1 Care map information

Quick info:

In scope:
- assessment and management of adults with life limiting illness who would benefit from a palliative care approach

Out of scope:
- children:
  - for paediatric palliative care contact MidCentral Health Children's Ward Charge Nurse (06) 356 9169 ext. 7073

Definition and principles:
A palliative approach embraces the World Health Organisation (WHO) definition of palliative care. It incorporates a positive and open attitude toward death and dying by all service providers working with people and their families, and respects the wishes of people in relation to their treatment and care.

The WHO defines palliative care as [1]:
- an approach that improves the quality of life of people and their families facing the problems associated with life-limiting or lifethreatening conditions, through the prevention and relief of suffering by means of:
  - early identification
  - impeccable assessment
  - treatment of pain and other problems:
    - physical
    - psychosocial
    - spiritual

Palliative care:
- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of a person's care
- offers a support system to help people live actively as possible until death
- offers a support system to help the family cope during the person's illness and in their own bereavement
- uses a team approach to address the needs of people and their families, including bereavement counselling, if indicated
- 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

A New Zealand specific definition of palliative care is [2]:
Care for people of all ages with a life-limiting or life-threatening condition which aims to:
- optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs
- support the individual's family, whaanau, and other caregivers where needed, through the illness and after death
Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable sometimes when treatments are being given aimed at improving quantity of life:
- it should be available wherever the person may be
- it should be provided by all health care professionals, supported where necessary, by specialist palliative care services
- palliative care should be provided in such a way as to meet the unique needs of individuals from particular communities or groups. These include Maaori, children and young people, immigrants, refugees, and those in isolated communities

End of life:
The end of life phase begins when a judgement is made that death is imminent. It may be the judgement of the health/social care professional or team responsible for the care of the individual, but it is often the person or family who first recognises its beginning.

Considerations for people who would benefit from a palliative approach who also have learning disabilities:
- remember that even people with a mild learning disability may understand language in a literal, non-euphemistic manner and therefore anything that is communicated should take account of this
• avoid the use of abstract language in discussions about palliative care approach, e.g. talk about ‘dying’ rather than ‘passing away’
• as the person’s ability to concentrate may be impaired it is better to have a number of short, single-focus conversations rather than try to communicate everything in one session - give the time needed to help the person understand
• take into account the environment in which discussions about a palliative care approach are to be held
• work within mental capacity legislation - to assert the rights of the individual to make important decisions whilst expressing empathy and understanding for the concerns of the family
For references see Provenance Certificate.

2 Information resources for patients and carers

Quick info:
Recommended resources for patients and carers:
• A Guide for Carers
• Home Nursing Tips
• Coping Tool for Caregivers
• Oral Care for Someone who is Dying
• When Death is near: things to know and do
• What to Expect When Someone is Dying
• Talking about dying - child focussed
• Coping with Bereavement
• Advance Care Planning
• Enduring Power of Attorney (Ministry of Social Development)
• Enduring Power of Attorney (Law Access)

Te Ara Whaanau Ora:
• Te Ara Whaanau Ora Brochure

3 Updates to this care map

Quick info:
Date of publication: March 2015
Please see the care map’s Provenance for additional information on references, accreditations from national clinical bodies, contributors, publication schedule, and the editorial methodology.

4 Hauora Maaori

Quick info:
Maaori are a diverse people and whilst there is no single Maaori identity, it is vital practitioners offer culturally appropriate care when working with Maaori whaanau. It is important for practitioners to have a baseline understanding of the issues surrounding Maaori health. This knowledge can be actualised by (not in any order of priority):
• acknowledging Te Whare Tapa Wha (Maaori model of health) when working with Maaori whaanau
• asking Maaori clients if they would like their whaanau or significant others to be involved in assessment and treatment
• asking Maaori clients about any particular cultural beliefs they or their whaanau have that might impact on assessment and treatment of the particular health issue (see Cultural issues)
• consider the importance of whaangauntanga (making meaningful connections) with their Maaori client / whaanau
• knowledge of Whaanau Ora, Te Ara Whaanau Ora and referring to Whaanau Ora Navigators where appropriate
• having a historical overview of legislation that has impacted on Maaori well-being
For more information about Hauora Maaori, click here for a list of local Maaori Health Providers Central PHO Maaori Health website.
5 Pasifika

