Ngā Tūāpapa o te Pairuri Tāngata

Fundamentals of Palliative Care

FACILITATORS NOTES

SLIDE 1



The Palliative Care Approach Programme

WORKSHOP

SLIDE 2



Welcome and introductions section – approx. 25 mins (5 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 us

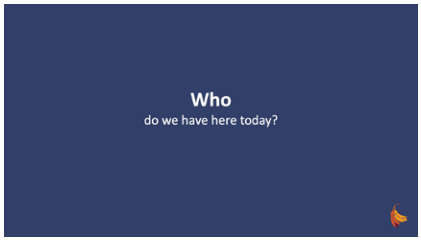
Self care

- 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



Ask the group what Ask the group what they think is important when applying the palliative approach. You can ask them to reflect on what they learnt from the online learning.

SLIDE 6



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

SLIDE 7



Communication section – approx. 40 mins (3 slides)

Explain that you will be looking at communication first today.

Key points

These are the key communication points from the online learning.

- The aim of communication in palliative care is to assess, receive and provide clear and accurate information, reduce uncertainty, build relationships and help the person and their family and whānau know what they need to do next.
- Use the ABCs technique to help you communicate well.
- Use active listening when you are communicating.
- Ask open-ended questions to allow the person and their family and whānau to tell their story and express their needs and fears. This shows them that you are interested in what they have to say.
- No time is too soon to discuss future goals of care with a seriously ill person and their family and whānau.

Suggested approach (aim for 10 mins)

Do a quick recap of the online learning on communication and how it applies to palliative care. Ask the participants questions, for example:

- What was new information for you?
- What did you find interesting?

SLIDE 8



Key points

Introduce that there are barriers to communication, and it is important to understand how to overcome them when talking to a person and their family and whānau.

Suggested approach (Aim for 15 mins: 5 mins for the scenario, 10 mins for the discussion)

Provide the learners with this scenario:

You have gone into a shop and you need some advice about your purchase. The shop assistants ignore you and just keep talking to each other. You are in a hurry to get to work.

(a) What barriers are there to communication?

(b) How do you feel?

(c) What would you do?

(d) Would you go back to the shop?

Remember, the people we care for cannot walk away and are dependent on the people caring for them to communicate well.

SLIDE 9



Suggested approach (Aim for 15 mins: 5 mins to set up, 10 mins for the activity)

The options below all demonstrate how communication can break down and misunderstandings can arise.

Ask participants to write down six words to describe a bed/chair/banana, then get them to compare it with neighbour to illustrate how communication is more than just words. Everyone has different interpretations of things, which are associated with their life experiences.

OR

Play 'secret message' to highlight how everyone has different interpretations of things. Get everyone to stand in a row and whisper a phrase made up of a couple of sentences into the first person's ear. This person then needs to pass this message along the line. When it gets to the last person in the row, ask them to say what they heard. Compare how similar or different this is to what you said to the first person.

OR

If this is a virtual workshop, provide the participants with these images. Have them take it in turns saying the first three words that came to them when they saw the images. Everyone has different interpretations of things, which are associated with their life experiences.

Discussion points

After the activity, discuss these key questions and points with the group.

- Who gives the news to the family when if a person deteriorates or dies unexpectedly?
- How might you do that?
- How do you and the team support the family and whānau – what do you say?
- How comfortable do you feel with this?
- Who informs the care staff?

SLIDE 10



Ethical dilemmas section – approx. 55 mins (7 slides)

Explain that building off what participants learnt in the online learning, you will be focusing on ethical dilemmas today.

Suggested approach (Aim for 10 mins of storytelling)

In the online learning, the participants were asked to consider an ethical situation they have been involved in (either at work or in their personal life).

They were asked to write down their story and bring it along to this workshop.

Ask the participants if any of them would like to share the story they brought along.

If they are reluctant to share, start them off with an experience of your own.

SLIDE 11



Key points

Discuss the key ethical dilemmas that can happen in palliative care and how the participants can best approach them.

- Making ethical decisions is about carefully weighing up the benefits and burdens and trying at all times to honour and value the person.
- When cure is not possible, the balance between benefits and burdens should shift to greater consideration of the potential burdens.
- In palliative care, time is limited, so these discussions need to be considered as early as possible. Some people may have been thinking through what the end of their life will be like for some time as they have lived with chronic illness or undergone cancer treatments, or as they age.
- Talk about developing therapeutic partnerships with the person, their family and whānau, and other team members and strategies to make this happen.
- Remind them that communication is key to developing therapeutic partnerships and managing ethical issues.
- Encourage the participants to document or at least talk to another team member or manager if they observe something that they think is an ethical issue.

