

Advance Planning for Quality Care at End of Life

Action Plan 2013–2018



Health

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FOREWORD



It is an inevitable part of the human condition that we die. Each of us will, at some stage, face death and for each of us it is and will be a unique journey.

Our experience and apprehension of death depends on many factors including our religious or spiritual beliefs, our experiences with the deaths of families, friends and others and our understanding of our own personal and medical conditions and options. The way we grew up, the culture in which we live, the things in which we believe, all influence the way we think about dying and how those we love or on whom we rely relate to us in this process.

We have very little choice over when exactly we will die but increasingly we are gaining some degree of control over how we might die.

In recent months the government has released policies on *Pain Management and Palliative Care*, both of which address aspects of the dying process. They focused on the management of pain and the dignity with which we face our final days. They were based fundamentally on the principle of attempting to give each of us maximum control and autonomy over our own lives and our own decision-making.

Advance Planning for Quality Care at End of Life is based on those same principles, and addresses another issue – how we can, as individuals, exercise the maximum realistic degree of control over the circumstances in which we die. As far as possible people should be able to make decisions about such questions as where we want to spend our final days, what sort of treatment we want, who we want to help us arrange our affairs or make decisions on our behalf and what arrangements we want to make after our passing.

Advance Care Plans will help our families and those providing us with care and treatment to act, as far as possible, in accordance with our own express and considered wishes and expectations. They will allow others to know what we want and encourage them to respect our decisions.

My own mother, who was a nurse, had made me and my siblings promise that there would be 'no heroic interventions' as she put it, as she neared the end of her long life. In effect, she was outlining for us her 'Advance Care Plan' which gave us great comfort that, in determining her last months, we were honouring her wishes.

Making an Advance Care Plan should be seen as a central part of our own health care planning, integral to how we want to live as much as how we want to die. It should be, like making a Will or deciding to become an Organ Donor, something we should talk to our families, friends, legal advisors, carers and medical practitioners about. Each of them may have some part to play – each need to know what we want so that each of them can help provide it for us.

I encourage everyone to take the opportunity to develop their own Advance Care Plan, share it with families and others who will be involved in their care, incorporate it into their individual medical records and thereby, hopefully, be able to face their inevitable passing, with a greater degree of calm confidence that they are in control and that this inevitable process has not robbed them of the freedom to make decisions about their own lives.

A handwritten signature in black ink that reads "Jillian Skinner". The signature is written in a cursive, flowing style.

Jillian Skinner MP
Minister for Health
Minister for Medical Research

Figure 1.

PLAN AT A GLANCE

Our goal

To normalise Advance Care Planning and improve end of life care by integrating patients' wishes into and throughout the management of chronic life-limiting illness

Our values

Collaboration, Openness, Respect and Empowerment (NSW Health CORE values)

What we want to achieve

1. Patients consider earlier in life and throughout the course of illness who can best make treatment and care decisions on their behalf should they lose the capacity to do so.
2. Patients' wishes are appropriately documented and understood by their treating health professionals.
3. Patients are provided with care consistent with their wishes, within therapeutic limits, always focused on quality symptom management and best practice.
4. Patients' preferences about where they want to die are respected and appropriate support and resources are available to provide this.
5. Families and carers are clear about patients' wishes in advance so that they experience reduced burden of decision-making on patients' behalf.
6. Health professionals consider Advance Care Planning for end of life as an expected part of clinical care, understand the clinical and other requirements for doing so, and are supported in providing best practice treatment and care to dying patients.

How we will achieve this

- Promote routine Advance Care Planning for residents of aged care facilities.
- Develop Advance Care Planning tools that help patients and health professionals document decisions made during Advance Care Planning conversations.
- Develop ways of caring for patients that mean Advance Care Planning conversations occur at key points in life and in managing chronic life-limiting illness and that all appropriate documentation is completed.
- Develop resources and training that support health professionals to talk to patients sensitively about Advance Care Planning and end of life.
- Monitor progress in implementing Advance Care Planning and to reflect on whether end of life care improves.
- Change routine admission, clinical review and discharge procedures so that prior Advance Care Plans are recognised, used in clinical decision making, and transferred between acute, community and aged care settings.
- Develop tools and resources to help health professionals in end of life decisions, including resolving related conflicts.
- Ensure that directions in Advance Care Plans are incorporated in all electronic health records
- Improve collaboration between NSW Health entities, general practitioners and aged care services in developing Advance Care Planning and improving end of life care.
- Develop tools to support lawyers to promote Advance Care Planning with clients as part of planning for later life, for example when making a will.

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OUR GOAL AND APPROACH TO IMPROVING PLANNING FOR END OF LIFE CARE

How people die matters. Ensuring that patients' wishes are respected and that quality, timely and appropriate care is provided to dying patients is an important health system responsibility which should form part of the quality agenda of all health organisations.

Dying in one's place of choice is one important aspect of quality end of life care. Despite strong community preferences for supported dying at home, nearly 50% of all patients die in acute care settings in NSW. Dying 'at home' includes dying in a residential aged care facility and 10% of deaths nationally occur within these facilities with most within a year of admission.

Advance Care Planning is one means of improving end of life care as it enables a person's prior wishes to be known should they lose decision-making capacity. Losing this capacity to make decisions is common as end of life approaches. However, Advance Care Planning is not only applicable to end of life decisions. It can, and should be started well before the last months or year of life. Figure 2 provides an overview of Advance Care Planning across the lifespan, and as end of life approaches.

Opportunities need to be made to promote Advance Care Planning and to encourage the individuals in the community to begin planning for later life earlier, such as deciding who they would want to make decisions on their behalf and appointing them as Enduring Guardians. Events in life such as making a will, marriage or divorce, or recording organ donation decisions should be used as prompts for this. Lawyers have an important role in this regard.

What is Advance Care Planning?

Advance Care Planning involves thinking, discussing and documenting. It generally involves ongoing conversations between patients, their families and their treating health professionals introduced gradually over a period of time. These conversations enable planning ahead for potential deterioration in future health when that person becomes unable to make decisions about their own treatment and care. It involves eliciting that person's choices, wishes and values and how these affect preferences for care and goals of treatment. As such, Advance Care Plans only become active if the patient loses decision-making capacity. Ideally, Advance Care Planning is introduced when a person is still well.

NSW Health will work with partner agencies including the Department of Attorney General and Justice and the Office of Ageing to encourage the wider community to consider planning for a time of incapacity much earlier than currently occurs, for example in healthy mid-life.

NSW Health will also work with partners in health care to ensure Advance Care Planning is addressed early in the management of chronic life-limiting illness, for all aged care facility residents and in all of the settings where people die.

This *Advance Planning for Quality Care at End of Life: Action Plan 2013-2018* (the *Plan*) recognises the importance of teamwork, partnerships and collaboration. It will inform and support Local Health Districts (LHDs), Specialty Health Networks (SHNs), the Agency for Clinical Innovation (ACI), the Clinical Excellence Commission (CEC), the Health Education and Training Institute (HETI), NSW Kids and Families, Ambulance Service of NSW and the Ministry of Health (MOH) in developing and implementing a range of tools and initiatives.