Quick info:
Click here to download the Pacific Cultural Guidelines (Central PHO) 6MB file. Our Pasifika community:

- is a diverse and dynamic population
- more than 22 nations represented in New Zealand
- each with their own unique culture, language, history, and health status
- share many similarities which we have shared with you here in order to help you work with Pasifika patients more effectively

The main Pacific nations in New Zealand are:
- Samoa, Cook Islands, Fiji, Tonga, Niue, Tokelau and Tuvalu

Acknowledging The FonoFale Model (pasifika model of health) when working with Pasifika peoples and families. Acknowledging general pacific guidelines when working with Pasifika peoples and families:

- Cultural protocols and greetings
- Building relationships with your pasifika patients
- Involving family support, involving religion, during assessments and in the hospital
- Home visits
- Contact information

Pasifika Health Service - Better Health for Pasifika Communities
- the Pasifika Health Service is a service provided free of charge for:
  - all Pasifika people living in Manawatu, Horowhenua, Tararua and Otaki who have long term conditions
  - all Pasifika mothers and children aged 0-5 years
- an appointment can be made by the patient, doctor or nurse
- the Pasifika Health Service contact details are:
  - Palmerston North Office - 06 354 9107
  - Horowhenua Office - 06 367 6433
- for more information, please refer to the Better Health for Pasifika Communities brochure

Additional information:
- Ala Mo'ui - Pathways to Pacific Health and Wellbeing 2010-2014
- Primary care for pacific people: a pacific health systems approach
- Tupu Ola Moui: The Pacific Health Chart Book 2004
- Pacific Health resources
- Click here for a list of local Maori/Pacific Health Providers
- Central PHO Pacific Health website

6 Assessment

Quick info:

Accurate assessment ensures appropriate management:

- accurate and meticulous assessment is essential
- assess and address physical and non-physical symptoms – a holistic approach is required
- difficult to control symptoms may require several different approaches
- aim for highest possible quality of life
- use risk vs benefit assessments when side-effects of therapy occur
- listening to the person's story and language used assists assessment
- explain issues as much as possible to the person, family/whanaau and carers
- use a multidisciplinary approach
- assess and reassess continuously
7 Physical including nutrition and hydration

Quick info:

**Physical:**
Most commonly experienced physical symptoms for those with advanced disease are:
- pain:
  - there are different types of pain and many people have more than one
- fatigue
- anorexia and weight loss
- anxiety
- dyspnoea
- nausea and vomiting
- change in bowel habits including constipation

Most people experience a combination of these symptoms which may change rapidly and require regular reassessments. Functional ability may change with deteriorating condition.

Assessment tools aid objectivity and lead to accurate diagnosis and management:
- pain assessment tools

**Nutrition and hydration:**

*NB: There are no designated tools to guide the use of nutrition and hydration at the end of life.*

Consider benefits, burdens and risks of providing clinically assisted nutrition and hydration. This will be influenced by the prognosis, the best interest of the patient, and the views of the person and/or Enduring Power of Attorney (EPOA).

The guidance for health professionals is that people are supported with oral hydration and nutrition unless there is a strong reason not to do so.

Treatment and care towards the end of life: [good practice in decision making](#).

Useful guidance includes 'Meeting patients nutritional and hydration needs' page 52 and 'Decision making models' page 14.

For those people in the last hours to days of life, The independent review of the Liverpool Care Pathway document (2013) identifies pertinent aspects related to this issue (pages 26-28).

8 Psychological and social

Quick info:

**Psychological:**
- assess psychological effects on:
  - mood
  - anxiety
  - relationship
- listen to the person's story and language used.
- use validated assessment tools to assess psychological distress including anxiety and depression:
  - assessment of psychological symptoms

The person and their family/whaanau are the unit of care. Relationships with others are significant at end of life and there may be many changes in roles within relationships due to progressive illness.