Suggested approach (Aim for 45 mins: 5 mins to set up, 15 mins for discussion in three groups, 20 mins discussing the cases, 5 mins to wrap up)

- Split the participants into three groups. Assign each group with a case study. Use the provided case studies (Huiliang, Richard and Sefina) or scenarios from your own experience.
- Have the participants:
  - > identify the issues in the scenario
  - > identify the opposing or competing values
  - > discuss then list the options
  - > if possible, identify an outcome or decision.
- Bring the group back together to discuss what they identified and discussed for their particular ethical dilemma.

Case studies:

Huiliang – symptom management at the end of life.

Richard – making decisions to withhold or withdraw treatment.

Sefina – artificial nutrition and hydration.

OR

If this is a virtual workshop, use the same approach as above but split the groups up into breakout rooms. Before they go to their breakout rooms, share a case study with each group. Check in on each of the groups, then bring them back together.

SLIDE 12



Ask the group who had Huiliang to present back. Check that they cover these points. If they don't cover these key points, raise them.

Key points

Symptom management at the end of life

- Healthcare workers are sometimes reluctant to administer medication to a dying person for fear of 'killing them', but it is imperative that good symptom management is maintained.
- Healthcare workers need to be aware of the purpose of giving medication. If it is to maintain comfort, then it must be given.
- Reminder: palliative care does not aim to hasten or postpone death.
- Medications for symptom management that cannot be taken orally need to be continued subcutaneously and extra medication charted for breakthrough symptoms.
- Anticipatory prescribing when people are deteriorating allows nurses to respond to patient distress without delay.
- Bereavement can be complicated if relatives have to see their loved ones in distress.
- In ethical terms, a person has the right to be free from suffering and the clinician has a responsibility to see that it happens.

SLIDE 13



Ask the group who had Richard to present back. Check that they cover these points. If they don't cover these key points, raise them.

Key points

Making decisions to withhold or withdraw treatment

- Advances in medicine mean that an increasing number of interventions need to be considered in the context of palliative care, e.g., ureteric stenting, PEG feeding tubes, etc. Just because they are available does not necessarily mean they are appropriate or have to be used.
- Personal autonomy and the right of self-determination are the basis of the right to refuse treatment. They do not, however, grant the person the right to demand treatments that the responsible doctor regards as not clinically indicated, whether that be antibiotics or renal dialysis.
- The goal of palliative care is to maintain quality of life while neither hastening nor postponing death.
- Whether it is appropriate to offer, withhold or withdraw a particular treatment depends on what is in the person's best interests – the balance between possible benefits and potential risks.
- Futile treatment with no chance of benefit is never justified.
- At times, loved ones find this difficult to understand and need sensitive communication and support as decisions are made. It often requires compromise and time. Patient-centred care should include the relatives. Development of a trusting relationship with the person and family and whānau is essential for these discussions, and advance care planning will make them much easier.
- Communication is key.

SLIDE 14



Ask the group who had Sefina to present back. Check that they cover these points. If they don't cover these key points, raise them.

Key points

Artificial nutrition and hydration

- Fears of starvation.
- Organs slow down in preparation for death.
- The burden of artificial hydration outweighs the benefits.
- There is little link between hydration and hunger and dry mouth.
- Mouth care with familiar tastes.
- The issues to be considered vary according to whether the person is in the dying phase of their illness. If they deteriorate rapidly or unexpectedly, which results in the inability to take oral fluids, then a full assessment needs to be made and reversible causes may need to be treated appropriately. For example, hypercalcaemia may mimic dying but it is reversible with bisphosphonates and artificial fluids, or if the person has gastroenteritis or a treatable infection then they may need artificial fluids as they recover from this.
- Legally, artificial nutrition and hydration is a medical treatment that may be refused like any other treatment. However, not all people understand that they have a choice.
- Artificial nutrition and hydration does not offer the sensory rewards, social interaction and comforts that come from the pleasure, taste and texture of food and fluids.
- Refusal of food and fluid is a natural part of the dying process.

SLIDE 15



Discuss these points with the group.

Key points

It's important to understand this term. This is considered when all other symptom-relieving measures have failed and the patient is clearly distressed. It should always be used in consultation with a specialist service.

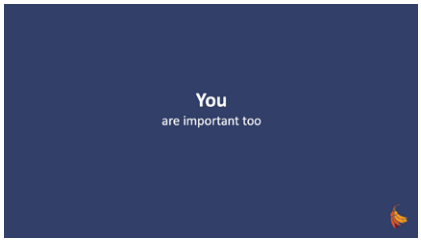
Reasons for palliative sedation include:

- terminal agitation (or restlessness)
- uncontrolled delirium
- severe breathlessness (or dyspnoea)
- massive haemorrhage
- Neurogenic or cardiogenic pulmonary oedema
- intractable distress.

