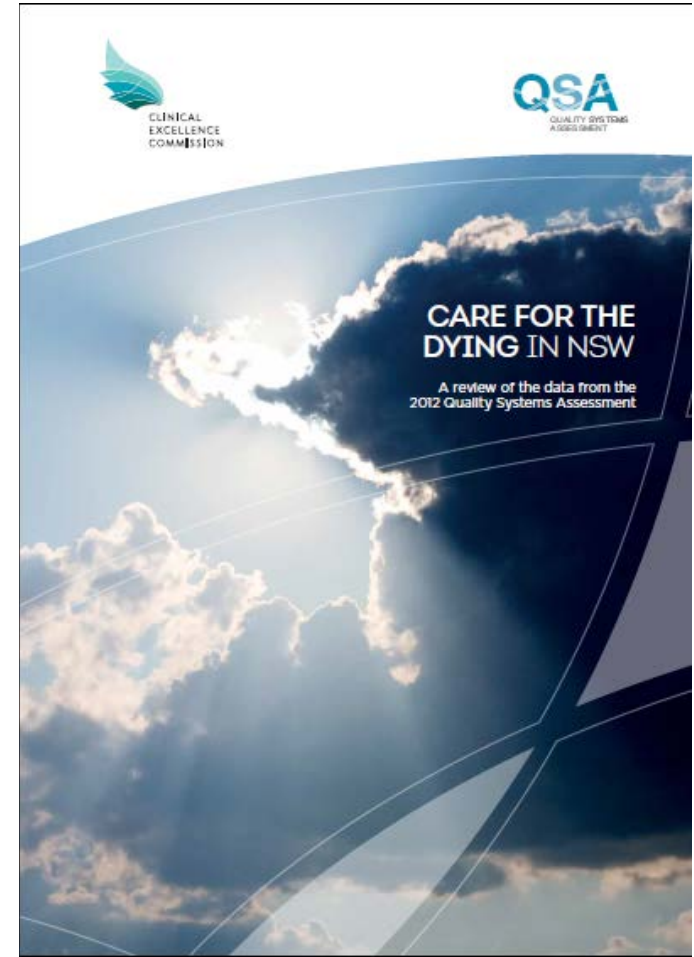
- Learnings from
    - Incident Information Management System
    - Root Cause Analyses
- identify across the board that clinicians are failing to
- recognise when patients are at risk of dying
  - developing appropriate treatment plans and
  - communicating with patients and carers.

# Further Background

- NSW data demonstrates that up to 30% of Rapid Response calls are for patients who are dying as a natural and unpreventable progression of their illness
- Documentation rarely demonstrates that patients and carers have been consulted about their preferred place of care

# Dying in NSW\*

- Greatest challenges related to
  - staff discomfort initiating conversations with patients and carers;
  - failure to recognise when patients are starting to die; and
  - poor communication between staff and patients and carers.
- Lack of a standardised approach in the last days of life

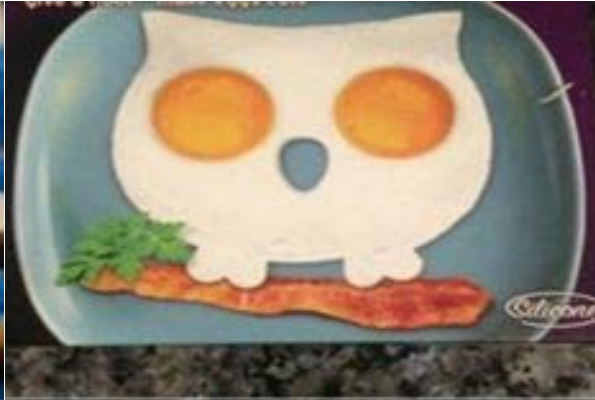


*\*results from 2012 QSA self assessment*

# Straw poll



# Nailed it ???!!



“End of Life Care isn’t a problem here!” ...

Is it safe to die in your facilities

On weekends...

Out of business hours...

When X is not rostered on...

When Y is rostered on...



# From the Rolls Royce experience



# To the burning car wreck...





Minimising Harm  
Increasing Reliability



# Some challenges





# State vs Federal divide





# Allowing for Uncertainty









# What to do?

NEW

# AB hancer

Get a 6-Pack in seconds!

- Dramatically enhances Abs.
- Adjustable straps.
- Light-weight frame.
- Fits beneath clothing.

Recommended by pseudo-athletes.