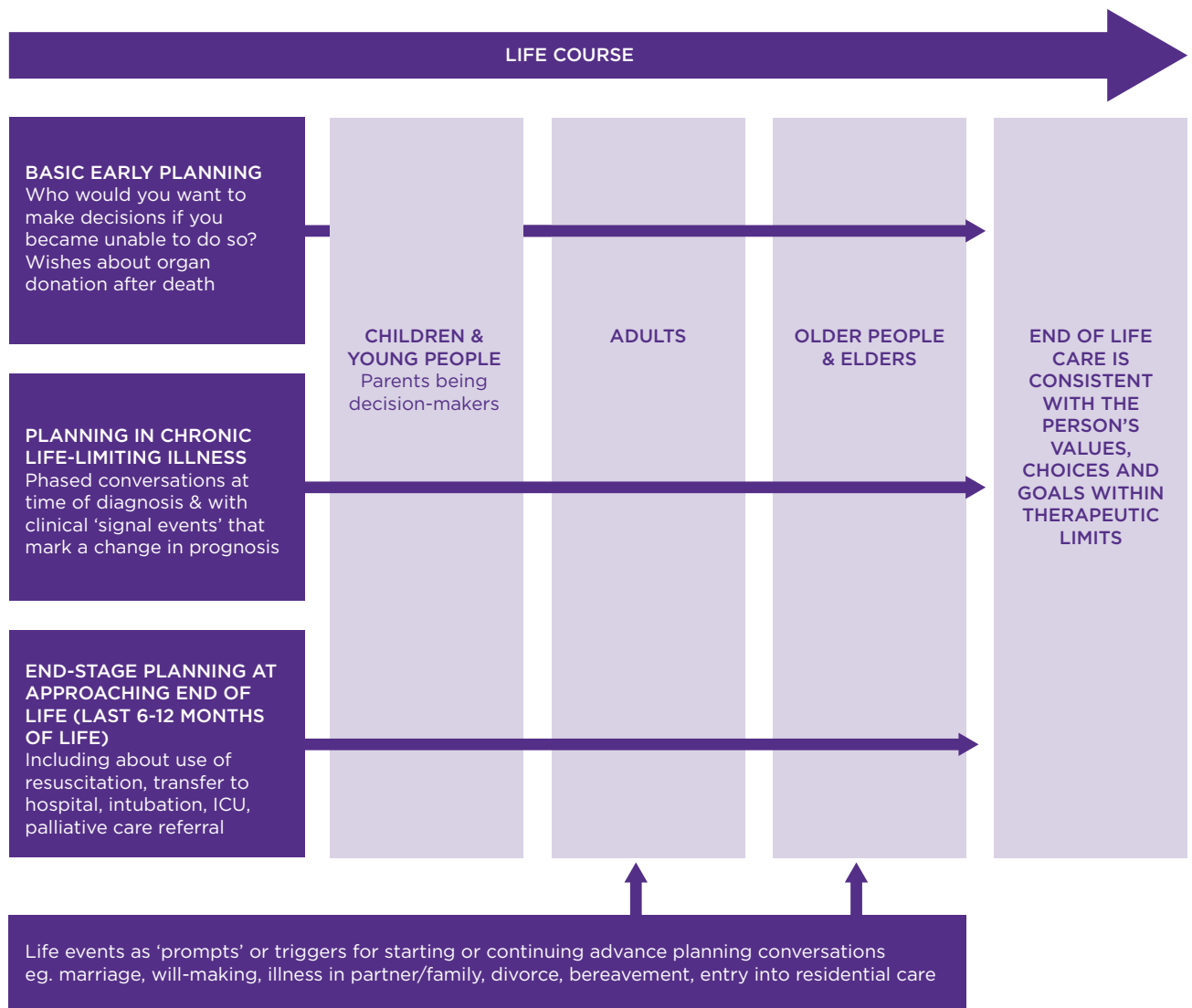
NSW Health will also work with Medicare Locals, aged care services and residential aged care facilities, government and non-government partners and carer and consumer groups to improve end of life planning. NSW Health will work with the Commonwealth, in particular in relation to key developments incorporating Advance Care Planning into the national Patient Controlled Electronic Health Record and enhancing its uptake in Residential Aged Care Facilities.

This *Plan* was informed by the *NSW Health Conflict Resolution in End of Life Settings Project 2010* and it links to other recent work undertaken by NSW Health to improve end of life care including:

- *NSW Dementia Services Framework 2010-2015*
- *The NSW Government Plan to increase access to palliative care 2012-2016*
- *Care for the Dying in NSW: A review of the data from the 2012 Quality Systems Assessment* (CEC 2013)
- *Framework for the State-wide Model for Palliative Care and End of Life Service Provision* (ACI 2013)

Areas of excellence and innovation in relation to Advance Care Planning for end of life already exist in the NSW Health system. This *Plan* builds on that work and encourages coordination of effort, cross-learning and capacity building.

Figure 2. Life transitions and Advance Care Planning (NSW Health 2013)



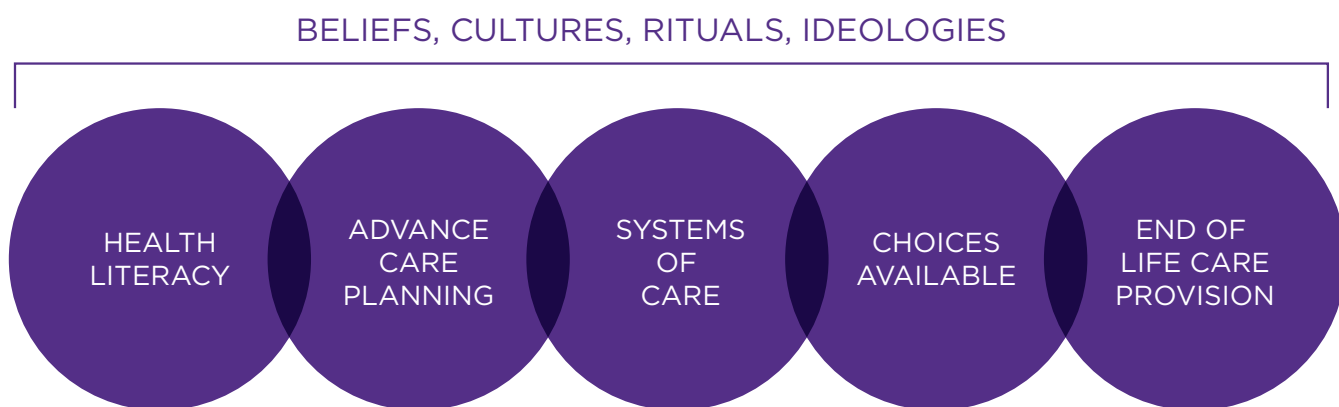


THE NEED FOR ADVANCE PLANNING FOR QUALITY END OF LIFE CARE

To achieve real improvements in end of life care there must be a significant culture change in the community and the health professions about dying as a normal part of living; understanding the limits of medicine; and the taboo in our culture around discussing dying. While quality of life is frequently discussed, quality of dying is not.

This *Plan* acknowledges that Advance Care Planning is only one aspect of improving end of life care. Others include improving patients' understanding of how to make plans and record their decisions; improving knowledge of their illness and its course; ensuring all aged care service residents have the opportunity to make Advance Care Plans; providing systems of care where there are genuine choices and palliative care is available to support dying in place of choice, for example at home; and providing expert clinical care with a planned approach or pathway, good documentation and access to specialist palliative care when needed.

Figure 3. Advance Care Planning as one 'link in the chain' for improving end of life care (NSW Health 2013)



New demographics of ageing

The large proportion of people who currently die in acute care facilities, the projected ageing population, and the rise in dementia over the next 20 years, suggest the current approach to end of life decision and care will increasingly become inadequate in meeting the community's needs over the next decades.

By 2050 there is projected to be a 400% increase in the number of people over 85 years and the proportion of the population aged over 65 years will account for one third of admissions and half the total bed days in acute care facilities.

We need to work collaboratively with aged care service providers, community organisations and consumers to plan to meet the projected demand for end of life care services. Systematic uptake of Advance Care Planning, in particular for residents of aged care facilities, is a fundamental requirement to address current expectations of patients and families and to ensure a responsive health system. Advance Care Planning resources and forms will be developed for use for people in residential aged care and community settings.

Chronic life-limiting illness and approaching end of life

Despite our knowledge about the common trajectories of some life-limiting illnesses, it is difficult to precisely predict when an individual patient will die. This uncertainty can complicate timely planning for end of life care.

