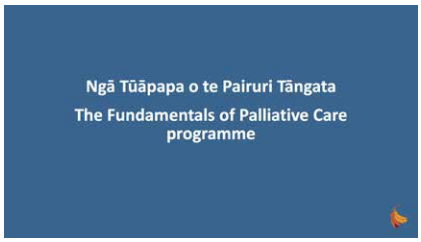
Ngā Tūāpapa o te Pairuri Tāngata

Fundamentals of Palliative Care

FACILITATORS NOTES

SLIDE 1



Managing Pain and Long-term Illness

WORKSHOP

SLIDE 2



Welcome and introductions section – approx. 25 mins (4 slides)

Welcome the participants as they settle in.

If this is the participants' first workshop in the Fundamentals programme, welcome them with a karakia or pepeha.

Karakia

Kia hora te marino
Kia whakapapa pounamu te moana
Kia tere te kārohirohi
I mua i tōu huarahi
Ara nei ake tonu atu.

May calm be widespread
May the sea glisten like greenstone
May the shimmer of sunlight guide your pathway of life
Now and always.

Otherwise, welcome them and introduce yourself.

You might want to consider greetings in other languages depending on your participants.

SLIDE 3



Before getting started, cover the following.

Involvement in the workshop

- Talk about how everyone should honour other cultures, and respect the different perspectives everyone brings to the session
- Encourage everyone to get involved in the workshop
- Talk about phone use

Self care

- Toilets
- Drinks
- Acknowledge that the content covered can be difficult so if anyone needs to leave or have a break at any point they are welcome to. Explain that this workshop will talk about death and dying and might trigger memories that cause emotional distress. Reinforce that they can leave at any point of the workshop if they start to feel upset

Emergency plans

- Fire and earthquakes
- Assembly points

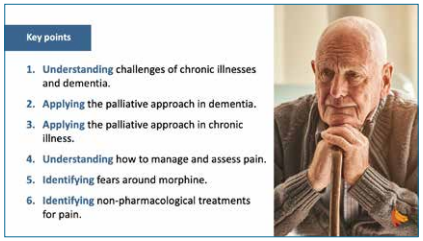
SLIDE 4



Ask the participants to introduce themselves with:

- their name
- the workplace they work at
- a short explanation of their journey into this role.

SLIDE 5



Introduce the topic.

Explain that these are the key points that you will focus on in today's workshop.

Note:

There is a pharmacology session (with accompanying PowerPoint) that can be delivered after this session, or as a separate session with registered nurses and anyone else interested in the topic. It addresses the learning outcome:

- demonstrate an understanding of the common medications used for pain and symptom management.

SLIDE 6



Challenges of chronic illnesses and dementia section – approx. 15 mins (1 slide)

Remind participants that they were introduced to the chronic illness and frailty trajectories in the online learning, and that they were asked to reflect on the challenges and dilemmas caring for people with chronic illnesses and dementia.

Key points

- It can be difficult to diagnose dying
- In the late stages of both chronic illness and dementia medical and social needs can be complex.
- Care requires a collaborative effort from primary, aged, palliative and dementia care services.

Suggested approach (Aim for 20 mins of brainstorming and discussion)

As a group, brainstorm and discuss the challenges and dilemmas the participants have come across.

Examples could include:

- Difficulty assessing pain and other symptoms in dementia
- Strain on family – often over years
- Constant loss as the person slowly deteriorates and loses independence and memories
- Making decisions about care
- Difficult communication
- Unpredictable disease trajectory – uncertain prognosis
- Often periods of acute illness then improvement
- Sometimes die suddenly
- Sometimes recover from dying
- May have multiple co-morbidities
- Often lose independence long before death
- Simple tasks can be very challenging
- Eating problems
- Concerns about using opioids for non-malignant disease

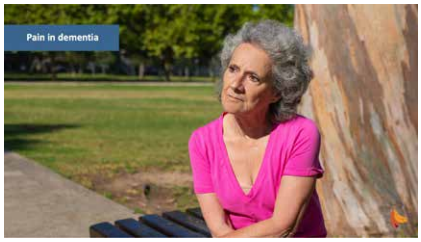
SLIDE 7



Applying the palliative approach in dementia section – approx. 30 mins (3 slides)

Explain that building on what they learnt in the online learning, the participants will learn how to apply the palliative approach to dementia.

