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Consumer Role Statement Palliative Care Clinical Health Service Plan Steering Committee

Metro North Hospital and Health Service (MNHHS) is currently developing a five year Clinical Services Plan (the Plan) for the management and treatment of palliative care patients in the following service settings:

- emergency department
- inpatient acute
- inpatient designated palliative care
- ambulatory
- residential aged care
- community
- home.

The scope of the Plan includes palliative care service provision to manage the needs of adult patients (over the age of 16 years) moving through palliative care phases (attachment 1, table 2) across all MNHHS service setting (described above) provided by MNHHS.

The Plan will be in line with the State of Queensland (Queensland Health) Statewide strategy for end-of-life care 2015 and deliver over the next five years; service directions to manage the needs of palliative care patients and provide high-quality palliative care services and continuity of care.

Selection of a Consumer

The MNHHS Palliative Care Steering Committee (the Committee) will oversee the Plan and seeks a consumer representative who would be able to provide consumer, carer or community perspectives about palliative care throughout the phases and settings. It is expected the successful consumer representative would be available for at least four meetings over the term of a six month appointment.

Attributes

- Experience with involvement in the care or support of palliative care patient/s across the described phases (attachment 1, table 2) and above service settings as a patient/consumer or carer.
- Experience or strong interest in managing challenges associated with palliative care, for example:
 - having access to required palliative care pain medication when needed
 - having access to support services including psychological, social, spiritual and practical support
 - having access to cultural and linguistic needs
 - having access to key documentation used to enable patient to proactively manage their own



palliative care needs e.g. Advanced Care Planning,

- having access to or use of 'My Health' records
- having access to after-hours palliative care
- enabling palliative patient wishes respected and followed.
- Experience or understanding of palliative care being provided in different services settings (described on page 1).
- Have community links and networks to represent the views of a range of consumers.
- Ability to articulate a consumer perspective and respect and appreciate different perspectives expressed within the Committee.
- Commitment to positive patient experiences and the delivery of safe, high quality, health services by MNHHS.
- Ability to commit sufficient time to participate fully in the work of the Committee, for example, attending meetings, reading documents and reports.
- An appreciation that the role of consumers on this Committee is to influence long term change and improvements across the health service.

Meetings

It is expected the Committee members would meet at least four times over the next six months. The specific timing of these meetings will be determined in the initial Committee meeting. The venue will be advised when dates and times are determined.

Reimbursement and payment of engagement fees

The consumer representative will receive first tier remuneration in line with the MNHHS Engaging Consumer in Advisory Roles – *Reimbursement of Expenses and Payment of Engagement Fees Procedure*:

- \$187 for activities up to and including four hours duration
- \$374 for activities over four hours duration.

These payments are inclusive of preparation time. Travel time associated with participation will not be covered. Reimbursement of reasonable out-of-pocket expenses is not included in this rate and will be offered in addition to remuneration.

Register your interest

To be considered for the position, please complete the attached application form. Applications close Tuesday 30 August 2016.

Contact details

For more information, please contact Zarina Khan: Block 7, Level 14, Royal Brisbane & Woman's Hospital Health Service Strategy & Planning P: 07 3647 9564 E: MNHHS_PlanningStrategy@health.gld.gov.au



Code of conduct and confidentiality

Consumers, carers or community members appointed to the MNHHS Palliative Care Service Plan Steering Committee are required to sign the "Agreement for Consumers, Carers and Community Members Formally Appointed to Engagement Activities" which details a commitment to:

