

Statewide strategy for end-of-life care 2015

Service direction	Knowledge of end-of-life care throughout public health organisations is expanded and includes a comprehensive awareness of the benefits of the planning and delivery of end-of-life care and availability of supporting services/resources within and between health services.	Earliest possible identification of patients who will or are anticipated to have shortened life expectancy as a result of known health conditions is routinely achieved, together with timely Advanced Care Planning (ACP) and the initiation of co-ordinated planning of end-of-life care.	End-of-life-care delivered in Queensland public services consistently responds to the needs of patients throughout their illnesses and meets established clinical safety and quality standards.	The strategic capability and configuration of end-of-life care services in Queensland is strengthened to maximise system health service delivery and performance so as to provide access to appropriate services for the projected population, while making the most effective use of available resources.
Objectives	<ol style="list-style-type: none"> 1. Members of the broader community are aware of the benefits and indications for end-of-life care to support quality of life for those living with conditions anticipated to shorten life expectancy. 2. End-of-life care is recognised by healthcare professionals and providing organisations as a core component of health service delivery. 3. Healthcare professionals are aware of the core components of end-of-life care and how and when it may benefit patients in their care throughout all stages of illness. 4. Healthcare professionals are knowledgeable and supported in their role in the delivery of end-of-life care. 5. Patients have a clear understanding of their clinical condition, prognosis, and the likelihood (or not) of benefits being realised from healthcare interventions. 6. Patients (and their families and carers) have an understanding about how and when they may benefit from specialist palliative care. 7. Patients (and their families and carers) understand what health service types and supports are available and how to access these. 	<ol style="list-style-type: none"> 1. Healthcare professionals routinely practice optimal early recognition of life-limiting conditions and initiate care planning with patients. 2. The patient's values and goals of care are established (through ACP) and communicated within plans of care as early as possible. 3. Patients are supported by healthcare providers to consider goals of their healthcare and the identification of preferences with maximum lead time to support realisation of goals. 4. Healthcare professionals are supported with evidence-based resources to aid in the early identification of those who may benefit from end-of-life care. 5. Inter-professional teams are effective in responding to the best interests of patients with a life-limiting condition supported by available expertise. 	<ol style="list-style-type: none"> 1. End-of-life care is responsive to the needs of patients throughout the course of their illness and is inclusive of the management of pain and other physical symptoms as well as psychological, social, spiritual and practical support. 2. End-of-life care is accessible in parallel with active/curative and other supportive treatments for those with life-limiting conditions. 3. Patients have the opportunity to develop and participate in a documented planning process (ACP) to establish consent with the goals of their care incorporating personal preferences with the flexibility to be adapted as their condition changes. 4. Inter-professional teams clearly identify who is taking the lead responsibility for initiating and coordinating care for each patient. 5. Healthcare providers collaborate in the provision of care to those who are nearing the end of their life. 6. Families and carers are involved and supported in their roles when looking after someone who is nearing the end of their life, and in bereavement. 7. Practices aimed at responding to the needs of deteriorating patients incorporate mechanisms for recognising the need for end-of-life care. 	<ol style="list-style-type: none"> 1. Integrated end-of-life care services are accessible as close as possible to where people reside within Queensland. 2. End-of-life care services are networked at statewide and local levels to function effectively within and between Hospital and Health Services, including with external service providers. 3. Each Hospital and Health Service has a service model with capability across the full range of end-of-life care service types and across settings with capacity to respond to local population needs. 4. Each Hospital and Health Service has capacity for coordination of available specialist resources towards addressing complex needs, while providing capacity-building support to other services and care providers to meet basic and non-complex needs across general services. 5. Service enabling infra-structure expansions are aligned with need to support safe and effective inter-professional practice across service settings.
Priority actions	<ul style="list-style-type: none"> • Lead the development of an overarching public awareness strategy. • Determine an appropriate response to address knowledge deficits regarding the existing Queensland legislative framework around end-of-life issues. • Evaluate the effectiveness of available educational programs and re-focus design and approach (if necessary) to target the highest educational needs. • Prioritise (and consider making mandatory) routine/regular access to educational opportunities and training resources in end-of-life-care decision making for all healthcare professionals. • Establish resource hubs to advance end-of-life care initiatives e.g. core nucleus of experienced clinical leads who can teach and mentor, expert inter-professional working groups. 	<ul style="list-style-type: none"> • Establish evidence-based tools to support health professionals in the early identification of patients nearing the end of their life. • Progress and expand the uptake of advanced care planning activities across all service settings for all ages and life stages. • Implement mechanisms for improving clinical practice and promoting the benefits of end-of-life care e.g. introduce 'how' a person died to all mortality reviews, examining appropriate responses for deteriorating patients. • Introduce processes and interventions, including early referral pathways, within organisational entry points to identify patients who may benefit from early intervention of end-of-life care. • Maintain records of established goals of care and communications, which are accessible to inter-professional team members. • Establish service pathways between organisations for the transition of children and adolescents to adult services. 	<ul style="list-style-type: none"> • Develop system level clinical policy initiatives, implementation arrangements and staff resources to support safe and high-quality service delivery. • Implement available incentives which reward good practice e.g. quality improvement payment for enabling patient choice about care. • Implement service models that maximise opportunities for patient choice through the early identification and establishment of care goals in conjunction with the patient, their family or carers, and medical and nursing professionals. • Implement strategies to enable ease of access to palliative care beds in acute health facilities, particularly during exacerbations of symptoms and the terminal phase and to mitigate the need for emergency assistance after hours. • Establish mechanisms to provide specialist health and psychosocial support for families and carers, including options for respite and bereavement support. • Assess care provision and patient satisfaction through actively involving patients, families and carers in evaluations of care and the use of standardised benchmarking tools where available and appropriate. 	<ul style="list-style-type: none"> • Establish system organisational arrangements to oversee system clinical improvements, including the provision of strategic clinical advice and input into issues pertaining to statewide service delivery. • Explore and implement viable funding mechanisms that incentivise the delivery of quality end-of-life care. • Strengthen and/or formalise relationships with general practitioners, community based palliative care services and organisations to promote and integrated and coordinated approach. • Develop and upscale specialist palliative care inpatient and consulting service capacity, to provide daily coverage and accessibility throughout health services. • Coordinate effective interagency responses for children and young people to facilitate access to short breaks/family respite and medical equipment. • Undertake local end-of-life care needs analysis at the catchment level in partnership with non-government and community based service providers to develop plans to meet future need. • Promote patient uptake of the personally controlled electronic health record and trial addition of end-of-life care information in the Queensland Health integrated electronic medical records system to support end-of-life care.

