Te Ara Whakapiri: Principles and guidance for the last days of life 2017

What now?

From LCP to Te Ara Whakapiri

The long and winding road!

Session format

- Background to Te Ara Whakapiri
- Last Days of Life Working Party
  - *Principles and guidance for the last days of life* (Dec 2015)
  - *The Toolkit* and the revised principles and guidance (April 2017)
- Guiding vision and aims behind the *The Toolkit*
  - Quick tour of some of the contents
- Next steps
  - Ideas and aspirations
  - Challenges

History

- December 2013, Palliative Care Council (via Cancer Control New Zealand) was commissioned by the Don Mackie, Chief Medical Officer, Ministry of Health, to develop a *"consensus on a national approach for the care of patients in their last days of life in New Zealand"*
- 'Last Days of Life Working Group' established
  - Independent Review in UK analysed to assess relevance to NZ models of care, including the Liverpool Care Pathway
  - Stocktake of services and literature review of evidence and best practice
  - Survey of family / whānau

Survey findings

Barriers to communication (hospital);

“I did not know what ‘palliative care’ meant at the time. A doctor told me “we are offering palliative care now”. I thought it was a different type of medicine they were offering to make my Uncle well again, so it was a huge shock when he died.”

Place of death

“It was important for our mum to be surrounded by her whānau and mokopuna. But at the same time she didn't want to be a burden. She had been in and out of hospital but grieved for the sounds of her mokopuna playing in the background which for her gave her a sense of belonging and normality even though she was very unwell. Further, the whānau needed time to prepare for a pending death. this time with our mum sort of enabled that. She was also able to have access to constant karakia, waiata, and laughter. laughter is very healing for the spirit.” (home)

Experience after death

"When I saw him after he died I was amazed by the peacefulness and how they had cared for him (rest home staff). This was a huge help to me. I felt that he was my dad again. I did not expect this to be the case and this will be my lasting impression. I am very grateful for this." (aged residential care)

Salutary reminder…

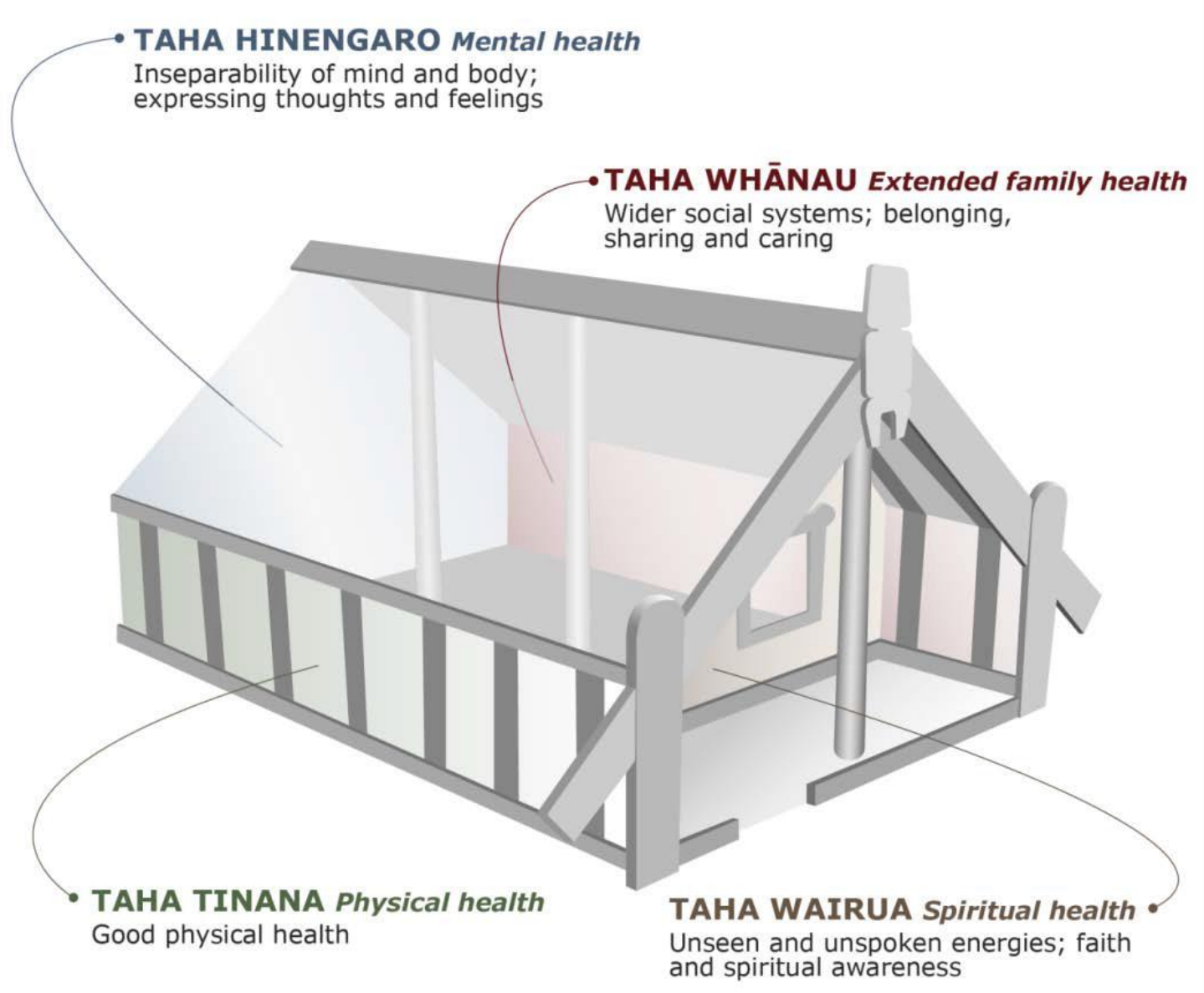
"Listen to the patient, and if the patient is unable to communicate then listen to the family/carers of the patient"