Chronic life-limiting illness includes cancers, dementia and frailty, as well as chronic cardiac, respiratory, renal and other diseases that predictably lead to death. The most common trajectories of these kinds of illness over time are:

- Long term maintenance of good function despite a known life-limiting illness with a few weeks or months of rapid decline as the illness becomes overwhelming and leads to death. The major cancers are a typical cause.
- Slow decline in physical capabilities punctuated by serious exacerbations with death often coming rather suddenly. If patients survive an episode, they may well return home without much worsening of their function, but at some point resuscitation fails. Chronic heart and respiratory failure are most common.
- Long term diminishing of function needing years of care. Dying often follows a physiological challenge like pneumonia, urinary infection or a broken bone. Dementia is a typical cause.

Patterns in end of life decision-making in NSW

Currently decisions about whether it is appropriate to escalate life-sustaining measures in patients deteriorating with chronic, life-limiting illness are often postponed until there is a sudden deterioration. Decisions must then be made by clinicians in intensive care, emergency departments or palliative care with input from families that may or may not know the patient's wishes or be in a position to convey these to treating clinicians. Frequently, life-sustaining measures are considered unlikely to benefit the patient at this stage.

Acute care is, by and large, not the optimal time to have Advance Care Planning conversations. These are better conducted ahead of need outside the hospital setting. Key partners to achieve this include general practitioners, Medicare Locals and residential aged care facilities. We can build on the work which has already occurred in residential, community and primary care facilities to support Advance Care Planning.

The CEC's report *Care for the Dying in NSW: A review of the data from the 2012 Quality Systems Assessment*, based on an analysis of data provided by NSW health care facilities provides a baseline for commencing implementation of this *Plan*. Nearly 50% of deaths in NSW occur in the acute care setting, with more than 23,000 deaths occurring in 2010 in hospital facilities. These deaths were accompanied by more than 3 admissions per patient in the last year of life.

The report highlights the following issues and key findings relating to NSW health care facilities:

- There is often a delay in identifying patients whose dying could have been anticipated;
- Outside of the context of palliative care, there is minimal examination of the quality of care provided to patients dying in acute care facilities;
- 61% of clinical units reported they routinely identified patients who were likely to die in the next 6-12 months; and
- 42% of those units indicated they followed a standardised approach to treating patients in their last days of life.

Clinical units indicated the most challenging issues when managing patients at the end of life were incomplete documentation in the medical records (59%); staff members not feeling comfortable initiating the conversation with the patient, their family or carer (53%) and poor communication between staff and family or carers (31%).

Impact of delayed planning for end of life care

Delayed end of life decision-making has led to a number of adverse outcomes including:

- Continued aggressive, unwanted and/or unwarranted life-sustaining measures instigated for those approaching end of life, including even those who are imminently dying;
- Poor experiences for families where distraught family members are called on at a time of grieving to engage in end of life decisions, and who often experience distress observing life-sustaining measures in their dying loved one;
- Potentially avoidable conflicts between families and the health care team, or within the health care team, about the best course of treatment and care for the dying patient;
- Care being delivered in acute settings when better patient outcomes could be delivered in supported community or home environments; and
- Stress for health professionals balancing their obligation to act in the best interests of dying patients, sometimes differing views amongst treating clinicians and families about what that entails, and good stewardship of health resources.

LEGAL FRAMEWORK FOR ADVANCE CARE PLANNING AND END OF LIFE DECISIONS IN NSW

The existing legal framework in NSW supports end of life decisions and permits¹:

- Refusal of any and all life-sustaining treatments by a person with decision making capacity at the end of life;
- Advance refusal for a time of future incapacity; and
- Decisions made by a doctor, in consultation with and preferably with agreement of an appropriate substitute decision maker, where a person has no decision-making capacity to withhold or withdraw life-sustaining measures so as to focus primarily on palliative care.

Generally, sensitive and inclusive Advance Care Planning conversations with patients and families combined with thorough documentation reduce legal risk and potential for family complaints.

Advance Care Directives have authority under common law² (in NSW) or by legislation in other states. An Advance Care Directive can record a person's health and personal care and treatment goals (instructional Advance Care Directive); and/or formally appoint a substitute decision maker (Enduring Guardian). In NSW an Advance Care Directive must be adhered to provided that it is made voluntarily by a capable adult; was made without undue influence; and it is clear and unambiguous in applying to the circumstances at hand.

The NSW Guardianship Act provides legislative authority to substitute decision makers through the Person Responsible hierarchy and allows appointed Enduring Guardians to consent to end of life decisions³. A Person Responsible who has not been appointed as Enduring Guardian or by the Guardianship Tribunal does not have the same decision authority in end of life decisions in NSW.

Euthanasia

Euthanasia is a term about which there is considerable ambiguity and confusion. In this document, the term 'euthanasia' – now more commonly replaced with the term 'assisted dying' – means any act or omission provided at that person's request which is intended to cause death with a view to eliminating suffering. Examples of assisted dying or euthanasia include i) administering deliberate overdoses of otherwise appropriate medications and ii) unjustified withholding or withdrawal of life-sustaining measures. Advance Care Directives or Plans can only direct families and health professionals to make a preferred choice between courses of treatment that are both medically and legally defensible. Euthanasia is illegal in NSW.

There is ongoing concern in the community and among some health professionals about what is, or is not, assisted dying (or euthanasia). In NSW it is illegal to aid or abet the suicide or attempted suicide of another person. However, this does *not* include:

- Giving doses of necessary pain relief, including opioids, commensurate with a person's clinical need. Good pain management in skilled hands neither under- nor over-doses the patient;
- Complying with a competent patient's refusal of treatment; and/or
- Withholding or withdrawing life-sustaining treatments that are no longer effective or that do not benefit the patient.

1 These positions are supported in the Australian Medical Association's statement *The Role of the Medical Practitioner in End of Life Care 2007* and the Australian Medical Council's *Good Medical Practice: A Code of Conduct for Doctors in Australia 2010*. Also *E Lane v Northern NSW Local Health District [2013] NSWDC 12* (15 Feb 2013) and *Messiha v South East Health [2004] NSWSC 1061*

2 *Hunter New England Area Health Service v A [2009] NSWSC 761*

3 *FI v Public Guardian [2008] NSWADT 263*

Advance Care Directive

An Advance Care Directive is a type of advance planning tool that can *only be completed by a person with decision capacity*. These were formerly known, particularly in the US, as “living wills”.

Advance Care Plan

An Advance Care Plan is the outcome of an Advance Care Planning process. Like an Advance Care Directive, an Advance Care Plan also records preferences about health and personal care and treatment goals. However, it may be completed by discussion or in writing and it may be made by, with or for the individual. If a health professional, a family member or someone who knows the person well makes an Advance Care Plan on the person’s behalf, the known preferences of the person should be recorded.

Acute Resuscitation Plan

An Acute Resuscitation Plan is a medically authorised order to use or withhold resuscitation measures and document other time critical clinical decisions related to end of life. These were formerly called No CPR Orders. An ARP is made:

- with reference to pre-planning by patients (such as Advance Care Plans or Directives);
- in consultation with patients/families; and
- by taking account of the current clinical status, as well as the wishes and goals of the patient.

Substitute decision maker

Substitute decision maker is a collective term for those appointed or identified by law to make substitute decisions on behalf of a person whose decision-making capacity is impaired. A substitute decision maker may be appointed by the person (e.g. one or more Enduring Guardians appointed by the person under statutory provisions), appointed for (on behalf of) the person (e.g. a guardian appointed by a Guardianship Tribunal), or identified as the default decision maker by the *NSW Guardianship Act 1987* (such as a spouse or carer) as the Person Responsible.

Person Responsible

The *NSW Guardianship Act 1987* establishes who can give valid consent for medical treatment to an incompetent patient aged 16 years and over. The Act establishes a hierarchy for determination of who is the Person Responsible as follows:

- The patient’s lawfully appointed guardian (including an Enduring Guardian) but only if the order or instrument appointing the guardian extends to medical treatment.
- If there is no guardian, a spouse including a de facto spouse and same sex partner with whom the person has a close continuing relationship.
- If there is no such person, a person who has the care of the patient (otherwise than for fee and reward).
- If there is no such person, a close friend or relative.