**Social**

Assessment of social effects on:
- family and whaanau:
  - referral to Whaanau Ora Navigator may be appropriate:
- Palmerston North, Manawatu, Tararua:
  - Te Tihi o Ruahine Whaanau Ora Alliance - Miriama Kereama - 021 499 298 or (06) 357 3400
- Otaki, Levin, Horowhenua:
  - Te Runanga o Raukawa (06) 368 8678, Muauopoko Tribal Authority (06) 367 3311
  - carers:
• see 'carer assessment' node
• social interaction
• employment and financial status:
  • a person with advanced disease may have had to stop work and a change in family income can be extremely stressful
  • a social worker referral may be required to assist and navigate to access maximum support and entitlements:
    • phone: (06) 350 8320
    • fax: (06) 350 8122
    • postal: Central Referral Management Rehabilitation Service, Palmerston North Hospital, Private Bag 11036, Palmerston North
• sexuality

9 Spiritual and cultural

Quick info:
Assess spiritual and cultural needs:
• persons feeling of self worth and identity
• need for hope
• cultural/spiritual attitudes towards:
  • disease
  • suffering
  • dying
  • death
Some useful prompts:
• what can we do now to help you and those people important to you to feel safe and comfortable
• do you have beliefs and family traditions that are especially important to you?
• what are the important things about you and your whaanau/family that we need to know right now?

To assist in the assessment of a patient's spiritual needs a series of questions follows below.
Each question has the potential for exploring a particular aspect of a patients spirituality:
• what are the things in life that give you strength and sustain you?
• what keeps you going each day?
• what is helping you get through this present crisis?
• how has your illness affected your attitude to life?
• how do you express your philosophy of life?
• do you belong to any specific religion, faith or community?
• is God, religion or any other spiritual belief significant to you?
• are your beliefs being challenged by your current experiences?
• is prayer, scripture, music, meditation or reading helpful?
• what does suffering mean to you?
• have you been with anyone else going through the same thing/dying?
  • how was it for them?
  • is here anything about what happened to them that worries you?

10 Environmental

Quick info:
Assess environmental needs:
• quality of environment has a direct effect on peoples experience of care
Consider living conditions:
11 Confirm Advance Care Plan and Enduring Power of Attorney

Quick info:
Confirm:
- confirm the following discussions have taken place and appropriate documentation completed:
  - Advance Care Planning
  - Enduring Power of Attorney (Ministry of Social Development)
  - Enduring Power of Attorney (Law Access)

Communicate and explain:
- do not resuscitate decisions where appropriate with due respect for confidentiality with the person's family/whaanau, other carers, or other representatives

Ensure read codes have been entered.

12 Carer assessment

Quick info:
Carers are:
- the family, whaanau or friends who have the role and responsibility of assisting in the care of the person with palliative care need
- frequently untrained and unpaid

Caregiving for a person at end of life requires:
- knowledge
- time
- skill

It is important to ask carers how they are managing and whether they need extra support. Support could include:
- information
- practical skills training (turning, medication management)
- emotional support for themselves

Asking open ended questions with carers is useful e.g:
- what concerns do you have about caring for ....?
- how are you caring for yourself?
- how are you sleeping?

13 Carer support
Quick info:

Give carer information as condition worsens.
Refer to Palliative Care - Services Pathway for information on support available for carers.

14 Identification of level of palliative care need

Quick info:

**Identifying the level of palliative care need:**
- is not based on exact time lines but on the needs of that person and their family
- will change over time with the different disease trajectories
- earlier recognition of possible illness trajectories means needs can be better anticipated and addressed

**Early palliative care:**
- a person may be recognised as having a life limiting illness however may have stable symptoms and have months or years to live

**Increasing palliative care need/increased symptom burden:**
- palliative care need may be increasing and symptoms may be changing frequently requiring frequent reassessment and change in management
- prognostic timeframe may be estimated to be within weeks or approximately up to 6 months

**End of life care/last days of life care:**
- prognosis estimated to be within hours or days
- symptoms can change frequently in the last hours and days of life

15 End of life care / last days of life care

Quick info:

**End of life care/last days of life care: care planning and management:**
- each person recognised as dying should receive coordinated care in accordance with their care plan, across sectors including out of hours
- the lead provider is the General Practice Team in collaboration with Specialist Services and Specialist Palliative Care Services as required
- communicate between all healthcare workers and organisations involved in the persons care in a timely manner