- Abide by the spirit of the Code of Conduct for Queensland Public Service and will treat others including patients and staff in a respectful manner at all times.
- Keep as confidential all information regarding patients and their families, staff members, Metro North Hospital and Health Service (Metro North HHS) business and any other information of a confidential nature that you may have access to through your participation in Metro North HHS formal engagement activities, unless explicitly agreed otherwise by the Chief Executive, or their delegate. You will maintain the confidentiality of this information even after you are no longer participating in the Metro North HHS formal engagement activity.
- Obtain agreement from the Chief Executive or their delegate or Chair of the Committee before publicly discussing any issues which have been discussed by the committee or working group to which you belong.
- Disclose any potential conflict of interest prior to formal appointment to an engagement activity, or as soon as you become aware of the conflict or potential conflict of interest if it arises during your appointment.
- If appointed as a representative of an organisation or consumer group, you agree to engage with the group that you represent without breaching the confidentiality. In general, confidential material that is provided to a committee or working group will be marked confidential and it will be stated that information being provided verbally is not for wider discussion. However, it is not always possible to do this, particularly during frank discussions. Members will therefore be sensitive to their responsibility to be circumspect in their use of any information they acquire by virtue of their participation.
- Refrain from identifying any Metro North HHS staff involved in your care, or the care of others, if there are circumstances where as a consumer or member of a consumer group, you wish publicly to discuss or debate issues arising from personal circumstances.
- Raise any questions or concerns you may have about the work of the committee or working group with the committee chair in the first instance.
- Raise any concerns you may have about the professional behaviour of staff with the relevant authority within Metro North HHS.

ATTACHMENT 1

Table 1: Definitions

End of life	The period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma.	Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high -quality end-of-life care. Sydney: ACSQHC, 2015. General Medical Council. Treatment and care towards the end of life: good practice in decision making. (Accessed 16 July 2014,at www.gmc- uk.org/guidance/ethical_guidance/end_of_life_care.asp.)
End-of-life care	 Includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient's body after their death. People are 'approaching the End of Life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with: advanced, progressive, incurable conditions, 	Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high -quality end-of-life care. Sydney: ACSQHC, 2015. General Medical Council. Treatment and care towards the end of life: good practice in decision making. (Accessed 16 July 2014, at www.gmc- uk.org/guidance/ethical_guidance/end_of_life_care.asp.)
	• general frailty and co-existing conditions that mean that they are expected to die within 12 months,	
	\cdot existing conditions, if they are at risk of dying from a sudden acute crisis in their condition,	
	· life-threatening acute conditions caused by sudden catastrophic events.	
Palliative care or palliative approach	An approach to treatment that improves the quality of life of patients and their families facing life- limiting illness, through the prevention and relief of suffering. It involves early identification, and impeccable assessment and treatment of pain and other problems (physical, psychosocial and spiritual).	Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high -quality end-of-life care. Sydney: ACSQHC, 2015.
Palliative Care	World Health Organisation definition of Palliative Care	World Health Organization. WHO definition of palliative care (Accessed 16 July 2014, at http://www.who.int/cancer/palliative/definition/en/ Palliative Care Australia. National Standards Assessment Program: Quality Report 2010-2015
	Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:	
	 provides relief from pain and other distressing symptoms; 	
	 affirms life and regards dying as a normal process; 	
	 intends neither to hasten or postpone death; 	
	\cdot integrates the psychological and spiritual aspects of patient care;	
	\cdot offers a support system to help patients live as actively as possible until death;	
	 offers a support system to help the family cope during the patients illness and in their own bereavement; 	
	\cdot uses a team approach to address the needs of patients and their families, including bereavement	

	counselling, if indicated;	
	\cdot will enhance quality of life, and may also positively influence the course of illness;	
	 is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. 	
Terminal phase	The hours, days or, occasionally, weeks when a patient's death is imminent. This is sometimes referred to as the period when a patient is actively dying.	Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high -quality end-of-life care. Sydney: ACSQHC, 2015.

Table 2: Palliative Care Phases

Patient problems and symptoms are adequately controlled by an established care plan, further interventions to maintain symptom control and quality of life have been planned, the patient is identified as palliative care with Ambulance Service and online records, the family/carer situation is relatively stable and no new issues are apparent.	
 An urgent change in the care plan or emergency treatment is required due to at least one of the following: the patient experiences a new problem that was not anticipated in the existing care plan, the patient experiences a rapid increase in the severity of a current problem, or the patient's family/carers circumstances change suddenly impacting on patient care. 	
The care plan is addressing anticipated needs but requires periodic review because the patient's overall functional status is declining and the patient experiences a gradual worsening of existing problem and/or experiences a new but anticipated problem. The family/carers experience gradual worsening distress that impacts on the patient's care.	
Death is likely within days and no acute intervention is planned or required. The use of frequent, usually daily, interventions aimed at physical, emotional and spiritual issues is required.	
The patient has died. Bereavement support is provided to family/carers is documented in the deceased patient's clinical record.	