Te Ara Whakapiri - *the unifying path*

Published December 2015

Te Ara Whakapiri focuses care on what matters most

- Provision of person-centred and dignified care
- Clear and compassionate communication
- Attention to cultural and spiritual needs
- Attention to detail on symptom management
- Supporting the family/whānau
- Care after death



Te Whare Tapa Whā model of care supports the principles of care (Durie 1985)

3 components to care

1. A comprehensive **baseline assessment** involves identifying the lead practitioner, assessing clinical needs, sensitive and open communication, and clear documentation.
2. **Ongoing assessment** emphasises the importance of developing individualised care plans.
3. **After death care** includes verification of death and the need of the family/whānau for information and privacy.

Each of these is addressed from the perspectives of;

- the person who is dying and their family/whānau
- the health professional(s) providing care
- the specific clinical service or health care organisation (primary palliative care provider and/or specialist palliative care service)
- the wider health system

Seven overarching principles

1. Care is patient-centred and holistic.
2. The health care workforce is appropriately educated and is supported by clinical champions.
3. Communication is clear and respectful.
4. Services are integrated.
5. Services are sustainable.
6. Services are nationally driven and supported to reduce variation and enhance flexibility.
7. Resources and equipment are consistently accessible.

Development of *The Toolkit*

- Working group re-convened with extended membership
  - ARC, rural hospital, hospital physicians, Māori Health Provider, health care assistant and consumer
- 4 subgroups
  - Initial (baseline) assessment
  - Symptom management guidelines and flowcharts (algorithms)
  - “Observation” chart
  - Care after death documentation

Aims

- Concise
- Readable
- True to the NZ environment (and the seven principles of TAW)
- Applicable across all health care settings
- Appropriate for the non-specialist workforce to initiate and use
- Focussed on outcomes