Currently in NSW a Person Responsible who has not been appointed as Enduring Guardian or by the Tribunal does not have the same decision authority in end of life decisions⁴.

The term 'Next-of-Kin' is not an applicable term in NSW for someone who makes health care decisions on a person's behalf.

For further information, see NSW Office of the Public Guardian Fact Sheet: [http://www.lawlink.nsw.gov.au/lawlink/opg/ll_opg.nsf/vwFiles/PR.pdf/\\$file/PR.pdf](http://www.lawlink.nsw.gov.au/lawlink/opg/ll_opg.nsf/vwFiles/PR.pdf/$file/PR.pdf)

Enduring Guardian

An Enduring Guardian is someone appointed by a person to make personal (including medical) or lifestyle decisions on their behalf when they are not capable of doing so for themselves. Enduring Guardians and those appointed by the Guardianship Tribunal may make end of life decisions on the person's behalf. The appointment of an Enduring Guardian comes into effect when the appointing individual loses capacity to make personal or lifestyle decisions. People can choose which decisions (called functions) they want their Enduring Guardian to make. These functions are governed by the *NSW Guardianship Act 1987*. (http://www.austlii.edu.au/au/legis/nsw/consol_act/ga1987136/)

See also the Guardianship Tribunal's website for more information: <http://www.gt.nsw.gov.au/plan/>

Capacity

To have capacity to make a particular decision means to have the ability to:

- comprehend and retain the information provided;
- believe the information;
- weigh the information in reaching a decision; and
- communicate the decision in some way.

Decision-making capacity is assessable; it may be partial or temporary, and may fluctuate. A person's level of decision-making capacity is assessed at the time a significant decision is required to ascertain the person's level of cognitive ability to make decisions (or to make a particular decision) about personal or health-care matters. See NSW Attorney-General's *Capacity Toolkit (2008)* for more information. Also <http://www.austlii.edu.au/au/journals/SydUPLawBk/2011>

4 FI v Public Guardian [2008] NSWADT 263



“All too often in health we are engaging with patients, families and carers about end of life preferences at crisis point when the patient is unwell and families and carers are understandably distressed by the acute deterioration in health of their loved one. Advance Care Planning gives patients and families the opportunity to have open and timely discussions about end of life preferences and can allay some of the stress experienced by families and carers where they are called on to help make decisions for a loved one who has lost decision-making capacity.”

Dr Jacqueline Close
Co-Chair

Agency for Clinical Innovation Aged Health Network

POPULATIONS WITH SPECIAL ADVANCE CARE PLANNING NEEDS

Children

The death of a child is particularly difficult for families and for health professionals. Advance planning with parents and guardians whose child is approaching end of life requires sensitivity and specific skills on the part of the health professional. Health professionals need to balance providing recommendations on management to parents and sometimes the child, and developing and discussing the plan with them towards a shared goal of care that is in that child's best interests. Related issues are explored in more detail in the *NSW Health Conflict Resolution in End of Life Settings* Project Report.

The *Paediatric Palliative Care Planning Framework 2011-2014* guides the delivery of service to children. Sydney Children's Hospital Network has developed local policies and procedures tailored to its population that have good uptake. These include an *Allow Natural Death* policy and form (2010) and an *End of Life Care Plan* and related guideline (2012). These documents can be found at:

<http://www.archi.net.au/documents/resources/hsd/paediatrics/and/and-form.pdf>

http://www0.health.nsw.gov.au/policies/gl/2011/GL2011_014.html

People with mental illness

Advance planning for end of life for those with mental health problems is often complicated by, among other things, episodic loss in decision-making capacity. However, the presence of a mental illness is only relevant to the capacity of the patient to make decisions for each specific situation. For most people with a mental health illness, the same approach to Advance Care Planning should be taken as is outlined in this *Plan*.

However, there is a sub-population of patients for whom specific concerns arise when planning for end of life, such as those receiving treatment under involuntary care provisions of the *NSW Mental Health Act*, those in forensic facilities and patients who are in long-term residential psychiatric facilities. Patients who are institutionalised in longer stay units and who are dying are considered to be dying 'at home'. As in other settings, early planning, full consultation, well documented decisions and proper review promote good end of life care.

Depression is under-diagnosed in all patient populations approaching end of life, and warrants close attention in Advance Care Planning to ensure that the patient has the capacity to make advance decisions, as well as in order to decide when to activate their Advance Care Plan.

The *NSW Mental Health Act* and the *NSW Guardianship Act* differ in how the substitute decision maker is called upon and the extent of powers under each Act to make end of life decisions on a person's behalf. The difference needs to be considered in Advance Care Planning.

Information resources on Advance Care Planning for end of life will be developed for mental health professionals in consultation with the mental health sector and the Coroner during the implementation of this *Plan*.

People with disability

People with significant disability for whom advance planning for end of life may be appropriate include those with physical, psychological or sensorial disabilities, acquired brain injury and age-related cognitive impairments, such as dementia.

People with disabilities live in many various types of accommodation and their interaction with the NSW health system will differ accordingly. Depending on the nature and degree of their disability, people may, or may not have the capacity to make their own decisions about treatment and care as death approaches.

Health professionals need to investigate the support networks of people with a disability when planning for end of life care, engage in proper discussions with parents and carers and maximise the disabled individual's involvement in the process to the optimal degree.

The NSW *Guardianship Act* provides for decision making for people with disability when their own decision-making capacity is insufficient and a range of policies exist to help guide this process. These include the NSW Department of Family and Community Services *Palliative Care Policy and Procedures (2012)* and the NSW Council for Intellectual Disabilities *End of Life Care* fact sheet (2011). These can be found at:

http://www.adhc.nsw.gov.au/___data/assets/file/0003/228126/Palliative_Care_Policy_April_2012.pdf

<http://www.nswcid.org.au/health/se-health-pages/end-of-life-care.html>

People in custody

Prisoners should be supported in making goals of care decisions in Advance Care Planning as end of life approaches. There are some complexities related to decisions for people who will receive end of life care in prison, similar to forensic mental health patients.

Management of prisoners with chronic life-limiting conditions may be fragmented when they are transferred between custodial and community-care settings. Clear processes for talking to prisoners about Advance Care Planning are needed.

For a range of reasons, family members may not be willing, or suitable, to act as substitute decision makers in health-care decisions for long-term prisoners with compromised decision-making capacity.

Specific issues identified by NSW Health professionals in this setting which will be addressed as part of implementation of this *Plan* include:

- improving health professionals' understanding of the Guardianship Tribunal's role and the application of the *Guardianship Act* in custodial settings;
- helping health professionals to understand a prisoner's capacity for decision making; and
- clarifying the roles of the various participants in end of life decisions for prisoners in custody, including the prisoner-patient, family, Tribunal, Coroner and Commissioner.

People from Culturally and Linguistically Diverse (CALD) communities

Almost one in three NSW residents were born overseas and around one in five speaks a language other than English at home. This means that flexibility and openness to differing attitudes and cultural practices is needed from health professionals in regards to end of life decisions and care.

Death and dying and associated rituals and meanings vary considerably across and within different cultural communities. Some cultural groups also have differing preferences about who should make end of life decisions on behalf of a dying family member, for example elder children, members of extended family, or collective agreement with religious leaders. This may not always accord with the Person Responsible hierarchy. Careful exploration is needed with individuals and families about how these decisions should be approached. Related issues are explored in more detail in the *NSW Health Conflict Resolution in End of Life Settings* Project report.

Health and other institutions that help people to make end of life decisions should form partnerships with CALD services and communities to receive cultural information, and establish protocols and procedures to contact and use Health Care Interpreter Services and the Telephone Interpreter Service when an interpreter is not available.

Aboriginal and Torres Strait Islander peoples

Advance planning for end of life care poses particular challenges for Aboriginal people, given the cultural, spiritual and community needs and sensitivities about dying. Place of dying is important and end of life planning may need to support people who choose to go back to country to die.