SLIDE 8



Key points

- Recognising pain in late-stage dementia can be difficult.
- Studies have shown that pain is often undertreated in dementia.
- Remind the participants of pain assessment tools specifically for dementia:
- Abbey Pain Scale (http://www.wales.nhs.uk/sitesplus/documents/862/foi-286f-13.pdf)
- Pain Assessment IN Advanced Dementia (PAINAD) (https://geriatricpain.org/painad)

It is helpful to ask: 'Is this behaviour or sign new?'

It is helpful to ask: 'Is this behaviour or sign associated with known distress?' (for example, agitation during an episode of constipation) – emphasise that this can only be done if behaviour, signs and expressions are regularly documented.

Remember to document the effect of analgesia.

Suggested approach (Aim for 15 mins: 5 mins to set up, 5 mins for group work, 5 mins for discussion)

People with dementia may experience physical pain for the same reasons as everyone else, but are often less able to communicate to their carers that they are in pain.

Split the participants into small groups.

Provide them with the Carol case study.

Ask them to discuss Carol and think about the different ways she could be responding to and communicating that she is in pain.

Bring the group back together to discuss their findings.

Examples could include:

Sounds – groaning during transfer. Can also include crying, screaming, sighing, moaning or grunting.

Facial expression – grimacing, clenched teeth, shut eyes, wide open eyes, frowning, biting lower lip or looking sad or angry

Actions – clenching fists, pushing caregivers away or grabbing their arms. Can also include rubbing or holding a painful area, keeping an area still or refusing to move.

Posture – flexing arms. Can also include flinching, head in hands, limping or knees drawn up.

OR

If this is a virtual workshop, split the group up into breakout rooms and share the Carol case study in the chat/message thread. Remember to bring the group back out of their breakout rooms when they have finished their discussion.

SLIDE 9



Key points

Acknowledge that Harry is eating less and has lost weight.

This weight loss can be a normal consequence of advancing dementia.

Early discussions and regular communication with families and whānau help to reduce anxiety and help them understand the process.

It is important to continue offering food and fluids.

Discuss strategies for improving oral intake.

Emphasise that artificial nutrition is generally not recommended for people with dementia as it is associated with harm and does not increase survival.

Suggested approach (Aim for 15 mins: 5 mins to set up, 5 mins for group work, 5 mins for discussion)

Advancing dementia is often associated with a reduced desire to eat and a loss of chewing and swallowing abilities which can be difficult for families to understand.

Split the participants into small groups.

Provide them with the Harry case study

Ask them to think about how they will respond to John's question.

Bring the group back together to discuss their findings and provide feedback on their responses.

OR

If this is a virtual workshop, split the group up into breakout rooms and send them the Harry case study in the chat/message thread. Remember to bring the group back out of their breakout rooms when they've finished their discussion.

SLIDE 10



Applying the palliative approach in chronic illness section – approx. 30 mins (3 slides)

Explain that building on what they learnt in the the online learning, the participants will learn how to apply the palliative approach to chronic illness.

SLIDE 11



Key points

Feel free to share a few of the points below with the group, or ask the group what they know about heart failure and fill in the blanks.

Heart failure occurs when the heart is unable to keep enough blood moving around the body. It does not mean the heart is about to stop, but it does mean that there is a problem with the heart's pumping action.

Heart failure usually develops slowly and gets progressively worse, although it can occur suddenly. It typically begins with the left ventricle, which is the heart's main pumping chamber – the chamber may not fill between beats or have become stiff and unable to squeeze effectively.

Common symptoms in heart failure- breathlessness, fatigue, cough, swelling of the feet, ankles, legs and stomach. People may also experience chest pain, nausesa.

Challenges of the chronic illness trajectory, potentially long and unpredictable.

Refer participants to Heart Foundation NZ and Health Navigator NZ for more information.

Suggested approach (Aim for 15 mins: 5 mins to set up, 5 mins for group work, 5 mins for discussion)

Bring up the Wiremu case study.

Ask the participants the questions on the case study:

Nina is asking what she should expect as Wiremu gets worse. How could you respond?

How will she know when he is dying?

What should she be telling the whānau?

What pharmacological treatments would you consider to assist Wiremu in managing breathlessness and anxiety? Use the Palliative Care Handbook to support your answer.

Use these questions as a base for group discussion.

Refer to the Wiremu help sheet if participants need prompts for the group discussion.