The toolkit

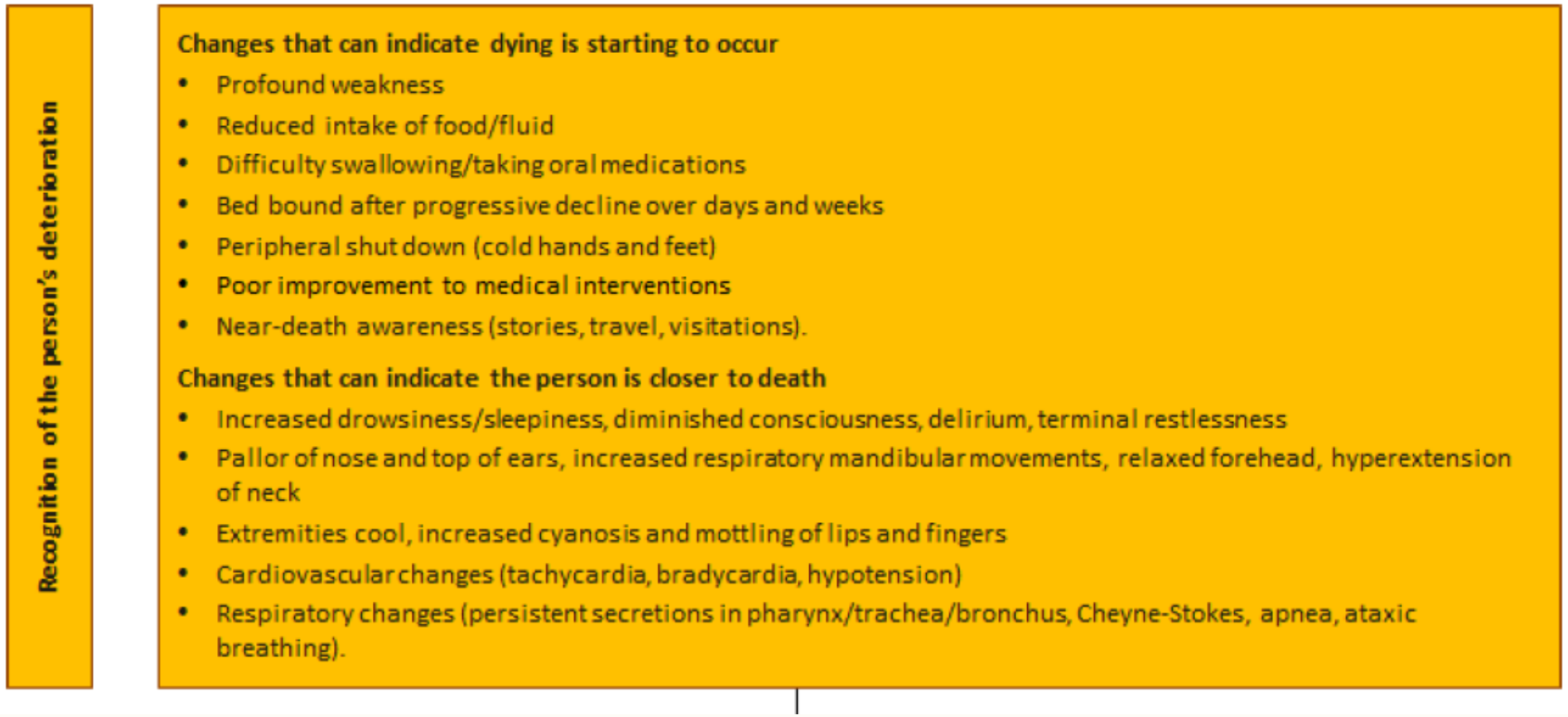
Fixed (apart from local logo)

- ***Care in the last days of life*** - Baseline assessment and care after death (4 pages)
- ***Ongoing care of dying person -*** 2 page “observation chart”
- ***Home care in the last days of life -*** 2 page “observation chart”
- ***Recognising the dying person flowchart***
- ***Medical management planning - general principles***