16 Increasing palliative care need/increased symptom burden

Quick info:

Increasing palliative care need/increased symptom burden: care planning and management:
- each person should receive coordinated care in accordance with their care plan, across sectors including after hours
- the lead provider is the General Practice Team in collaboration with Specialist Services and Specialist Palliative Care Services when required
- General Practice Teams may consider referral to Specialist Palliative Care Services if required (see Arohanui Hospice Referral Form)
- communicate between all healthcare workers and organisations involved in the persons care in a timely manner

17 Early palliative care: care planning and management

Quick info:

**Early palliative care: care planning and management:**
- each person should receive coordinated care in accordance with their care plan, across sectors
- the lead provider is the General Practice Team in collaboration with Specialist Services
• communicate between all healthcare workers and organisations involved in the persons care in a timely manner

18 Management and reassessment of symptoms: Increasing

Quick info:
Address and manage symptoms as assessed:
• increasing disease burden can often result in escalating or new symptoms
• re-assessment/review may be indicated to ensure current management is effective, and any new symptoms are identified and managed
• ongoing communication with other services remains very important so care remains well coordinated
• refer to:
  • Palliative Care Symptom Management - Community
  • Drug information for Palliative Care
  • Syringe Driver Management in Palliative Care
• for symptoms that are becoming more difficult to manage and/or requiring frequent review a referral to Arohanui Hospice maybe appropriate. Please discuss with the Arohanui Hospice Team (06) 356 6606

19 Management and reassessment of symptoms: Early

Quick info:
Address and manage symptoms as assessed:
• earlier in the trajectory other services, including secondary care specialists such as medical and radiation oncology, and Arohanui Hospice, may be involved and contribute to the persons symptom control management
• communication between all the services and with the General Practice is vital so care is well coordinated
• refer to:
  • Palliative Care Symptom Management - Community
  • Drug information for Palliative Care
  • Syringe Driver Management in Palliative Care
• for symptoms that maybe more difficult to manage a referral to Arohanui Hospice maybe indicated. Please discuss with the Arohanui Hospice Team (06) 356 6606

20 Anticipatory medication

Quick info:
Supply anticipatory medication as needed:
• symptoms can change rapidly and require frequent assessment
• anticipatory prescribing ensures responsiveness for changing needs particularly for after hours
• when prescribing anticipatory medication consider:
  • route of administration
  • afterhours access of medication
  • who is to administer medication
• refer to:
  • Drug information for Palliative Care
  • Syringe Driver Management in Palliative Care
• consider referral to District Nursing for after hours management of unstable symptoms
• after hours plan needs to be completed and known to all involved in care see:
  • individualised after hours care plan
  • individualised after hours care plan - example
21 Review persons wishes, goals and plan of care

Quick info:
If discussions have been had, review documentation and update status to ensure patient’s wishes and goals are well known:

- advance care planning:
  - work through the plan or review
- advanced directives:
  - advise and refer on to appropriate person to achieve this or review
- enduring power of attorney (EPOA):
  - achieved or enacted/review
- will:
  - achieved and where it is held and review
- Internal Cardiac Defibrillator (ICD):
  - discussions around deactivation of this device may occur early (see End of Life Management of Implantable Defibrillators)
- conversations:
  - document all relevant conversation as to patients wishes and goals, update and review at each visit and/or regularly

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23 Information for person/family: Early

Quick info:
Ensure person and family have palliative care information including written information:

- Coping Tool for Caregivers

For further information see:

- ‘Information resources for patients and carers’ node

24 Information for person/family: Increasing need

Quick info:
Ensure person and family have palliative care information including written information:

- Home Nursing Tips
25 Discuss and document after hours care plan

Quick info:
GP team or normal after hours arrangement.
Care plan should include:
  • main contacts with specified times of availability
Ensure after hours care plan has been given to person's family/whaanau and sent to those involved in care:
  • individualised after hours care plan
  • individualised after hours care plan-example
An action plan regarding management of specific symptoms may have been developed by a health professional involved in care.
Key Dates

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