SLIDE 12



Key points

Feel free to share a few of the points below with the group, or ask the group what they know about advanced neurological diseases, such as Multiple Sclerosis, Multi System Atrophy, Huntington's Chorea and Motor Neurone Disease (MND), and fill in the blanks.

Explain that for this case study, you will focus on MND.

MND key points:

MND is an uncommon, but by no means rare, disease.

In New Zealand, over 400 people are living with MND.

MND can affect adults at any age but most people diagnosed with MND are over the age of 40, with the highest incidence occurring between age 50 and 70.

Most people with MND live for 20 to 48 months after symptoms begin. Five to ten percent of people with MND live for 10 years or more.

Each week MND causes the death of two people in New Zealand.

Early symptoms are mild and may include stumbling due to leg muscle weakness, difficulty holding objects due to hand muscle weakness and slurring of speech or swallowing difficulties due to tongue and throat muscle weakness.

Cramps and muscle twitching are also common symptoms.

For some people, the symptoms are widespread from the onset. However, MND usually begins by affecting a single limb or aspect of motor function, becoming more generalised as the disease progresses.

Refer participants to MND Association NZ and the Red Flag MND diagnosis tool for GPs for more information.

Suggested approach (Aim for 15 mins: 5 mins to set up, 5 mins for group work, 5 mins for discussion)

Bring up the Advik case study.

Ask the participants the questions on the case study:

What sort of decisions will Advik and Aesha need to consider as his disease progresses further?

How could Advik and his family be supported?

What pharmacological treatments would you consider to assist Advik with constipation and nausea? Use the Palliative Care Handbook to support your answer.

Use these questions as a base for group discussion.

Refer to the Advik help sheet if participants need prompts for the group discussion.

SLIDE 13



Managing pain – approx. 35 mins (3 slides)

Explain that building on what they learnt in the the online learning, you will look at managing and assessing pain in palliative care.

Key points

The effect of emotion on pain

Knowing the cause of the pain often reduces anxiety

The effect of different past experiences and different pain thresholds

Some types of pain are easier to tolerate

The need for effective pain relief

Suggested approach (Aim for 10 mins)

In the online learning, participants were asked to write about the worst pain they have ever been in and bring it along to the workshop.

Ask participants to share this reflection and ask them to try to remember their thoughts and feelings.

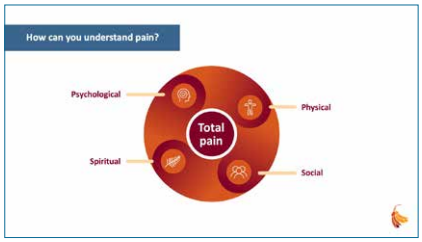
Summarise responses on the whiteboard under two headings: 'Acute' and 'Chronic'. Examples might include back pain, migraine, toothache, childbirth and appendicitis. Thoughts and feelings could include anxiety, stress, irritability and depression.

Ask the participants to call out the types of pain they see in the people they care for.

OR

If this is a virtual workshop, use the same approach as above, except share your screen and type the headings and responses onto a blank word document for learners to see.

SLIDE 14



Remind the participants that they were introduced to the concept of total pain in the online learning.

Key points

The focus of this exercise is to recognise the different dimensions of pain.

The best way to understand pain in palliative care is to see it in its 'total' context.

Suggested approach (Aim for 10 mins: 5 mins for group work, 5 mins for discussion)

Split the participants into small groups. Provide each group with the following documents:

Total pain handout

Judy case study.

Ask the participants to discuss and list the factors they think might be influencing and contributing to Judy's pain under the four key areas of total pain on the diagram.

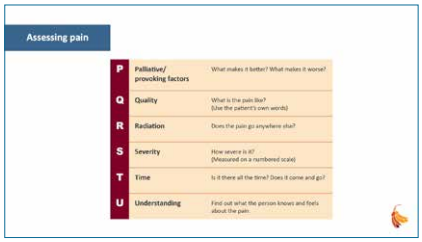
Once they have discussed in their small groups, bring the whole group back together to summarise their findings.

Refer to the 'Total pain answers' sheet to help participants out, if needed.

OR

If this is a virtual workshop, split the small groups up into breakout rooms and share the Total pain handout and Judy case study with them in the chat/message thread. Continue the rest of the approach as above, remembering to bring them back from their breakout rooms once they have completed their discussion.

SLIDE 15



Remind participants that in Essence they learnt the WHO definition of palliative care, and that it talks about 'early identification, correct assessment and treatment of pain and other problems'.