Localisable

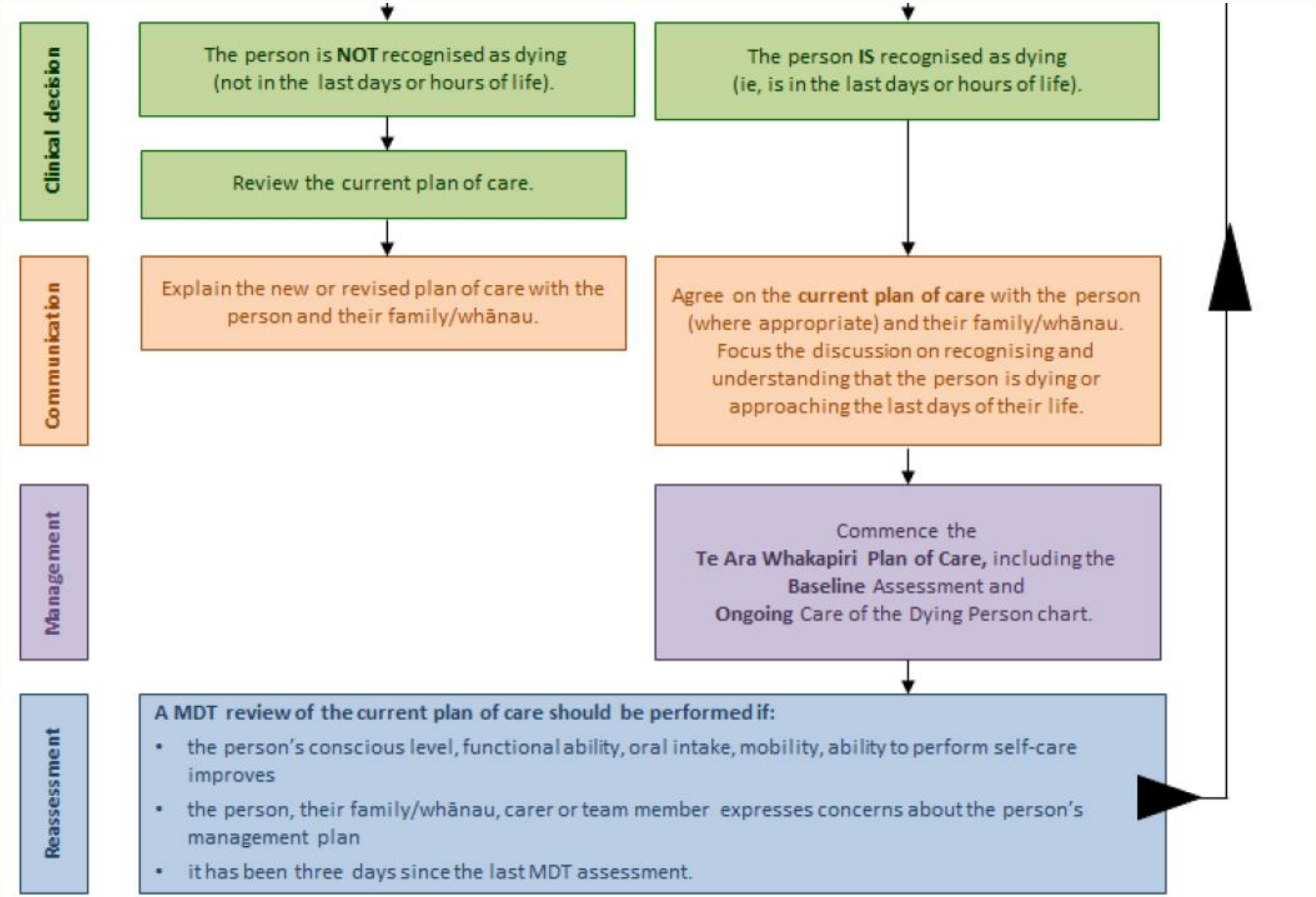
- ***Staff signature sheet***
- ***Bereavement risk assessment tool (BRAT)***
- ***Discharge checklist***
- ***Symptom management guidelines*** (incorporating symptom flowcharts)
- ***When death approaches*** (family/whānau pamphlet)
- ***Dying at home*** (family/whānau pamphlet)

Recognising the dying person flow chart



About getting everyone on the same page…

..often the biggest challenge



Te Ara Whakapiri – Recognising the dying person flow chart

Localise headers and footers

MINISTRY OF HEALTH
MANATŪ HAUORA

Nurse Maude
HOSPICE

Patient name:
NHI:
DoB:

Staff signature sheet

Te Ara Whakapiri – Medical management planning: general principles

Southern District Health Board
Piki Te Ora

When death occurs

The person will be unresponsive and not breathing, there will be no visible pulse or heartbeat and the facial muscles will relax, with the mouth and eyes falling open slightly.