"I couldn't believe how effective the Ab-hancer was, chicks dig it." - Jeff

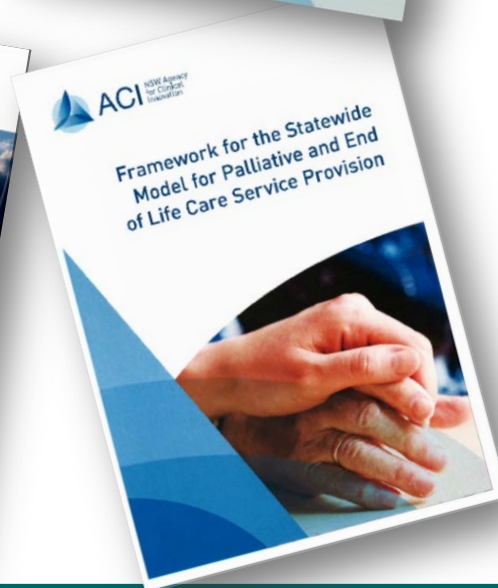
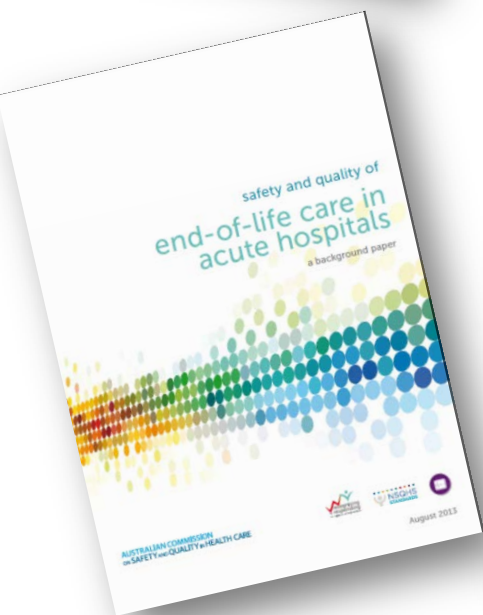














# ACI Palliative Care Network

## ACI Blueprint



## Palliative & End of Life Care

A Blueprint for Improvement



Search this website...

# Palliative Care Network

Working to ensure that all NSW residents have equitable access to quality care based on assessed need as they approach and reach the end of their life.

[Read more about the Palliative Care Network](#)

PALLIATIVE CARE NETWORK

- About
- Resources
- News
- Events
- Join the Network

CONTACT

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Join us on the Palliative and End of Life Blueprint for Improvement journey at: [www.aci.health.nsw.gov.au/palliative-care-blueprint](http://www.aci.health.nsw.gov.au/palliative-care-blueprint)

- start setting priorities for local action on the Blueprint's Essential Components of Care
- find tools and resources to work on each Blueprint Essential Component of Care
- come to the first [Statewide Forum](#) in March.



RECENTLY ADDED

## Diagnostic Report To inform the Model for Palliative and End of Life Care Service Provision

February 2014



## Framework for the Statewide Model for Palliative and End of Life Care Service Provision



## Fact of Death Analysis 2011/12 – Summary

Click on Tools, Comment and Share to access additional features: **Core**

**Fact of Death Analysis 2011/12: Use of NSW public hospital services in the last year of life.**

This 'fact of death' exploratory analysis examines healthcare utilisation patterns and trends using linked death, admitted patients and emergency department (ED) datasets for people who died in 2011/12 and were hospitalised and/or presented to ED a year prior to their death.

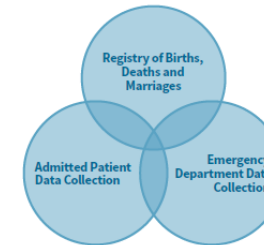
### Conclusions

- Relatively intense use of admitted hospital services in the last year of life.
- Relatively low use of admitted "coded" palliative care services.
- High proportion of emergency/unplanned hospitalisations.
- High level of multiple hospitalisations.
- High number of deaths in hospital.

### Cohort

NSW residents of all ages who died in 2011/12 (regardless of the place of their death) with information on those who presented to emergency departments (EDs) and/or were admitted to NSW public facilities in the year prior to their deaths.

### Methodology



### Key Results

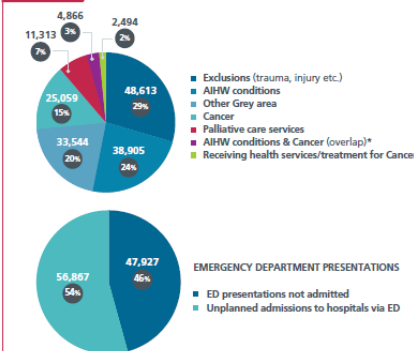
#### Hospitalisations

- 77% of all people who died in 2011/12 were hospitalised at least once in the year before.
- There were 164,794 hospitalisations using approximately 1.4 million bed-days.
- 5738 people died during the first admission.
- Of those admitted, 76% of patients had more than one admission.
- Those hospitalised in their last year of life had an average of four admissions.
- For those admitted other than day-only, the average length of stay was 13 days.
- Nearly two thirds (61%) of the cohort died in hospital.
- For those that did not die in hospital, the average survival time from last hospitalisation to death was 84 days.

