Metro South Health End-of-Life Strategy

2016

Queensland Government

Introduction

In Australia, the demographics of dying are changing rapidly. Today most people live longer and die an expected death usually from chronic progressive conditions, both malignant and non-malignant [(1).] If death is expected it stands to reason that it can be prepared for with a systematic, patient and family centred approach that aligns patient choices and preferences with clinical safety and quality standards. Evidence suggests that such an approach relieves patient and family distress, clinical tensions and may constrain health care costs incurred by use of inappropriate care at the end of life [(2).] High quality end-of-life care helps people to live as well as they are able within the context of their lives and to die in comfort with dignity.

It is recognised across jurisdictions that end-of-life care in Australia is not always optimal. In view of this, Queensland Health developed an end-of-life strategy to strengthen the capacity of health services to respond to the needs of those living with life-limiting conditions and dying. In tandem, Metro South Health (MSH) developed its *My Care, My Choices* Strategy that specifies service directions with associated clinical processes and actions. This ensures patients approaching end-of-life can be proactively identified and receive care based on agreed goals that align with their preferences.

The My Care, My Choices Strategy – Defining End-of-Life Care

The *My Care, My Choices* Strategy is effective for people approaching end of life. People are defined as approaching end of life when they are likely to die within the next 12 months[(3)]. The primary focus of end-of-life care is on the quality of life remaining rather than prolonging biological life by extraordinary means at any cost.

Effective end-of-life care that meets the multi-dimensional needs of people is dependent upon complex relationships between patients, their families and carers, health care professionals and health services. End-of-life care combines the broad set of health and community services that care for people as they approach the end of life.

The care phases associated with end of life are inherently linked, from the point at which a need for such care is identified (by the clinician or patient) to the point of death (which may be days, months, or a year), and includes bereavement support after death. The *My Care, My Choices* Strategy emphasises three key clinical processes that underpin quality end-of-life care service provision which include:

- advance care planning,
- comprehensive care, and
- terminal phase care management.

Advance care planning is an iterative process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known and are used to guide decision making at a future time if that person cannot make or communicate their decisions[(4).]

While advance care planning is relevant to everyone, this strategy focuses only on people approaching the end of their lives. Such people are likely to include:

- those with a likely prognosis of a year or less;
- those with advanced chronic and progressive conditions, whether malignant or non-malignant;
- those managing multiple and life-limiting comorbidities, including extreme frailty;
- those living with advanced progressive conditions who have chosen to cease disease modifying treatments.

Comprehensive care is individually tailored holistic care based on identified goals. These goals are aligned with patients' expressed preferences and health care needs, consider the impact of patients' health issues on their life and wellbeing and are clinically appropriate.

Terminal phase care refers to care that is provided in the patients' final days or week of life, when a diagnosis of dying has been made.

The My Care, My Choices Strategy – Outcomes

My Care, My Choices Strategy aims to provide clear and useful tools and guidelines to improve end-of-life care across Metro South Health facilities and services. The strategy will promote consistent practice and will inform the development of training, governance and quality systems that support the key end-of-life clinical processes.

Outcomes

The expected outcomes of the *My Care, My Choices* Strategy are:

- increased awareness across the community, both public and clinical, of the benefits and components of end-of-life care
- clinician use of a best practice framework for end-of-life care which is embedded into routine practice across MSH
- patients routinely given the opportunity to participate in the process of advance care planning, including the nomination of a substitute decision maker
- clear documentation and storage of a person's end-of-life care preferences in a way that facilitates change by the individual as required and which are easily retrieved by clinicians
- early identification of patients who will have, or are anticipated to have, shortened life expectancy as a result of known conditions. This includes providing these people with a realistic understanding of their disease progression and available care choices
- comprehensive care management plans in line with the person's preferences and delivered within a framework of care developed, documented and available to all those involved in the care
- terminal phase care is well managed irrespective of the environment of care
- health system limitations which are currently barriers to end-of-life care are addressed

- patients, families and carers have greater access to end-of-life services
- end-of-life care meets established clinical safety and quality standards.

Service Directions

This document, mirroring the Queensland Statewide Strategy for End-of-Life Care 2015, presents five overarching service directions collectively aimed at achieving the intent of this Strategy. Within each service direction a number of actions are outlined to establish a more proactive approach to end-of-life care throughout Metro South Health. Each action should be interpreted as being applicable across all health and service delivery settings regardless of the level of clinical need.

Service Direction 1

Knowledge of end-of-life care is expanded and incorporated as a core component of integrated health care service delivery.

Rationale

All people die and all clinicians deal with dying patients at some point in their career. A greater awareness of the issues surrounding dying, including clinical recognition that a person is approaching end of life, is essential to accessing and achieving quality end-of-life care. Health care professionals from all specialties need to be aware of the core components of end-of-life care and when to implement a framework of care that proactively supports each individual patient as they journey towards a temporally uncertain but inevitable death.