What to do:

- There is no rush to do anything immediately. You may wish to spend time with the person.
- It is helpful to note the time of death.
- Contact your nurse. If death occurs during the night, then it is OK to wait until the morning.
- The person's GP must visit to confirm a death at home and write a death certificate.
- Most people contact a funeral director (through the Yellow Pages or an internet).
- There may be many people to notify. Consider delegating this task to family (whānau) or friends.

When Death Approaches

MINISTRY OF HEALTH
MANATŪ HAUORA

Canterbury District Health Board
Te Poari Hauora ō Waitaha

Patient name:
NHI:
DoB:

Care in the last days of life

Baseline assessment

Recognition that the person is dying or is approaching the last days of life

Is the *Recognising the Dying Person Flow Chart* available to support decision-making? Yes ☐

Diagnosis: ..... Ethnicity: .....

Lead practitioner name: ..... Designation: .....

Lead practitioner's contact no: ..... After-hours contact no: .....

Note: The lead practitioner is the person's GP, hospital specialist or nurse practitioner.

The person's awareness of their changing condition

Is the person aware they may be entering the last few days of life? Yes ☐ No ☐

The family/whānau's awareness of the person's changing condition

Is the family/whānau aware that the person may be entering the last few days of life? Yes ☐ No ☐

Family/whānau contact

If the person's condition changes, who should be contacted first? Name: .....

Relationship to person: ..... Phone (H): ..... (Mob): .....

When to contact: At any time ☐ Not at night-time ☐ Staying overnight ☐

Is an enduring power of attorney in place? Yes ☐ No ☐

Has it been activated? Yes ☐ No ☐ N/A ☐

Advice to relevant agencies of the person's deterioration

Has the GP practice been contacted if they are unaware the person is dying? (If out of hours, contact next working day.) Yes ☐ No ☐ N/A ☐

Note: Consider notifying the person's specialist teams, district nursing services, residential care and other agencies involved in their care.

Has this assessment been discussed with the person and family/whānau and priorities of care been identified? Yes ☐ No ☐

If not, discuss reasons: .....

Baseline assessment and a section on care after death

Completed together by nursing AND medical staff

Prompts charting of anticipatory medications and review of resus status, fluids, treatments/ interventions and cardiac devices

Covers physical health PLUS psychological, spiritual and family health

Ongoing care of the dying person

Use the ACE coding below, initial each entry and record details in the progress notes. Seek a second opinion or specialist palliative care support as needed.

A C E codes:	A = Achieved No additional intervention required	C = Change Intervention required and documented	E = Escalate Medical or senior nurse review required and documented

Domains and goals	Date	/ /						/ /					
	Time												
Te taha tinana – *Physical health*													
Pain The person is pain free at rest and during any movement.													
Agitation/delirium/restlessness The person is not agitated or restless and does not display signs of agitated delirium or terminal anguish.													
Respiratory tract secretions The person is not troubled by excessive secretions.													
Nausea and vomiting The person is not nauseous or vomiting.													
Breathlessness/dyspnoea The person is not distressed by their breathing.													
Other symptoms (document fully in clinical notes) The person is free of other distressing symptoms, eg, myoclonic jerks, itching.													
Mouth care The person's mouth is moist and clean.													
Nurse initials each set of entries													

Replaces the assessment/obs chart (double-sided)

Physical, psychological, spiritual & family health

4hrly review of symptoms, others reviewed once/shift

<u>**ACE** codes show priority</u>
A = Green (achieved/absent)
C = Orange (a change has been required but issue is under control)
E = Red (escalate – needs medical review or a change in plan)