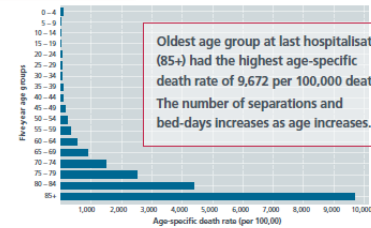
#### Presentations to emergency departments

- 76% of all people who died in 2011/12 presented to ED at least once.
- There were 104,794 presentations to ED in the year prior to the persons' death.
- Of the total presentations, more than half (54%) were admitted to hospital.
- Of the total ED presentations approximately 6% of people were dead on arrival and 5% died in ED. The median age for these people who were dead on arrival or died in ED was 65.

### Activity



### Health Outcomes



### Cost

Total Activity Based Funding	
	Costs
ED presentations (non-admitted)	\$32,505,369
Hospitalisations (admitted)#	\$977,417,084
<b>Total \$</b>	<b>\$1,009,922,453</b>



## Palliative & End of Life Care

A Blueprint for Improvement

Your Feedback

Search...



Need for Change

The Blueprint

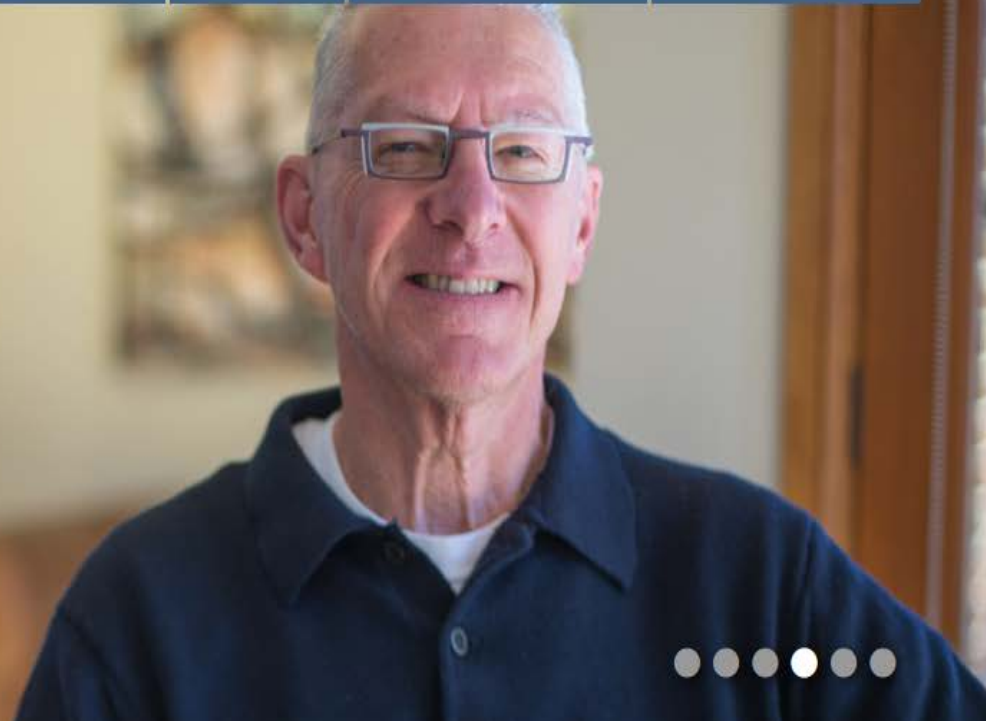
Blueprint Implementation

For Patients and Carers

# Our Vision:

To ensure that all NSW residents have equitable access to quality care based on assessed need as they approach and reach the end of life