In particular, culturally sensitive approaches to decision making, breaking bad news and gathering information are needed when planning for end of life. The variation in beliefs about death and dying between Aboriginal peoples must be recognised.

These and other issues relevant to end of life care planning and care are addressed in *Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander people: National resource kit* (2004) and *Building Partnerships: a workbook for implementing best practice palliative care for Aboriginal and Torres Strait Islander people in NSW* (2005). See:

<http://www.healthinfonet.ecu.edu.au/key-resources/programs-projects?pid=455>

http://www.caresearch.com.au/Caresearch/Portals/0/Documents/WhatisCaresearch/NationalPCProgram/NSW_content_workbook_Building_Partnerships.pdf



“People with disability have the right to the range of medical services and treatments available to the rest of the community: this includes the right to good quality care at the end of life.

Planning ahead creates time for discussion and a space for wishes to be heard. People can make decisions about their health options and choices before they lose the ability to communicate their wishes. With advance planning, substitute decision makers can have greater certainty about the kinds of decisions the person would have made for themselves, and avoid unnecessary and burdensome treatment.”

Mr Graeme Smith
NSW Public Guardian
Department of Attorney General and Justice

CONSULTATION WITH THE COMMUNITY AND HEALTH PROFESSIONALS

Extensive consultation was undertaken to inform development of this *Plan*. Four consultation rounds involved LHDs, SHNs, pillar agencies, non government organisations, health profession organisations, universities, ACI Clinical Network Reference Groups, the NSW GP Council, the NSW Health Clinical Ethics Advisory Panel and the community. One hundred and fifteen formal submissions were received. There was also a dedicated ACI Consumers' Network forum. This level of consultation has ensured that the spectrum of sensitive issues were properly considered and that the recommendations and outcomes within this *Plan* have taken account of the research and scientific literature, feedback from a diverse range of stakeholders, consumer preferences and expert advice.



THE WAY FORWARD

OUTCOME 1

Patients consider earlier in life and throughout the course of illness who can best make treatment and care decisions on their behalf should they lose the capacity to do so

There was strong support for normalising Advance Care Planning and promoting it earlier in life. People should be encouraged to start planning for later life and for unexpected situations where they cannot make medical decisions for themselves. Planning might begin at the time of making a will, marriage, divorce or other significant life events. People should be encouraged to consider choosing a willing, competent person to act as their substitute decision maker or 'Person Responsible'; and consider what kind of unexpected and seriously impairing condition involving loss of the ability to make decisions would lead to the goals of care shifting to comfort measures, for example in serious permanent brain injury.

Advance Care Planning should also include consideration and discussion of organ donation decisions, as recommended in *Increasing Organ Donation in NSW Government Plan 2012*.

http://www0.health.nsw.gov.au/pubs/2012/organ_donation.html

Community and professional groups agreed that asking people to identify their preferred substitute decision maker is the least confronting way to begin Advance Care Planning conversations.

Completing an instructional Advance Care Directive or appointing an Enduring Guardian will be of particular relevance for a proportion of the younger healthy population. An example may be where religious beliefs or cultural values affect choices about treatment and care, such as refusal of blood transfusion by Jehovah's Witnesses.

There was a clear consensus that Advance Care Planning and end of life concerns must be addressed explicitly and comprehensively early and throughout the management of chronic life-

limiting illness. Health professionals agreed that repeat conversations over time from when a diagnosis of chronic life-limiting illness is made through to end-stage illness are crucial. Also that known key cross-roads in illness signifying a change in prognosis (called 'clinical triggers') should be used to prompt the next stage of conversation.

Patients expect their health professionals to raise Advance Care Planning with them. Starting conversations before the need for crisis care arises was recognised as necessary and helpful for families. General practitioners are important in Advance Care Planning because of their role in providing primary care services.

Patients and families identified that having effective conversations requires: privacy; health professionals who are good listeners and willing to be honest and empathetic; and, importantly, have enough time. A common theme in community feedback was how rushed clinical encounters are common but not conducive to the conversations required in these situations.

It was recognised that personal stories must be made more accessible to patients and the wider public if cultural change around the taboo on talking about death is to change. Stories need to be included in educational materials about planning ahead, how Advance Care Planning can help prepare and deal with illness and decline and quality care while dying.

Advance Care Planning is more likely to be effective, and there is less likelihood of later disagreements between family members and treating doctors, when the family and substitute decision-maker have been engaged, with patients' permission, in ongoing Advance Care Planning conversations. This also applies to organ donation, where it is well known that the family is more likely to support the deceased person's wishes when they have prior knowledge of them.

There will be a proportion of individuals who do not wish to plan ahead for a time of incapacity and prefer to leave these decisions to family and treating doctors to make at that time. This should be respected.

What we will do

Action	Lead/Partners
1.1 Promote Advance Care Planning earlier in life by supporting lawyers to prompt clients to consider appointing an Enduring Guardian.	MOH/Dept of Attorney General and Justice
1.2 Incorporate Advance Care Planning into models of care for chronic disease self-management and decision-making from diagnosis through to end stage clinical management.	ACI/LHDs/SHNs
1.3 Promote use of specialty-agreed clinical triggers for Advance Care Planning.	ACI/LHDs/SHNs
1.4 Identify appropriate subgroups of patients with chronic life-limiting illness for introducing or strengthening Advance Care Planning.	LHDs/SHNs
1.5 Ensure the Person Responsible is documented for patients who enrol in the <i>Chronic Disease Management Program</i> .	ACI/LHDs/SHNs
1.6 Support development of Advance Care Plans for all residents in aged-care facilities and advocate with the Commonwealth for integration of Advance Care Planning into Residential Aged Care standards and policy.	ACI/MOH/NSW Office of Ageing/Commonwealth Health and Ageing
1.7 Promote family discussion about, and documentation of organ and tissue donation decisions in Advance Care Plans (see also 5.3).	MOH/LHDs/SHNs
1.8 Promote compatible, consistent approaches for Advance Care Planning across acute, community and primary care sectors.	MOH/LHDs/SHNs/ACI

OUTCOME 2

Patients' wishes are appropriately documented and understood by their treating health professionals

The plethora of Advance Care Planning documents within NSW Health, primary, community and residential care sectors makes it difficult for health professionals to confidently act on them when patients are transferred between care settings. This uncertainty can mean that the content of prior Advance Planning documents is not adequately considered in clinical decision making.

A suite of standardised Advance Care Planning tools and forms is required, acknowledging that a single Advance Care Directive may not meet the needs of all patients. However, development of a Resuscitation Plan for use by doctors to authorise or withhold resuscitation in dying patients across acute, primary and community settings would be ideal. Documents developed for use in community settings and aged care facilities should also include advance decisions about the use of artificial hydration and nutrition and the appropriateness of transfer to an acute hospital for escalation of treatment and life-sustaining measures.

Advance Care Planning documents, especially Advance Care Directives, must be read in the context of a patient's deteriorating clinical condition by treating clinicians and converted into an appropriate clinical care plan. The way in which attending health professionals interpret these directives will determine how they respond to the patient's changing clinical condition. Decisions about how health professionals should respond to sudden clinical deterioration need to be made quickly. For example, agreement in advance and documentation using an Acute Resuscitation Plan is an important aspect of good end of life care. It is not widely understood that less than 10% of patients who receive cardiopulmonary resuscitation survive to leave hospital and for those with advanced disease and frailty the number is lower.

Use of positive language is critical for encouraging people to plan for end of life. This includes in Advance Care Planning documents and conversations will help people to recognise that Advance Care Planning is an expected part of living with chronic life-limiting illness and its management.