Home care in the last days of life

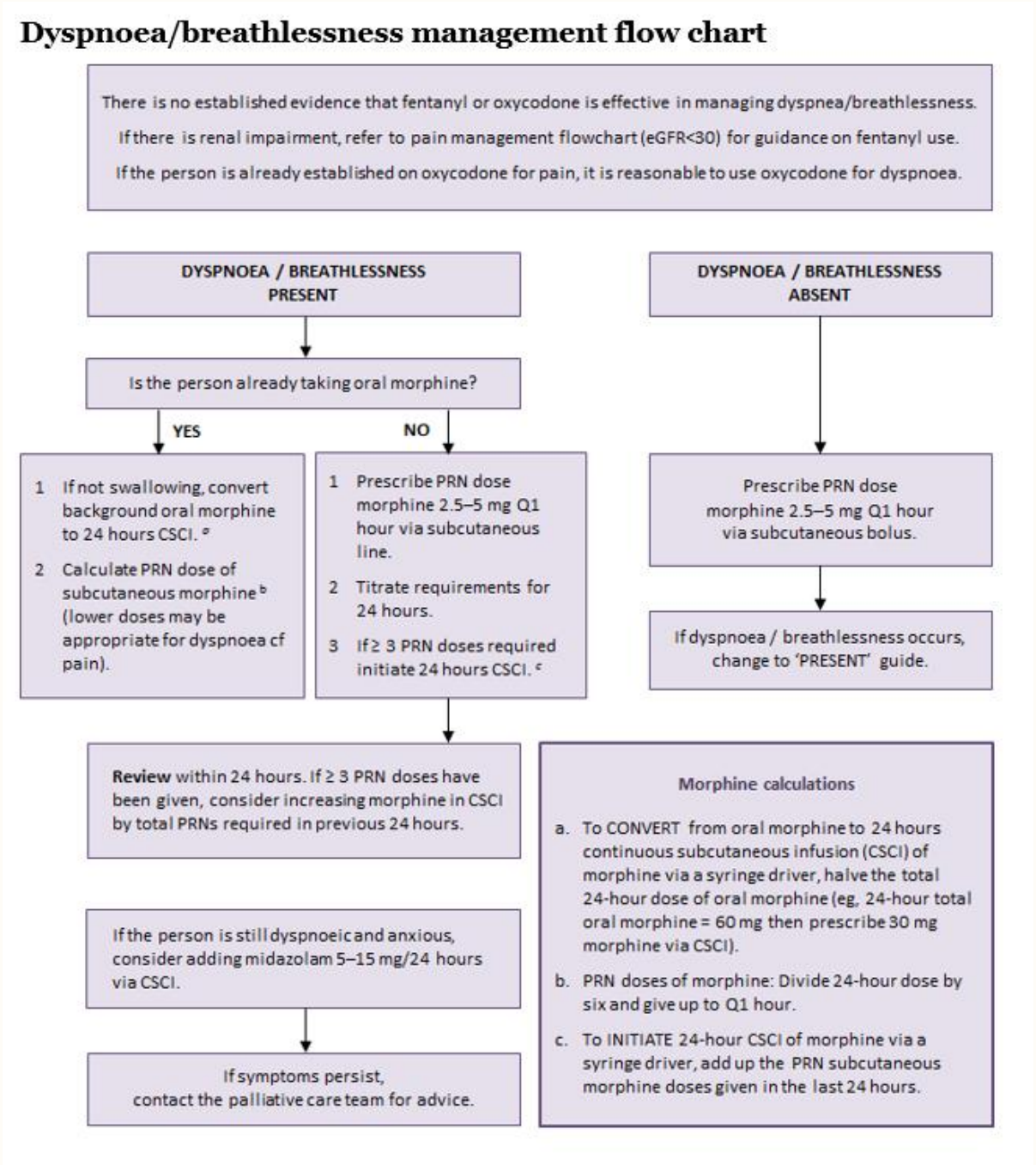
Complete at least once a day with the help of your nurse or doctor if needed.
Use the ACE codes in the boxes. Health professionals initial entries at the end of this care plan.