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Modern medical care has been very successful in improving both the quantity and quality of life for many, many people. However, in spite of all the gains, there is now a growing recognition amongst clinicians and community members that modern technologies (that can delay dying) do not always maintain or enhance the quality of the life being lived — this can be true for patients of any age. Everyone will die and there will come a time for each one of us that further attempts at life prolongation will become futile, burdensome and potentially unwanted. Many people are now choosing to concentrate on the quality rather than the quantity of the remainder of their lives. Health services must accommodate these realities and continue to provide appropriate care for people until they die.

In Australia, and indeed in most developed countries, improvements in the provision of care at the end of life have tended to lag behind most other fields of practice. This has occurred for a number of reasons, but not least because the focus of attention has been on life prolongation and the treatment of disease. Fortunately, over the past few decades the care of people who are nearing the end of their life has been recognised as a core component of modern health services.

Clinicians have a variety of means by which they can identify many of the patients who are likely to deteriorate in the near future, or may have entered the last year of their life. These assessments should be an integral component of routine practice and the results of such assessments communicated to patients and their carers. This information provides the opportunity for patients to make the choices that will determine how they, and their families, will experience the time remaining before they die.

With support from clinicians, the community is starting to participate in advance care planning that enables them to document their choices for their future healthcare and maximise the likelihood that those choices will be respected. This can be done at any time of life but is of particular importance as people become frail with age, and/or are identified as having a life-limiting illness.

As clinicians we have a responsibility to provide patients with appropriate care at the end of their life, or to refer to those who can. The best outcomes are achieved when we work collaboratively with other specialties and across health settings to provide the best possible advice about what can be realistically achieved, and help patients to make wise choices from the options that are available to them.

As health managers, we can work to ensure that we provide the services appropriate to the needs of our patients.

As members of our community we can all participate in the growth of our society by encouraging open conversation with our family and friends about death and dying, and the choices that we might wish to make towards the end of our life.

The quality of care provided to people at the end of their life is one of the key indicators of the values of a community. This Strategy is a vital step forward for Queensland as we all learn to deal with the normality of death.

Dr Will Cairns

Chair, Statewide Palliative Care Sub-Clinical Network
Statewide General Medicine Clinical Network 2015

Strategy summary

High-quality end-of-life care can help people to achieve the best possible quality of life as they approach death.

The Queensland Statewide end-of-life care strategy has been developed in collaboration with clinicians working with persons whose health is failing and with the input of patients, their families and carers. It is intended that the strategy will enhance end-of-life care in Queensland by:

- Promoting public, and specifically patient awareness, of the benefits of actively discussing their care options and preferences with their treating clinicians, family and friends and ensuring these are documented - often referred to as advanced care planning;
- Implementing strategies in our health services to support the early identification of patients who are anticipated to have a shortened life expectancy so there can be early discussion about their options;
- Promoting and supporting models of care and clinical practice that are responsive to patient's needs at the same time as meeting the highest standards for clinical effectiveness, safety and quality;
- Building capability and reconfiguring services as necessary to make the best use of available resources and expand access to quality end-of-life care.

Achieving the necessary changes will require commitment and action by healthcare professionals working both within the public and non-government health systems to work collaboratively both with and for the benefit of their patients.

For more information contact

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