Key points

Ask the person, their family and whānau, their friends and your colleagues.

Look for changes in behaviour or expression, difficulty moving, loss of appetite and withdrawal.

Suggested approach (Aim for 15 mins: 5 mins for discussion, 10 mins for group work)

Have a group discussion around these key questions:

How do we recognise pain in others?

Who might you ask?

What should you look for?

After you have discussed these questions, split the group into pairs.

Provide each pair with the following documents:

PQRSTU tool handout

Judy case study.

Ask them to complete a pain assessment on Judy, answering the questions as best they can on the PQRSTU tool handout.

Answer any questions as they arise.

Refer to the PQRSTU tool answers sheet to help participants out, if needed.

OR

If this is a virtual workshop, break the pairs off into breakout rooms and share the Judy case study and PQRSTU tool handout with them in the chat/message thread. Continue the rest of the approach the same, remembering to bring them back from their breakout rooms once they have completed their discussion.

SLIDE 16



Fears about morphine section – approx. 10 mins (1 slide)

Remind participants that, as part of the online learning, they were asked to reflect on whether they have talked to people and their families and whānau about concerns around morphine. There are many fears about prescribing opioids like morphine – not just among patients and loved ones but also in professional caregivers.

Key points

Fear of addiction

Fear that tolerance will occur, and higher doses will be needed

Fear of side effects

Fear that death is imminent

Suggested approach (Aim for 10 mins)

Have a group discussion around the key points.

Ask what participants' experience has been with these fears.

Talk through each of the fears and how the participants can work with the person and their family and whānau to ease these fears.

SLIDE 17



Non-pharmacological treatment section – approx. 15 mins (1 slide)

Recap with the participants that in palliative care it is almost always necessary to use a combination of treatments to manage pain effectively. Both non-pharmacological and pharmacological treatments are important.

Key points

Supportive talk

Music

Soft lighting

Decreased noise

Heat pack

Massage

Repositioning

Humour and distraction

Spiritual support

Favourite food or drinks

Reminiscing

A walk

Remind registered nurses that they can download the Palliative Care Handbook (https://www.hospice.org.nz/resources/palliative-care-handbook/) for their resource folder.

Suggested approach (Aim for 10 mins: 5 mins of key points, 5 mins of storytelling)

Discuss the key points with the participants and ask if any of them have examples from their practice where they used non-pharmacological approaches.

Provide the participants with the Pain Quiz relevant to their role. They can complete this as a review of their learning.

SLIDE 18



Wrap up section – approx. 20 mins (3 slides)

Recap what you've talked about today.

Key points

It can be difficult to diagnose dying in the late stages of both chronic illness and dementia. Medical and social needs can be complex.

Care requires a collaborative effort from aged, palliative and dementia care services.

People with dementia may experience physical pain for the same reasons as everyone else, but are often less able to communicate to their carers that they are in pain.

Advancing dementia is often associated with a reduced desire to eat and a loss of chewing and swallowing abilities, which can be difficult for loved ones to understand.

It is important to think about the different dimensions of pain.

The best way to understand pain in palliative care is to see it in its 'total' context.

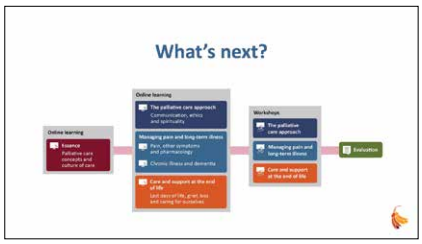
When assessing pain, ask the person, their family and whānau, their friends and your colleagues and look for changes in behaviour or expression, difficulty moving, loss of appetite and withdrawal.

There are many fears about prescribing opioids like morphine – not just among patients and loved ones but also in professional caregivers.

In palliative care, it is almost always necessary to use a combination of treatments to manage pain effectively. Both non-pharmacological and pharmacological treatments are important.

Ask the participants if they have any last questions.

SLIDE 19



Show the learner journey for the ***Fundamentals of Palliative Care*** programme and encourage participants to continue on with it.

Remember: There is a pharmacology session (with accompanying PowerPoint) that can be delivered after this session, or as a separate session with registered nurses and anyone else interested in the topic. It addresses the learning outcome:

Demonstrate an understanding of the common medications used for pain and symptom management.

SLIDE 20



Populate this slide with local specialist palliative care service contact details.

Leave this slide up as the participants pack up and head out.