A C E codes:	A = All good Issue is being managed well or is not a problem	C = Change of care made Have needed to make a change to care but everything is under control	E = Extra help requested Treatment is not working and is causing concern

Domains and goals	Date	/ /	/ /	/ /	/ /
	Time				
Te taha tinana – *Physical health*					
Pain The person is comfortable when resting and during any movement. They have told you if they can that they are not sore, achy or in pain.					
Restless, muddled or agitated You think the person is settled and not confused or distressed.					
Noisy breathing The person is breathing comfortably and is not making noises that they or you find upsetting.					
Nausea and vomiting The person tells you that they are not feeling queasy or want to be sick. They have not vomited.					

Careful use of language..

..designed for family to use if they wish



5 symptom flowcharts

1a. Pain
1b. Pain with severe renal impairment
2. Agitation / delirium/ restlessness
3. Nausea/vomiting
4. Excess respiratory tract secretions
5. Dyspnoea

April 2017

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http://www.health.govt.nz/publication/te-ara-whakapiri-principles-and-guidance-last-days-life

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MANATŪ HAUORA

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Te Ara Whakapiri: Principles and guidance for the last days of life

Published online: 12 April 2017

Te Ara Whakapiri: Principles and guidance for the last days of life outlines the essential components and considerations required to promote quality care at the end of life for all adults in New Zealand. It also provides examples of useful approaches and tools that will serve as aids for the development of national and/or local resources as part of implementation.

The guidance document is based on an extensive evaluation of the available literature and is informed by local research. This ensures it is applicable to the unique context that is Aotearoa New Zealand.

Downloads

- Te Ara Whakapiri: Principles and guidance for the last days of life (pdf, 914 KB)
- Te Ara Whakapiri: Principles and guidance for the last days of life (docx, 418 KB)
- Te Ara Whakapiri: Toolkit (docx, 522 KB)
- Te Ara Whakapiri: Toolkit (pdf, 906 KB)
- Ongoing care of the dying person (pdf, 181 KB)

Have we delivered?

- Only time will tell!
- Many positive features
  - True to the NZ environment
  - Feels like a step forward, whilst honouring what went before
  - Succinct, localisable, flexible, visual
  - Positive and supportive language

Power of language

Don’t shy away from *“Te Ara Whakapiri”*

- What does the phrase mean to you and how will you explain its purpose and its value?
  - *To staff*
  - *To patients*
  - *To whānau*
- More holistic and respectful than an acronym

Implementation tips

- Use whichever components work for your setting and implement incrementally
- Insert logo in header and local name in footer
- Patient/whānau information can be used *as is* or inserted into local templates
- The BRAT can be modified according to local circumstances OR used as a conversation starter about how bereavement services are coordinated locally and across settings
- NOTE: full documentation is still required in the clinical record/EMR

Next steps

- The BIGGEST challenge is implementation, without any new resources (yet)
- Hospice NZ are partnering with the MOH and other leaders to promote integration and socialisation across the health sector
- Dying happens everywhere and quality care cannot be reliant on specialists being there all the time
  - Need to find creative opportunities within existing systems
  - This is about everyone having a role, not just specialists

Role of specialist palliative care services

- Get the message out there
- Talk to people at the top (resources can be shifted to areas of need)
- Harness, support and nurture local champions (they are everywhere)
- Empower and support these champions to take the lead (with you there for guidance)
- Find out about and use local programmes (e.g. RT2C)
- *If care at the end of life is done well, for everyone, it's likely that palliative care in general will be valued and supported*

A proposed “to-do” list

- The development of a standardised audit tool
- The development of resources such as…
  - PowerPoint presentations on how to get started
  - A “Guide to use” on how to complete the documentation
  - Education packages such as inclusion in the HNZ Fundamentals of Palliative Care teaching packages, e-learning modules such as via HealthLearn or Ko Awatea etc
- A dedicated web area where the tools can be housed and where other resources that are been used around the country can be shared
- Others??

Feedback

- Use it, share it and tell us how it’s going
- We want to hear about any problems or potential improvements
- We also want to hear about all the successes (*to shamelessly steal/share other peoples ideas!)*
- If you are staying with an alternative programme, keep an eye on what’s happening with TAW as the ultimate aim is consistency wherever possible

Questions?