Colin Begg – Carer – Orange, NSW





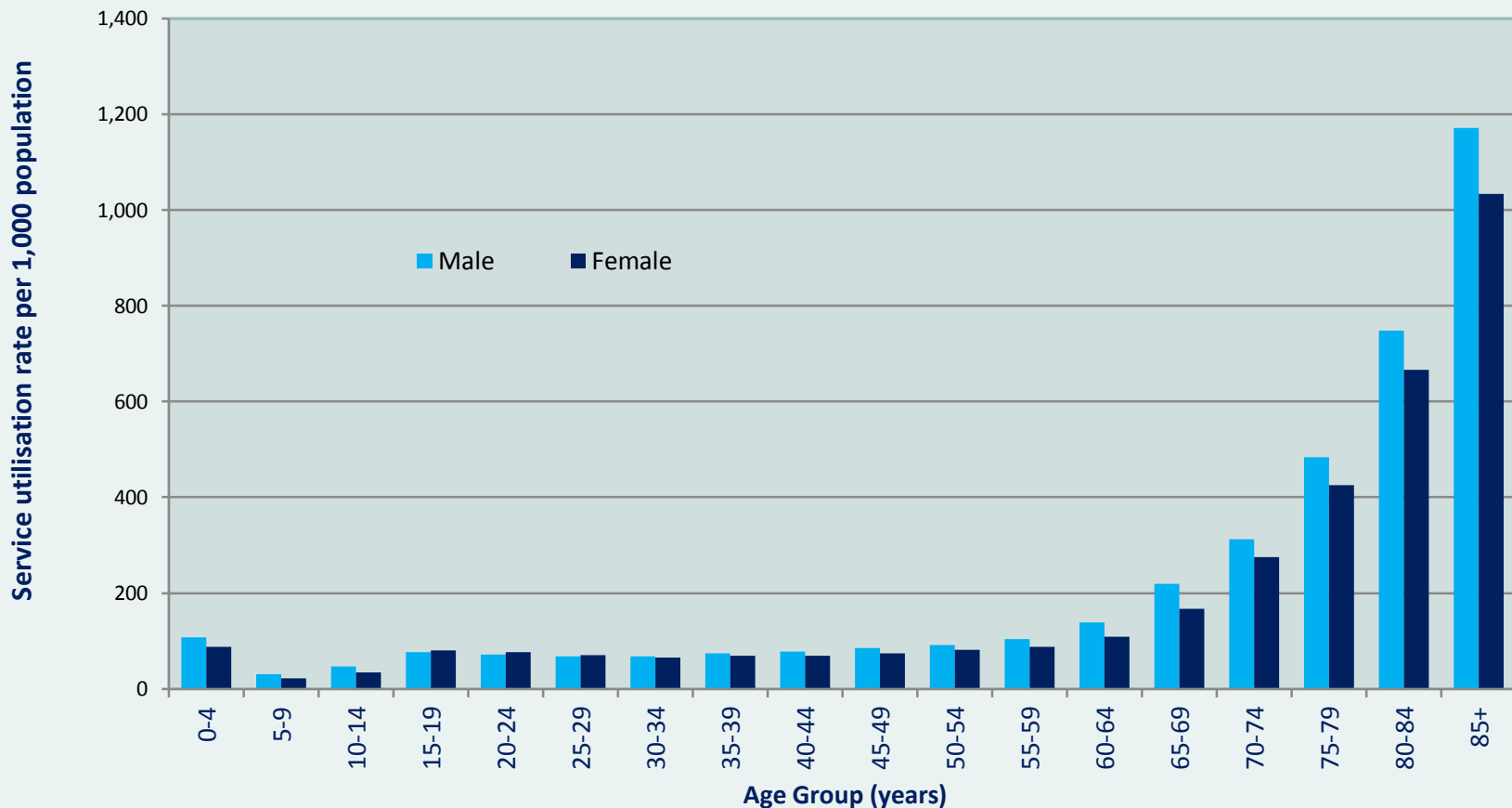
# NSW Ambulance

excellence in care





## Utilisation of NSW Ambulance services by age group



Data Source: ASNSW Patient records, 2010/11





# NSW Ambulance

excellence in care

## Changing role of paramedics

Historically callers to Triple Zero “000” had limited choices to address unplanned health care needs irrespective of severity or type of problem.



**Call Taking  
Dispatch**



**Emergency care  
& transport**



**Emergency  
Department**



This situation is certainly not ideal for the palliative patient seeking unplanned healthcare through a “Triple Zero (000) call.



# NSW Ambulance

excellence in care

## So, what are we doing in the palliative and end of life space?





## Supporting the Paramedic



- Palliative Care Physician facilitated training for Paramedic Educators
- Palliative and End of Life care is one of the scheduled training themes for the broad group of paramedics across the state
- Introduction of verification of death
- Development of resources to support paramedics when working in the environment
- Established a single point access email portal for paramedics





## Goals



The underpinning goals of the paramedic in providing care to the palliative or dying patient is to:

- Maximise comfort for the patient
- Maintain dignity
- Ensure adequate analgesia – by relieving pain and discomfort
- Controlling other symptoms such as nausea or increasing agitation with the aim to enhance the quality of life for the patient by helping to alleviate fear and anxiety for both the patient and the family that may be associated with death and dying.





## Supporting patients with palliative or life limiting illness and end of life care through Authorised Palliative Care Plans

- An Authorised Palliative Care Plan provides the option for the patient, and/or enduring guardian, family members and their clinician to discuss and document the wishes of the patient. These wishes or goals of care may be related to clinical decisions, treatment, medication options as well as location of care and post death arrangements.
- An endorsed Authorised Care Plan pre-authorises and supports the paramedic to respond to the individual patient needs beyond the NSW Ambulance protocols.

**NSW Ambulance**  
FACT SHEET  
excellence in care

### Authorised Care Plans

The purpose of NSW Ambulance Authorised Care Plans is to strengthen systems to support paramedic decision-making in meeting the needs of individual patients with specific medical conditions, as well as respecting predetermined and agreed palliative and end-of-life wishes.