What we will do

Action	Lead/Partners
2.1 Develop a suite of standard Advance Care Planning tools and forms for NSW Health and related resources and liaise with primary, aged and community care regarding uptake across care settings.	MOH/LHDs/SHNs/ACI
2.2 Develop new adult and paediatric Acute Resuscitation Plan forms and implementation policy.	MOH/LHDs/SHNs/ACI
2.3 Develop resources to support health professionals interpret and translate Advance Care Directives and Advance Care Plans into clinical care plans in emergency departments and acute care settings.	MOH/LHDs/SHNs/ACI
2.4 Revise NSW Health Guideline 2005_056 <i>Using Advance Care Directives</i> .	MOH
2.5 Revise NSW Health Guideline 2005_057 <i>Guidelines for end of life care and decision-making</i> .	MOH

Geriatric Rapid Acute Care Evaluation (GRACE) Service

The GRACE Service at Hornsby Ku-ring-gai Health Service provides support to over 33 Residential Aged Care Facilities (RACF) in the Hornsby LGA. The GRACE Clinical Nurse Consultant (CNC) works very closely with staff, residents and their families to assist them in their end of life care management.

Residents and their families are encouraged to review their end of life or Advance Care Planning documents and ask nursing or medical staff if they are unsure on how to answer certain questions. Families are given a couple of weeks to consider and complete the documents. During this time the GRACE CNC can meet with the family and assist by providing education sessions and family conferences. 90% of families complete the Advance Care Plan during their meeting with the CNC.

The Advance Care Plan clearly identifies the individual care needs of the resident and assists the families to make decisions for future emergency care situations such as cardiac,

respiratory and neurological events. The *Plan* also clarifies the need for artificial hydration, intravenous antibiotics and comfort measures for palliation.

A recent survey of staff in the Emergency Department (ED) at Hornsby Ku-ring-gai Health Service has shown that:

- 70% of medical and nursing staff are very satisfied with the provision of Advance Care Plans for those patients presenting to the Emergency Department.
- 90% of residents expressed a preference to be cared for in their RACF rather than presenting to the hospital.
- GRACE data indicates a reduction in the number of hospital presentations by 70% for those residents with a current ACD.

Feedback from families has indicated their satisfaction with use of the Advance Care Plan and how it has helped them to make decisions prior to hospital presentation of their loved one.

OUTCOME 3

Patients are provided with care, within therapeutic limits, that is consistent with their wishes, always focused on quality symptom management and best practice

Initiating Advance Care Planning becomes more important around the time of diagnosis of a chronic life-limiting illness. Patients and their families have many goals, such as relief from symptoms; good quality of life; an ongoing sense of being in control; and maintaining dignity. As illness progresses, these goals can coexist with those of preventing further illness and prolonging life, even when pursuing such goals requires aggressive or invasive treatments.

The ability to recognise approaching end of life and dying can be difficult, especially in chronic diseases that exacerbate and remit. Improving these clinical skills is essential to support end stage care planning. Since the goals of care will change at this time, interventions should be modified accordingly and palliative care services should be engaged.

Advance Care Planning must be integrated with timely palliative care in the patient's end of life management. The critical role of palliative care services is recognised as both providing direct care for patients with the most complex situations, as well as a resource for other generalist providers for patients in less complex circumstances. This is essential to support dying at home.

As patients with life-limiting illness approach end of life and dying, the appropriateness of specific medical treatments must be considered in consultation with them. A simple reflective question, called the 'surprise' question (Would I be surprised if this patient was to die in the next six-twelve months?), uses intuition, largely based on clinical experience, as a useful trigger for initiating or re-opening conversations with patients and families. The 'surprise' question should be a component of Advance Care Planning models of care as a screening tool to identify people who will benefit from the kind of services which address quality of life and care while dying. These services include Advance Care Planning, comfort care, psychological and spiritual support.

End of life conflict

End of life conflict is defined as disagreement which occurs about the goals of care or treatment decisions at the end of life and where such conflict is not resolved by the usual recourse to time and further discussion between the patient, the family and the treating clinicians, as appropriate (NSW Health 2010, *Conflict resolution in end of life settings project report*).

Life-sustaining treatment

Life-sustaining treatment is any medical intervention, technology, procedure or medication that is administered to forestall the moment of death, whether or not the treatment is intended to affect life-threatening diseases or biological processes. These treatments may include, but are not limited to, mechanical ventilation, artificial hydration and nutrition, cardiopulmonary resuscitation or certain medications (including antibiotics).

When this point in the course of the disease is reached, there is a group of decisions that should be considered and discussed with patients, families and carers in advance of need, including whether to:

- Attempt cardiopulmonary resuscitation;
- Hospitalise the patient for acute care when clinical deterioration occurs;
- Admit the patient to the intensive care unit;
- Intubate in the event of respiratory failure; and/or
- Consult with, or refer to palliative care services.

It is important that the Advance Care Plan is reviewed on a regular basis as the underlying disease may change quickly in this phase and the patient's views about benefits of treatment may change accordingly.

End of life data currently available in NSW should be improved so that it is easier to measure quality improvement of end of life care and to evaluate the implementation of this *Plan*. The data should include qualitative and quantitative information about dying for use at both local and state-wide levels. It should also include information about the structure, process and outcomes of care (see also Enabler 2).

AMBER Care Bundles

The AMBER[®] (Assessment Management Best practice Engagement Recovery uncertain) Care Bundle developed in the UK provides a systematic approach to manage the care of hospital patients who are facing an uncertain recovery and who are at risk of dying in the next one or two months. It is a simple tool which combines identification questions, four clinical interventions and systematic monitoring that can be applied in adult ward settings.

Evidence suggests the AMBER care bundle results in:

- improved decision making
- a positive impact on multi-professional team communication and working
- increased confidence of nurses about when to approach medical colleagues to discuss treatment plans
- patients being treated with greater dignity and respect
- greater clarity around preferences and plans about how these can be met

AMBER Care Bundles are being trialled by the NSW Clinical Excellence Commission in collaboration with Central Coast, South Eastern Sydney, South Western Sydney, Northern NSW, Western NSW and Nepean Blue Mountains LHDs and St Vincent's Health Network.



“I have Cystic fibrosis, a genetic lung condition that gets worse as time goes on and ultimately ends in an early death. I was listed for a double lung transplant when I was 15 years old.

I remember being so exhausted and run down that speaking about anything that involved thought was just way too much by the time I hit that point. Honesty and openness was what I had been trying to achieve from an early age, yet was constantly met with denial from those around me who I felt needed to be aware of how I felt, my fears and my thoughts and my wishes...my questions...anything.

The thing that unites us as humans, is that we all die.....this is going to happen to all of us...it's not avoidable.....so it is very important to speak about it.”

Ms Kylie Polglase
Health consumer

What we will do

Action	Lead/Partners
3.1 Improve identification of dying patients using the <i>Between the Flags Program</i> .	CEC/ACI
3.2 Pilot an End of Life Observation Chart based on <i>Between the Flags Program</i> documentation that helps monitor the quality of care provided to dying patients, including escalation for clinical review.	CEC/Hunter New England LHD
3.3 Pilot <i>AMBER Care Bundles</i> in selected NSW hospitals.	CEC/LHDs/SHNs
3.4 Promote use of Quality Systems Assessments by LHDs and SHNs and implement the findings to improve end of life care.	CEC/LHDs/SHNs
3.5 Measure the quality of care provided to dying patients and implement improvements where possible.	CEC/LHDs/SHNs
3.6 Enhance local death audit: <ul style="list-style-type: none"> 3.6.1 Improve audit tools to include evidence of Advance Care Planning and quality of dying and their use in target populations. 3.6.2 Determine how death audits will be reviewed at a local level, based on predicted, as well as unexpected, hospital deaths. 3.6.3 Review the care of dying patients in regular hospital mortality and morbidity review meetings. 3.6.4 Monitor documentation of organ donation decisions via the Donatelife Death Audit system. 	CEC/LHDs/SHNs Organ and Tissue Donation Service

OUTCOME 4

Patients' preferences about where they want to die are respected and appropriate support and resources are available to provide this

Multiple admissions to acute care units and emergency departments often take place in the patient's last year of life, even for those patients known to be dying and who are receiving care in community settings. Patients who are dying are often transferred to a hospital mainly because their symptoms cannot easily be relieved in their current place of care.