Actions

- Develop standardised communication resources that are freely available on the MSH intranet and internet sites to raise public awareness of the issues surrounding end of life
- Develop a best practice end-of-life framework of care based upon the National Consensus Statement [9] that is adaptable to all care settings. This framework will synchronise with similar frameworks developed nationally by two federal initiatives (the Residential Aged Care Palliative Approach Toolkit and the Decision Assist Program)
- Develop standardised clinical education packages based on the end-of-life framework to support best medical practice
- Develop an overarching clinical guideline document outlining appropriate care in the last year of life that is delivered through: orientation and training programs, mentoring and support and reflected in policy and procedures.

Service Direction 2

Promotion of advance care planning for the community and clinicians.

Rationale

The current experience of end-of-life care in Australia is disparate and inconsistent; health care systems cannot guarantee patients at the end of their life access to care that is customised to their preferences and that reliably delivers good symptom control[5]. A pivotal step to improve this situation is for people with life-limiting conditions to complete advance care planning documents in consultation with their family and significant others and the treating team.

Actions

- Use a systematic approach to promote uptake of advance care planning using activities tailored to particular health care sectors of MSH (including public domains, GP practices, residential aged care facilities and hospitals). Public presentations should include provision of supporting materials that guide people to incorporate key information required to support the realisation of the person's goals.

- Use a systematic approach to develop sustainable advance care planning education packages targeting all health care professionals that can be implemented and adapted to individual facility requirements. Packages should cover topics such as legal and jurisdictional differences between advance care planning and related documents, the benefits of advance care planning, who to consider for advance care planning, when to initiate advance care planning, how to prepare for discussions, what to discuss, how to document an Advance Care Plan, how to store and access Advance Care Plan documents.

- Explore hospital and community based Advance Care Planning clinics and conduct community forums.

- Develop interfaced communication systems to allow efficient flow of advance care planning information between private homes, GP practices, residential aged care facilities, Queensland Ambulance Service and hospitals.

- Ensure that MSH Statement of Choices documents can be stored, retrieved, modified at the patient's behest and transferred across health care settings.

Service Direction 3

Embed a best practice framework of end-of-life care into integrated health care practice.

Rationale

Clinicians can be hesitant to raise end-of-life issues [6,7]. A framework of end-of-life care, founded upon best medical practice can help clinicians to overcome that hesitancy regardless of clinical uncertainty or challenges with end-of-life communication. Such a framework guides clinical preparedness to initiate proactive and holistic needs assessment, shared decision making about goals of care, and anticipatory care planning.

Actions

- Adopt a system wide approach for the implementation of the framework for end-of-life care delivered by local working groups tasked with tailoring the framework to meet local needs and circumstances.
- Assist individual clinical specialties to define specific clinical indicators for their patient cohort that triggers use of the framework.
- Adopt routine use of evidence–based tools, based on appropriate end-of-life care and de-escalation of burdensome treatments, that support clinicians in their use of the framework.
- Support clinical practice with comprehensive care planning skills to optimise symptom management and psychosocial support in preparation for inevitable future clinical deterioration.
- Develop and implement a terminal care observation chart to ensure adequate comfort care for the patient in the terminal phase and recognition of carer distress.

Service Direction 4

Ensure continuity of high quality end-of-life care across all care settings in MSH.

Rationale

End-of-life care across primary, secondary and tertiary sectors in Queensland is often uncoordinated [8] and this can manifest as suboptimal clinical care. Uncoordinated care leads to potentially unnecessary use of acute hospital services through unplanned emergency admissions. It also diminishes the effectiveness of community-based primary health care providers further contributing to hospital teams becoming the default carers.

Actions

- Promote the availability and use of advance care planning templates, including the MSH Statement of Choices documents across MSH.
- Ensure the MSH Statement of Choices documents are available electronically to GPs and other health care providers.
- Promote accessibility of The Viewer which contains MSH Statement of Choices documents to GPs and the Queensland Ambulance Service.
- Develop common integrated practices for end-of-life care, including information transfer, with other providers, e.g. GPs, residential aged care facilities, Queensland Ambulance Service.
- Promote best integrated end-of-life care across service providers by forming operational and educational partnerships with the Brisbane South PHN, after hours service providers, domiciliary services, RACFs and hospital units.

Service Direction 5

Evaluation of the *My Care, My Choices* Strategy components against clinical safety and quality standards and development of clinical quality improvement activities.

Rationale

A cornerstone of contemporary best medical practice is evaluation of processes and patient outcomes against clinical safety and quality standards. Such evaluation demonstrates the extent to which objectives of the Strategy are being achieved and may indicate if changes are required in direction or processes of the Strategy. Further, evaluation is likely to influence funding decisions according to the Statewide Strategy. Ongoing quality improvement activities in the area of end-of-life care, including the review of Queensland legislation, are necessary to ensure end-of-life practice in Queensland is in harmony with that across other Australian jurisdictions.

Actions

- Develop and use robust data collection and quality audits to inform and improve end-of-life planning systems.
- Advocate for changes to Queensland legislative framework for end-of-life care so that Queensland is in harmony with other jurisdictions.
- Establish mechanisms that support the mutual recognition of Advance Care Plans developed in other settings or services.
- Identify and promote end-of-life care champions who model good practices in end-of-life care to guide and support the development of practice.

Governance

The implementation of *My Care, My Choices* Strategy is being guided by the Metro South Health End-of-Life Steering Committee under the auspice of the MSH Clinical Governance Unit.

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