Authorised care encompasses palliative care treatment and end-of-life decisions through the application of standardised Advanced or End-of-Life Care Plans. These plans authorise paramedics to provide care outside their usual scope of practice, whilst putting the patient's wishes first by providing the right care in the most appropriate setting.

Based on NSW Ambulance experience, Authorised Care Plans have been successful in meeting the goals for end-of-life wishes for patients and ensuring they receive care at the location of their choosing wherever possible, thereby reducing unnecessary and avoidable Emergency Department (ED) admissions.

In this program, NSW Ambulance issues with Local Health Districts (LHDs), Medicare Locals and the treating clinicians. The plans are registered with NSW Ambulance and uploaded into the computer aided dispatch (CAD) system, enabling a real-time automated alert to be provided to responding paramedics that an endorsed plan is in place.

The three core elements of NSW Ambulance Authorised Care Plans are:

- Authorised Paediatric Palliative Care Plan for children under the care of the Children's Hospital Network or their treating clinician. This plan gives the family and/or enduring guardian the opportunity to discuss treatment and transport options for the patient, namely to remain at home with support services in place for the length of care, or to be transported directly to a predetermined health facility.
- Authorised Adult Palliative Care Plan for adult patients under the care of their treating clinician where treatment and/or transport options have been discussed and noted in the Authorised Care Plan.
- Authorised Care Plan for patients with specific medical conditions under the care of their treating clinician. This plan enables paramedics to administer pre-authorised medications and procedures outside of NSW Ambulance's normal practice. Qualified paramedics are authorised to administer the medication, and/or procedure listed on the Palliative or Authorised Care Plan.

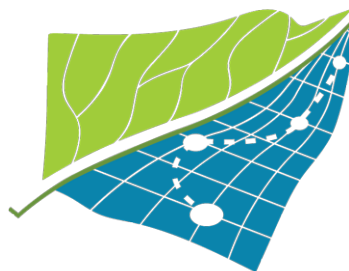
“ Supporting *paramedic* decision-making ”

“ Respecting *patient* wishes ”



## The care provided by NSW Ambulance paramedics fits well within four of the essential components of palliative care

- Access to care providers across all settings for people who are approaching the end of life – (paramedic safety net)
- Care is based on the assessed needs of the patient, carer and family
- Seamless transitions across all care settings
- Quality care during the last days of life



**Palliative &  
End of Life Care**

**A Blueprint for Improvement**



# NSW Ambulance

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## Verification of death – MOH Policy Directive PD2015\_040





# Advance Care Planning for End of Life Care

## NSW Ministry of Health



Clinical Ethics and Policy Unit  
Office of the Chief Health Officer

# Advance Planning for Quality Care at End of Life: Action Plan 2013-2018



- Normalise advance care planning to improve end of life care.
- Integrating the patient's wishes into any Advance Care Planning and End of Life decisions about them.
- Planning is the key.
- Working together is essential for successful implementation.

<http://www.health.nsw.gov.au/patients/acp/pages/default.asp>

x



[Home](#) > [Patients](#) > [Advance Care Planning](#)

## Advance Care Planning



### What is Advance Care Planning?

Advance Care Planning is important for patients, families and health professionals.

Advance Care Planning involves talking about your values and the type of health care you would want to receive if you became seriously ill or injured and were unable to say what you want.

[More Information](#)




### Patients, Families and Carers

Information, tools and resources on Advance Care Planning for patients, families and carers.

[More Information](#)



### Health Professionals

- ▶ [Advance Care Planning for End of Life for People with Mental Illness](#)
- ▶ [End of Life Decisions, the Law and Clinical Practice](#) 
- ▶ [Policy Directives and Guidelines](#)
- ▶ [ACI Palliative Care Network](#) 
- ▶ [CEC End of Life Program](#) 

[More Information](#)