It is important to:

- discuss and consult with the person and their family and whānau
- emphasise that the intent is not to hasten death.

SLIDE 16



Key points

Talk through the importance of the participants caring for themselves, as ethical issues can cause a great deal of distress to the care team as well as people and their family and whānau.

Remember that dealing with ethical issues is not just a matter of arriving at the right or legal decision, it is a 'process'. It is possible to arrive at a clinical decision that is ethically sound but leaves the people, families, whānau and clinical staff distraught if the process of arriving at the decision has not been carried out properly.

Reminders for participants.

- Ethical dilemmas may challenge our own values and beliefs.
- Work as a team – trust and support each other and consider all options.
- Open communication – share in decision making and confront difficult issues in a non-judgemental way.
- Share your feelings and concerns with other staff.
- Conflicts may be inevitable but should not be seen as negative, rather an opportunity for growth and improvement.
- Have strategies to preserve emotional and physical wellbeing.

SLIDE 17



Spirituality section – approx. 40 mins (3 slides)

Explain that building on what they learnt in the online learning, you will focus on how to respect spiritual needs in practice.

Key points

These are the key spirituality points from the online learning.

- Spirituality is a sense of connection to something bigger than ourselves – to self, to others, to nature and to the sacred.
- As a healthcare worker, you need to recognise spiritual distress in the people you care for and understand how you can help them reach peace.

Suggested approach (Aim for 10 mins discussion)

Do a quick recap on spirituality and how it applies to palliative care based on the online learning. Ask the participants questions, like:

- What was new information for you?
- What did you find interesting?

SLIDE 18



Key points

- Provide presence by 'being with' the patient and family.
- Encourage open communication and listen with sensitivity.
- Encourage exploration of beliefs
- Help the person, family and whanau complete unfinished business
- Supportive and trusting environment – discuss how they might create a safe space.

Key points

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- Supportive and trusting environment – discuss how they might create a safe space.

Suggested approach (Aim for 20 mins: 5 mins to set up, 10 mins for responses, 5 mins to wrap up)

- Introduce the participants to Matilda.
- On the whiteboard or using a sticky note on a wall, write up these four questions:
  - > What could you say in response?
  - > How can you get more details from Matilda?
  - > What are her spiritual needs?
  - > How might you address them?
- Provide the participants with whiteboard markers, or pens and sticky notes.
- Ask them to read each question and write down their answers on the board or on sticky notes under the relevant question.

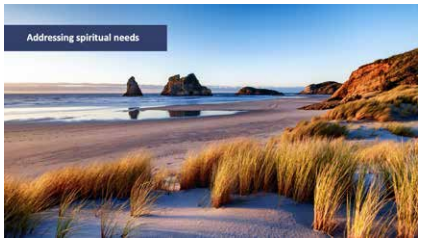
Once the participants have all contributed and they have finished writing their responses, work through each response and discuss as a group what the best approach would be for each question.

OR

If this is a virtual workshop, type one question at a time in the chat/ messaging thread. After you have typed the first question, ask the participants to type up their answers. Once they have responded to the first question, type up the next one, and so on.

Once you have all the questions and their responses typed, work through each response and discuss as a group what the best approach would be for each question.

SLIDE 19



Key points

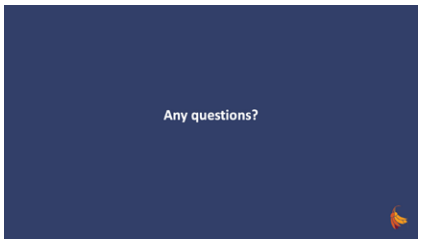
Discuss with the group how their organisation values spirituality and what they can do to help facilitate this.

Suggested approach (Aim for 10 mins of discussion)

Group discussion around these two key questions:

- What value does your organisation place on spirituality and how do you contribute to this?
- What rituals have your noticed in the people you have cared for that have bought them peace? How have you facilitated these?

SLIDE 20



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

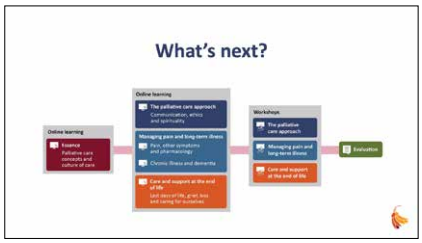
Recap what you have talked about today.

Key points

- How they can overcome communication barriers.
- How best they can address ethical dilemmas.
- How they can learn more about a person's spiritual needs and how they can address them.

Ask the participants if they have any last questions.

SLIDE 21



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

SLIDE 22



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

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