People approaching end of life frequently need care from multiple services and may need to be transferred between locations (home, hospice, hospital, residential aged care facility). Systems are needed to enable transfer of Advance Care Planning information regarding a patient's wishes and preferences for end of life care and treatment between clinical settings.

Many stakeholders commented on issues about dying at home versus dying in hospital. Improved access to community care and palliative care enables people to be supported to die at home. It was recognised that while hospitals may not be the preferred place to die for many patients, there will always be a proportion of patients whose death can only be managed in an acute care hospital, or palliative unit or hospice.

If Advance Care Planning is to effectively allow people to determine their preferences for end of life care and place of death, then new models must be developed for palliative care and community services to support dying at home, including in residential aged care facilities.

Palliative care

Palliative care provides treatment and care for people who are dying and supports their families and carers. It neither hastens nor postpones death, but affirms life and approaches dying as a normal process. Palliative care may also start earlier in the course of an illness and evolve as a person approaches the end of his or her life. Elements of palliative care include:

- relief from pain and other distressing symptoms
- enhancement, as far as possible, of quality of life
- psychological and spiritual care
- support to help patients live as actively as possible
- assistance for families coping with illness, death and bereavement.

Palliative care can be provided in a range of settings and can involve doctors, nurses, allied health workers, volunteers, families and carers. They will often work in networked teams to allow best access to high quality care. These networks include primary care providers (including GPs, generalist community nurses and allied health workers), tertiary care providers (including public and private hospitals and specialist hospices), community support services and aged care services.

The *NSW Government Plan to increase access to palliative care 2012-2016* sets out the NSW Government's policy to ensure that everyone has access to quality palliative care regardless of their economic or social circumstances, their geographical location or their medical condition. The *Plan* seeks to enhance existing palliative care services and to draw upon and expand the skills of the multi-disciplinary teams who provide such care.

The *Plan* is at <http://www.health.nsw.gov.au/publications/Pages/palliative-care-plan-2012-16.aspx>

What we will do

Implementation of The NSW Government Plan to Increase Access to Palliative Care 2012-2016 and the ACI Framework for the State-Wide Model for Palliative Care and End of Life Service Provision will ensure delivery of effective, accessible and efficient care to people in NSW who are approaching end of life. Together they set the groundwork for addressing the complexities of providing quality palliative and end of life care across acute, sub-acute, primary care, community, home and residential aged care settings.

Action	Lead/Partners
4.1 Develop admission procedures that routinely include identification of prior Advance Care Planning.	LHDs/SHNs
4.2 Ensure Advance Care Directives, Advance Care Plans and Acute Resuscitation Plans are flagged in medical records, patient data systems and electronic medical records.	LHD/SHNs/ HealthShare NSW
4.3 Ensure the <i>Safe Clinical Handover Program</i> addresses integration of Advance Care Planning documents into discharge planning and transfer between acute, community and residential aged care settings.	CEC/LHDs/SHNs
4.4 Promote use of Advance Care Plans and Advance Care Directives in the Personally Controlled Electronic Health Record.	MOH
4.5 Advocate for information system capacity to support electronic transfer of Advance Care Planning documents between primary and acute care.	MOH/LHD/SHNs/ HealthShare NSW
4.6 Implement the NSW Government <i>Plan to Increase Access to Palliative Care 2012-2016</i> to enable support for dying at home.	MOH/LHDs/SHNs/ACI
4.7 Develop the framework for the <i>State-Wide Model for Palliative Care and End of Life Service Provision</i> , including recognition of the need for support for care in non-hospital settings.	ACI/LHDs/SHNs
4.8 Revise the documentation and processes for certifying death at home to reduce the burden on families caring for people dying at home and enable timely transfer of the deceased to an appropriate location.	MOH/LHDs/SHNs/ACI/ Ambulance Service of NSW/NSW Police

OUTCOME 5

Families and carers are clear about patients' wishes in advance so that they experience reduced burden of decision-making on patient's behalf

Substitute decision makers⁴ who are identified or appointed too late, for example after the patient has lost decision-making capacity, are often unprepared, uninformed about the patient's wishes, or may not be the person that the patient prefers to make decisions on his or her behalf. Where the substitute decision maker and the family have not been part of Advance Care Planning conversations, it is more likely that there may be disagreements about end of life care.

A proportion of patients will want their 'Person Responsible' to be someone other than who is identified under the *Guardianship Act* provisions. Patients need to be encouraged to appoint their preferred substitute decision maker as an Enduring Guardian as part of Advance Care Planning. Others will not wish to appoint anyone to make decisions for them should they lose capacity. This wish should be respected.

As acknowledged in *Increasing Organ Donation in NSW: Government Plan 2012*, families generally support organ and tissue donation proceeding when they have discussed the issue with the deceased person and know their decision.

When patients planned ahead for end of life, both the patient and the family were more satisfied with the patient's hospital stay, and the family suffered less stress, anxiety and depression when the patient died.

(Detering KM et al, BMJ 2010)

4 The term 'Next-of-Kin' is not an applicable or appropriate term in NSW for those who make health-care decisions on a patient's behalf. This is the 'Person Responsible'. See http://www.lawlink.nsw.gov.au/lawlink/opg/ll_opg.nsf/pages/OPG_enduringguardianship

What we will do

Action	Lead/Partners
5.1 Encourage patients with chronic life-limiting illness to identify their substitute decision maker early in the course of illness.	LHDs/SHNs/ACI
5.2 Develop hospital admission procedures that identify the Person Responsible.	LHDs/SHNs
5.3 Encourage healthy adults to consider and discuss their organ and tissue donation preferences at the same time as they make plans about who should make treatment decisions on their behalf.	MOH/LHDs/SHNs

OUTCOME 6

Health professionals see Advance Care Planning for end of life as an expected part of clinical care, understand the clinical and other requirements for doing so, and are supported in providing best practice treatment and care to dying patients

There is a strong emphasis in the community and in health-care delivery on quality of life in chronic illness however there also needs to be a stronger and more positive focus on quality of care in dying. One of the main barriers to this is a reluctance or inability to discuss dying.

This reluctance to talk about death and dying appears to be greater amongst health professionals than patients and families. Health professionals, patients and families need timely, skilled and sensitively handled discussions about expectations, choices and therapeutic possibilities.

Health professionals in NSW are seeking practical guidance about how to have the sensitive and sometimes uncomfortable discussions with patients and families and specifically, how to elicit preferences for care as end of life approaches without being too confronting. This requires practical resources and training, as well as addressing concerns that such conversations diminish hope in patients.

Experience both overseas and locally recognises that single interventions, such as only encouraging patients to complete Advance Care Directives, are not effective in ensuring patients get the care they want if they lose ability to make their own decisions. Implementing effective Advance Care Planning requires changing institutional routines and integration of processes within and between health organisations. Some health professionals in NSW have expressed concern that discussing and documenting end of life concerns with families will lead to family complaints, conflicts about end of

life decisions, and legal exposure. Sensitively conducted and inclusive conversations with patients and families and thorough documentation generally reduce the likelihood of family complaints and risk.

As end of life approaches, care will often be coordinated and delivered by primary and community care providers. The role of general practitioners in Advance Care Planning is pivotal to its successful implementation and appropriate supports should be provided for them.

“Approximately one third of respondents (from clinical units) indicated patients approaching the end of life are not routinely identified. Thirty eight percent of unit level respondents also indicated this is one of the most challenging issues when managing patients. The implications of this can be delays in Advance Care Planning, informed decision making around treatment and providing adequate time for the patient to get their affairs in order.”