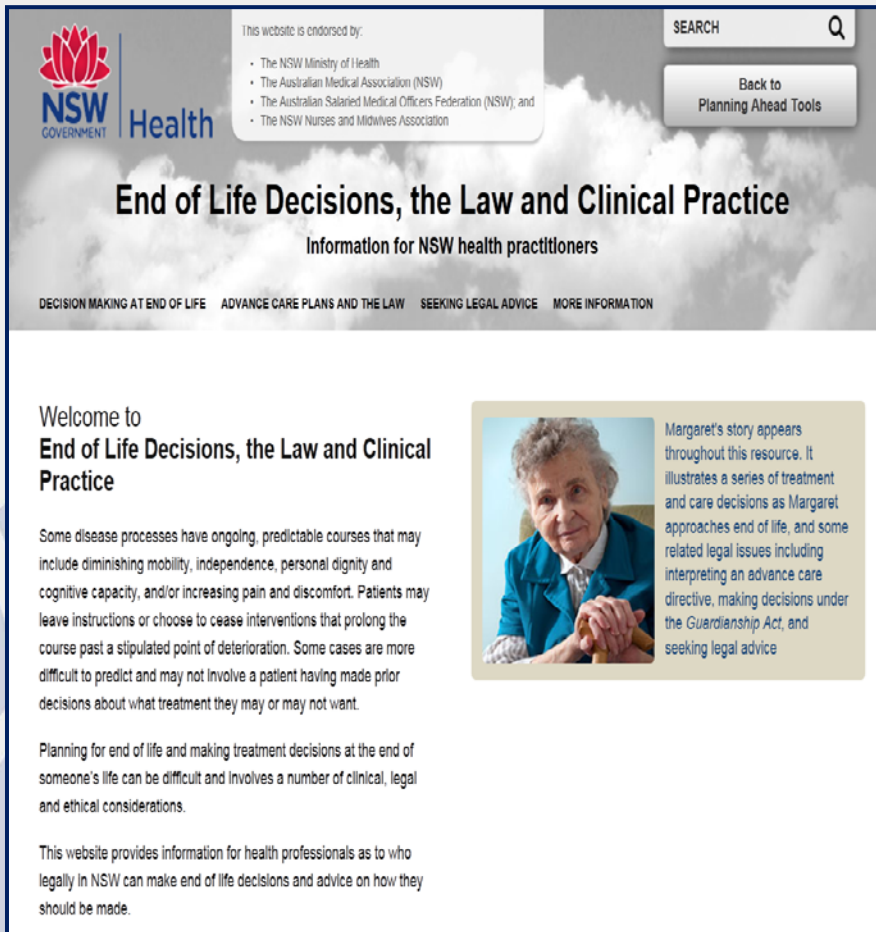
### Action Plan 2013–2018

NSW Health is committed to respecting an individual's values and wishes for clinically appropriate end of life care.

The Advance Planning for Quality Care at End of Life: Action Plan 2013–2018 provides the way forward for NSW Health implementing Advance Care Planning in the NSW public health system.

[More Information](#)

# Resources 1: End of Life Decisions, the Law and Clinical Practice



The screenshot shows the homepage of the website. At the top left is the NSW Government Health logo. To its right, a box lists endorsing organizations: The NSW Ministry of Health, The Australian Medical Association (NSW), The Australian Salaried Medical Officers Federation (NSW), and The NSW Nurses and Midwives Association. A search bar and a 'Back to Planning Ahead Tools' button are also visible. The main title is 'End of Life Decisions, the Law and Clinical Practice' with the subtitle 'Information for NSW health practitioners'. Below this is a navigation menu with links: 'DECISION MAKING AT END OF LIFE', 'ADVANCE CARE PLANS AND THE LAW', 'SEEKING LEGAL ADVICE', and 'MORE INFORMATION'. The main content area features a 'Welcome to' message, a paragraph about disease processes, a photo of an elderly woman (Margaret), and a text box describing her story. At the bottom, there is a paragraph about the difficulty of end-of-life decisions and a note that the website provides information for health professionals.

This website is endorsed by:

- The NSW Ministry of Health
- The Australian Medical Association (NSW)
- The Australian Salaried Medical Officers Federation (NSW); and
- The NSW Nurses and Midwives Association

SEARCH

Back to Planning Ahead Tools


## End of Life Decisions, the Law and Clinical Practice

Information for NSW health practitioners

DECISION MAKING AT END OF LIFE | ADVANCE CARE PLANS AND THE LAW | SEEKING LEGAL ADVICE | MORE INFORMATION

Welcome to  
**End of Life Decisions, the Law and Clinical Practice**

Some disease processes have ongoing, predictable courses that may include diminishing mobility, independence, personal dignity and cognitive capacity, and/or increasing pain and discomfort. Patients may leave instructions or choose to cease interventions that prolong the course past a stipulated point of deterioration. Some cases are more difficult to predict and may not involve a patient having made prior decisions about what treatment they may or may not want.



Margaret's story appears throughout this resource. It illustrates a series of treatment and care decisions as Margaret approaches end of life, and some related legal issues including interpreting an advance care directive, making decisions under the *Guardianship Act*, and seeking legal advice

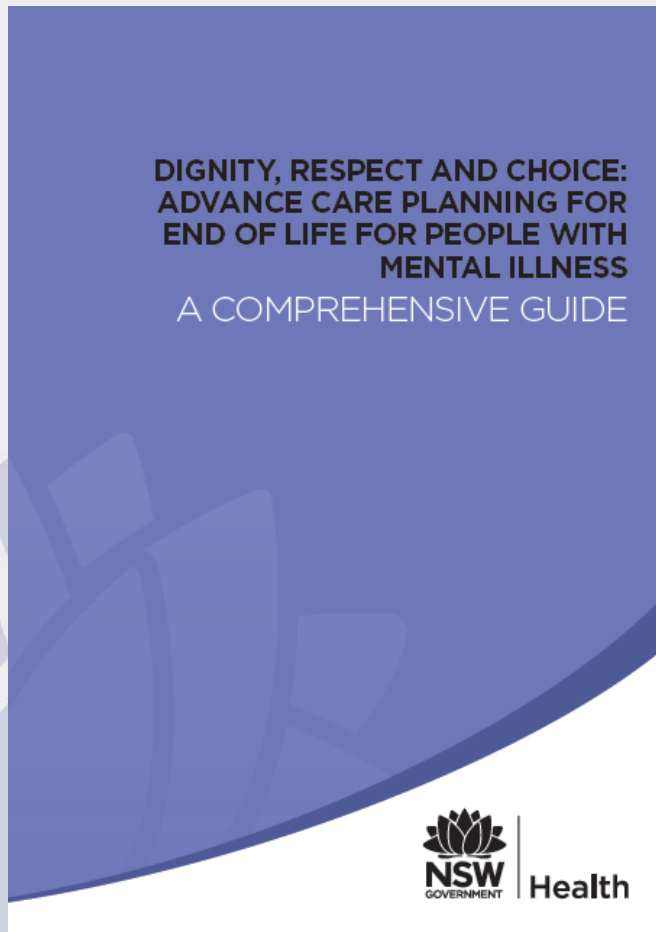
Planning for end of life and making treatment decisions at the end of someone's life can be difficult and involves a number of clinical, legal and ethical considerations.

This website provides information for health professionals as to who legally in NSW can make end of life decisions and advice on how they should be made.

- An online resource for NSW health practitioners
- Endorsed by AMA, ASMOF and NSW Nurses & Midwives Association.
- Addresses issues including substitute decision making, advance care plans and directives and refusal of life-sustaining treatment.

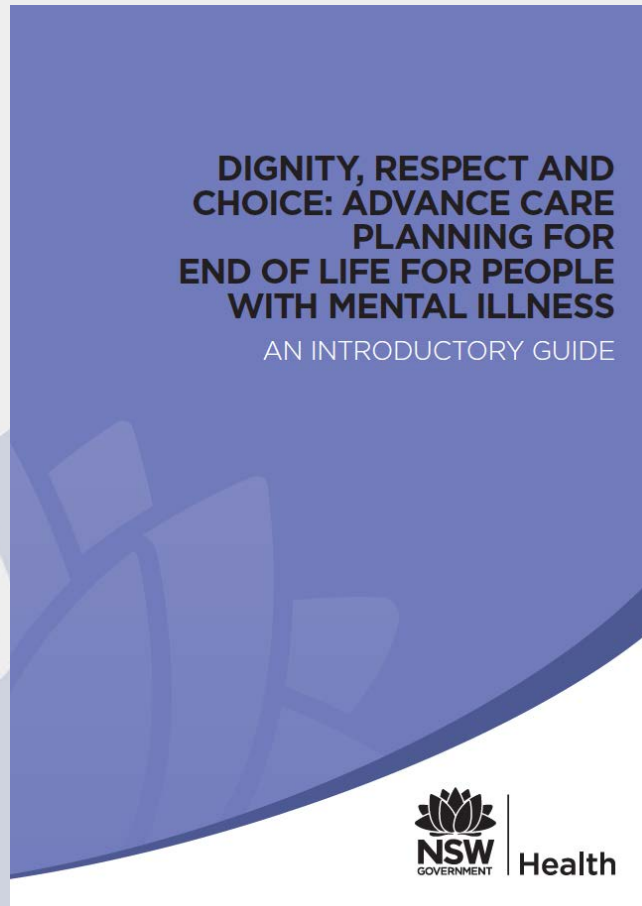
<http://healthlaw.planningaheadtools.com.au/>

# Resources 2: Dignity, Respect and Choice: Advance Care Planning for People with Mental Illness – Comprehensive Guide



- Contents:
  - Advance Care Planning
  - Capacity and Consent
  - Specific Issues
  - Case Studies
  - Resources
- For all health professionals, especially those who are not familiar with caring for people with a mental illness

# Advance Care Planning for People with Mental Illness – Introductory Guide



- The Introductory Guide will help support people with mental illness, their families and carers.
- Translations – 11 community languages:

Arabic, Cantonese, Greek, Italian, Korean, Macedonian, Mandarin, Serbian, Spanish, Turkish, Vietnamese