Clinical Excellence Commission. *Care for the Dying in NSW 2013*

http://www.cec.health.nsw.gov.au/___documents/programs/qsa/qsa-reports/cec-care-for-the-dying-may-2013.pdf

What we will do

Action	Lead/Partners
6.1 Provide training for health professionals in the communication skills required for Advance Care Planning.	HETI
6.2 Advocate for inclusion of Advance Care Planning in under- and post-graduate training of health care professionals.	MOH/HETI
6.3 Advocate for attribution of CPD points for Advance Care Planning education and training.	MOH/HETI
6.4 Develop and publish online 'myth busters' addressing legal and other common knowledge gaps and concerns related to Advance Care Planning, end of life decisions and care.	MOH
6.5 Develop and publish online a 'Frequently Asked Questions' resource about Advance Care Planning for end of life in mental health settings in consultation with the mental health sector.	MOH/Mental Health Commission of NSW
6.6 Develop an <i>End of life Decisions Conflict Toolkit</i> for health professionals and administrators.	MOH/HETI/LHDs/SHNs
6.7 Develop guidance for health professionals regarding Advance Care Planning and end of life care for prisoners and forensic mental health patients.	MOH/Justice and Forensic Mental Health Network/Mental Health Commission of NSW
6.8 Develop an e-learning resource for health professionals on Advance Care Planning.	HETI
6.9 Develop an education strategy to target priority health professional groups on Advance Care Planning.	HETI





“Advance Care Planning in health is extremely important to optimising the care of patients with chronic diseases and life limiting illnesses at the end of life. The lack of forward planning prevents patients and families from prioritising their goals, optimising quality of life and being included in clinical decision making. This planning process takes time and needs to be dynamic, with ongoing conversations about treatment options, medical care, end of life care and place of care. Professionals treating patients with chronic illnesses have a duty of care to explore these issues early with patients and their families, preventing a crisis situation. Good palliative care principles can be in place for all patients through this process.”

Dr Ghauri Aggarwal
*Head of Department
Palliative Care
Concord Hospital*



“Dying with dignity and in control is as important to me as living a full and happy life. In order to do that it is necessary to inform my family of what that is for me and how I want it to be organised. I do this for two reasons: the first is to fulfil my own need to have some say in how that is to happen; and the other and, for me, even more important, is to relieve them of the burden of being placed in a position of having to make decisions without being informed fully.

I just do not want my death to cause fractures in the family relationships.

It may sound a little controlled and contrived, and maybe it is, but I firmly believe that end of life issues are as important to plan as your financial future. We do not leave that to chance and I am not leaving my death to chance either.”

Ms Michelle Sharkey
Health consumer
Social worker

ENABLERS

1. GOVERNANCE AND COLLABORATIVE IMPLEMENTATION AND PLANNING

Practical advice is required to support LHDs and SHNs to implement NSW Health policies and guidelines on end of life decision making. There is currently significant variability in local models of Advance Care Planning across NSW. Some of this variability is appropriate but there is also limited evidence of effectiveness for most of these models at this time. There have been limited opportunities for cross-learning between LHDs and SHNs which has resulted in duplication of effort. Also, limited opportunities for implementation of Advance Care Planning across sectors, such as between acute, primary, community and residential aged care, needs to be addressed. Implementation planning needs to include these partners to align strategies, models of care and share resources.

There are a range of established local Advance Care Planning initiatives and local links between acute care, primary, community and aged care settings to support Advance Care Planning. These should be developed further and aligned, where appropriate, to support quality end of life care and planning. Clinician and Senior Executive champions will be important for successful implementation of this *Plan*.

As *The NSW Government Plan to Increase Access to Palliative Care* highlights, new partnerships and linkages are needed between specialist and generalist services to support provision of care to dying patients in the community and residential aged care services. This will expand access to palliative care, promote its introduction earlier in the course of illness and ensure care evolves as end of life approaches.

What we will do

Action	Lead/Partners
E1.1 Establish a governance group to oversee the implementation of the <i>Plan</i> and monitor performance.	MOH/ACI/CEC/HETI/LHDs/SHNs
E1.2 Include Key Performance Indicators and Service Measures in LHD and SHN Service Agreements and pillar Compacts to monitor implementation of this <i>Plan</i> .	MOH/ACI/CEC/HETI/LHDs/SHNs
E1.3 Ensure clinical leadership, cross learning and sharing about end of life initiatives between health services, residential aged care and GPs.	ACI



“I’m yet to meet anyone who looks forward to discussions about death. For patients and their families this is the most confronting conversation they will ever have. The level of discomfort is not much less for most renal physicians; we have often managed these patients for decades through dialysis or other chronic kidney disease treatments. We know their families well and sometimes talking about death can seem like a failure of our treatment. Yet what greater gift can we give our patients than to know that the last stage of their life is played out as they want, with comfort and support from us and their loved ones. As such we have a responsibility to ensure that Advance Care planning is part of our standard clinical practice; it’s not an easy task but one we should strive to achieve.”

Professor Mark Brown
*Director of St George and Sutherland Hospitals
Renal Service*

2. BUILDING EVIDENCE ABOUT THE EXPERIENCE OF DYING IN NSW TO IMPROVE CARE

There is inadequate information about current patterns of end of life care delivery and service utilisation as death approaches. A better understanding of these aspects of end of life care is essential to improve this aspect of the health system. Existing information systems can be utilised and enhanced to support this. It is also important to explore opportunities to use specialised collections, such as the Palliative Care Outcome Collaborative. Palliative care and other clinical specialists are critical in informing development of enhanced systems.

Data are needed on quantitative components of end of life care, such as place of death for subsets of dying patients. This includes whether death occurred in acute care settings (intensive care units, high-dependency units or emergency departments), residential aged-care facilities, homes or other locations. It is also important to understand hospital utilisation in the year before death, including visits to emergency departments, hospitalisations and admissions to intensive care units.

Qualitative data are also needed. Enhanced auditing of the records of patients who die will provide information on the extent to which the death was expected – for example, the existence of an Acute Resuscitation Plan; the way the death was managed; patient and carer involvement in end of life decision-making; and whether the death was reviewed via the local morbidity and mortality review process, where relevant.

What we will do

Action	Lead/Partners
E2.1 Develop an enhanced database to support end of life planning and service delivery.	CEC/ACI
E2.2 Develop quality indicators for care of the dying.	CEC/ACI
E2.3 Promote use of data linkage across care settings where end of life care is delivered.	MOH/CEC/ACI

3. ONGOING COMMUNITY CONSULTATION TO RAISE AWARENESS AND PARTICIPATION

Improving end of life care requires changing attitudes to death and dying in society, as well as in the health professions. Addressing the cultural barriers to accepting the inevitability of death is challenging in an environment where medical and scientific progress continue to promote expectations of a long and healthy life. Generating this shift in community attitudes requires partnership across government.

If community members are to be better placed to plan ahead, they need a better understanding of the normal trajectory of common, ultimately life-limiting conditions and the frailty that typically accompanies these diseases and old age. Patients and families generally want to know when end of life is approaching. A large number of patients would like to know more about how to manage

their own condition and understand its trajectory as end of life approaches. Improving health literacy is a key driver of effectively implementing Advance Care Planning in NSW.

There was support for community education that uses positive messages about living well until death, and 'dying well'. Advance Care Planning and the benefits it can confer on healthy individuals planning for later life, as well as patients, and their families should form part of these key messages.

The NSW Ageing Strategy was seen as an important whole-of-government, whole-of-community response to address issues arising from the ageing population. It has a commitment to assisting people to plan ahead for their future as they age and provides funding for community education strategies to increase awareness levels and completion rates of planning ahead documents including wills, powers of attorney, guardianship and Advance Care Plans and Directives.

www.ageing.nsw.gov.au

What we will do

Action	Lead/Partners
E3.1 Promote the NSW Attorney General and Justice Department's <i>Planning Ahead Tools</i> website www.planningaheadtools.com.au	MOH/NSW Attorney General and Justice Department/Office of Ageing
E3.2 Promote early phase Advance Care Planning with lawyers, thus prompting their clients to appoint Enduring Guardians, as part of broader planning for later life e.g. when making wills.	MOH/NSW Attorney General and Justice Department/Office of Ageing
E3.3 Work with NSW government agencies to promote improved processes for appointment of Enduring Guardians in community and residential aged care settings.	MOH/NSW Attorney General and Justice Department/Office of Ageing

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