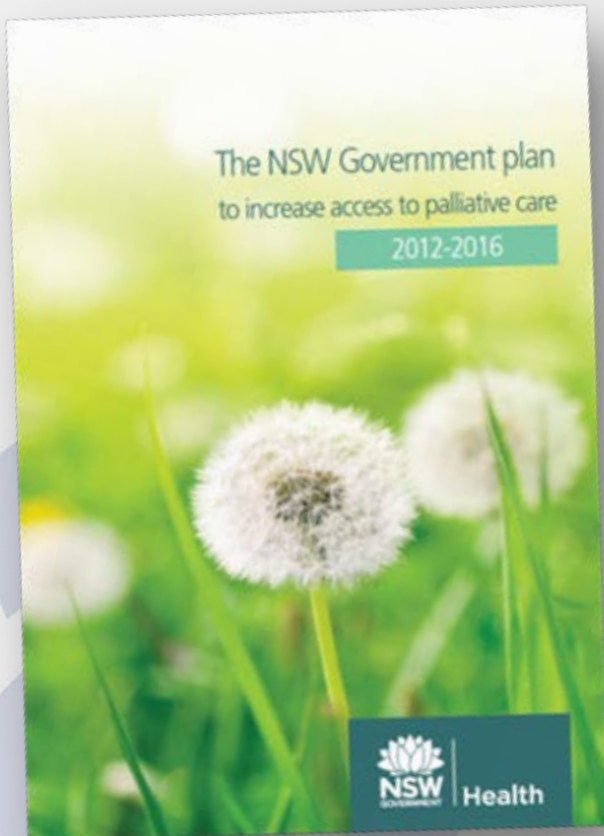
# Resources 3:

## SHAPE End of Life Conversations

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- **Supporting Health professionals in Advance Care Planning and End of life (SHAPE) Conversations.**
  - Education Framework: developed through an expert panel and broad consultation.
  - eLearning: available to NSW Health staff via HETI Online
  - Advanced Skills Workshops: designed to be run locally, for health professionals who may be required to have end of life conversations with patients and their carers and families.

# Integrated Care Branch - MoH



- Oversight of NSW Government Plan to increase access to palliative care
- Palliative Care Advisory Group
- PEACH packages
- Flexible Funding Pool to address gaps



# eHealth

## Electronic Documentation of End of Life Decisions / Medical Orders

### eMR for Palliative Care

# End of Life Program



Bernadette King,  
Program Lead

Amanda Walker,  
Clinical Director

# AMBER care bundle



- Clinical care bundle for patients whose recovery is uncertain (i.e. at risk of dying)
- Prompts multi-disciplinary decision-making and key conversations with patients and carers
- Phase 1 pilot completed
- Available for further roll out and ongoing qualitative evaluation

# Supportive and Palliative Care Indicators Tool

- Simple, one page format.
- Readily identifiable general indicators of deteriorating health commonly present in advanced conditions.
- Evidence-based clinical indicators of all the major advanced, life-limiting conditions and multimorbidity.
- Promotes early supportive and palliative care in parallel with optimal management of any underlying conditions as part of routine clinical practice.
- Contains accessible language and concepts that can be used to initiate discussions with patients and families about goals of care and improve communication between professionals/ teams.



**Supportive and Palliative Care  
Indicators Tool (SPICT™)**





# Last Days of Life

## Last Days of Life Toolkit

# Last Days of Life Toolkit

- Developed by a team of 71 specialist & generalist clinicians and consumers across NSW – one face to face meeting in June then via teleconference +/- webex – Thank you to all involved!
- The toolkit is being developed for use by clinicians working in non-palliative care inpatient settings in NSW.
- Supporting resources and education strategies will be developed alongside each of the tools.

# Last Days of Life Toolkit

- The Last Days of Life Toolkit includes:
  - Tools to prompt & support communication - (both verbal and written)
  - Comfort Observation & Symptom Assessment Chart for the dying patient (including pre & post care)
  - Guidelines for standardised medications for the individual dying patient
  - Transition to die at home

# Death Review Database



  
**Death Review**  
reporting system

Remember Me

**LOGIN**

By logging into a Clinical Excellence Commission database, you acknowledge that you will abide by the principles set out in the NSW Health Privacy Manual 2006, P12006\_393 and the Electronic Information Security Policy 2008, EIS0113\_033, or their current equivalent policy.  
© Clinical Excellence Commission 2014



- The CEC has developed a database to support the admitted patient screening tool and this is now being used in 17 LHDs
- Over 21, 000 deaths have been screened
- Shifting focus from “preventable” mortality to the experience of dying
  - Communication
  - Patient Comfort



# Opportunities

- Identifying and supporting those with chronic non-malignant conditions
- Identifying those at risk of dying
- Prevalence vs Mortality
- Earlier & “better” conversations – owning uncertainty
- Better support of those in RACF setting – accreditation & funding drivers
- Documentation & Data collection
- Outcomes assessment – “Voices”

# A very big “Thank you”!

To all who organised today

To all who attended

To Prof Gomez-Batiste & Lynn Gillam

# Contacts

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# Any questions?

