TRAIN THE TRAINER PROGRAM MANUAL

The Trajectory of Dementia Illnesses and the Namaste Care Program for People Living with Advanced Dementia in Residential Aged Care Facilities

SESSION GUIDES

Funded by the Tasmanian Government, Department of Health End-of-life Care Grant: *Education and training on the end-of-life Namaste Care program on aged care staff' knowledge, skills, attitudes and perceived competence in end-of-life dementia care*

DISCLAIMER

This document is a general guide to appropriate practice and the information is provided to assist decision making and support care provision based on best evidence available at time of creation. While every effort has been made to ensure the material in this document is accurate, the University of Tasmania provides no warranty, guarantee or representation that any material is accurate or complete, up to date, non-infringing or fit for a particular purpose. The use of this material is entirely at the risk of the user and the guidance suggested in this document is subject to the carer's judgement and the person's preference in each individual case.

Session Guide 1: Trajectory of dementia illnesses (2 hours)

Learning objectives:

1. Understand Dementia and the illness trajectory.
2. Discuss the benefits of a palliative approach to care.
3. Build communication skills to aid talking about dementia and dying.
4. Develop pain assessment skills.

Facilitator resources: workshop slides: Dementia and the illness trajectory PPT (Dr Melissa Abela); Namaste Care workshop PPT (Dr Sara Karacsony); copies of organisation's pain assessment tool; whiteboard markers, paper; sticky labels for name badges.

1. Introduction

- Workshop facilitator to briefly introduce self to participants. Staff may already know each other; however, please provide them with the opportunity to acquaint themselves with others sitting in their table group.
- Explain workshop schedule: 1. The first session provides an overview of dementia and the trajectory that dementia is likely to take throughout a person's life. Advise staff that they will consolidate knowledge and be introduced to research being conducted in the dementia space. They will learn skills in how to communicate with someone living with advanced dementia, and strategies for talking with family carers about goals of care for the person in the advanced stages of their dementia. The second session will provide an overview of the Namaste Care program for people living with advanced dementia. The third session is experiential and aims to simulate the experience of the Namaste Care program.

2. Show slides 1-5 on dementia, common causes of dementia and life expectancies using the notes as talking points.

Whole group discussion:

- Are staff seeing more people living with advanced dementia being admitted for care? Discuss why this is the case.

3. View slide 6 & 7 Stages of Dementia and Alzheimer's Disease

List the following words on the whiteboard and ask the group to describe what they mean.

- Agnosia

Inability to recognise familiar stimuli and occurs because the brain is unable to correctly interpret information from within the environment. This can be visual agnosia e.g., not recognising objects or familiar faces, but can also be sensory e.g., forgetting that day outside is cold and wearing shorts.

- Aphasia
  Defined as the impaired ability to produce (expressive) or understand (receptive) speech. When a person has expressive dysphasia, he or she has difficulty finding the correct word and difficulty speaking. With receptive aphasia, people do not understand what is being said.

- Apraxia
  Is the inability to carry out learned behaviours or complete a task
  Examples:
  - *The brain is unable to coordinate required actions to complete the task e.g., dressing, walking, eating*
  - *The person cannot remember the correct sequence of events e.g., putting socks on before shoes*
  - *The person forgets the purpose of objects, e.g., a comb for grooming hair, cutlery*

- Executive dysfunction
  Disruption of higher-order thinking and processes, such as the ability to plan, problem solve, perform sequential actions, and respond appropriately to other people. Executive dysfunction occurs due to damage in the frontal lobes of the brain which impairs ability to function effectively on a day-to day basis.[1]

- Ask the group if they can think of any residents who might be displaying these symptoms?

4. Group activity: Behavioural and Psychological Symptoms of Dementia (BPSD)

- Write BPSD on the whiteboard and ask staff to discuss the meaning. Explain the change in terminology from BPSD (behavioural and psychological symptoms of dementia) to responsive behaviours or changed behaviours (*refer to a needs-based approach to behaviours*).

- Ask staff to describe some of the common signs of responsive behaviours they have seen in their residents.

- Ask staff to describe what unmet needs might be (e.g., pain, hunger, needing to go to the toilet, boredom, being fearful etc.

- Discuss what this change in terminology reflects? *Why is it important to shift blame away from the person with dementia and to recognise that responsive behaviours are generally in response of an unmet need?*

5. View slides 8-11 for following group discussion. Facilitator to write up responses on a whiteboard

- Work in pairs or small groups and write down 3 key words/phrases that describe a palliative approach to care. Discuss these meanings in your group.

- Describe the main ways pain is currently managed in your service.

- How do you currently evaluate the effectiveness of interventions?

- What is your vision/goal/aim when a resident is dying?

  (Leave responses on the whiteboard for session on Namaste Care)

6. Whole group activity: Communication skills in managing end-of-life care

- View slides 13-14 on Dementia and Dying Talking about Dementia and End-of-Life Care [2, 3].
- Review how goals of care discussions are conducted within your service and how these might align with the formal process in the discussion guide.
- Ask staff to identify opportunities in which they have found themselves engaging in informal discussions with either residents or family carers

- Ask staff how comfortable they might be in discussing dying and death.

7. Case Study: 87-year-old man with AD – to hospitalise or not? (10 minutes)

- Use section of whiteboard to record staff responses on why/why not send to hospital.

8. Assessing and managing pain

Pain in older people is often unrecognised and undertreated, especially in older people with cognitive impairment. If pain is not managed, people can become confused, they can have interrupted sleep, not get the nutrition they need, be less mobile, feel depressed and isolated and take longer to get better [4]. In line with the Aged Care Quality Standards,

- Review the assessment tools or processes the organisation uses to monitor and respond to pain.
- Share copies of a pain tool with staff and discuss the importance of staff observing for pain using a valid and reliable pain assessment tool.
- Discuss the importance of evaluating pain management strategies and accurately documenting findings in care plans and escalating as required.

Session Guide 2: Introduction to the Namaste Care Program (30 minutes)

Learning objectives:

1. Understand the importance of the environment (pillar 1) in promoting comfort and quality of life.

1. The Namaste Care program – What is Namaste Care

- View slides 1-6

2. Seeing is Believing YouTube video slide 7

ADS Namaste Care - Seeing is Believing - short version [1]

3. Will Namaste Care make a positive difference in the resident's life?

- View slides 8-14

Whole group discussion:

- What is your preliminary understanding of the Namaste Care program?
- Which residents do you think the program is intended for?
- Discuss benefits of Namaste Care to residents, family carers and staff [5-12].

BREAK

[1] (Acknowledgements: Produced and directed by Sean Macreavy and Izzie Latham Camera - Rob Salmon of Orfactor Productions Camera, Sound, Editing and Music by Sean Macreavy)

Session Guide 3: Welcome to the Namaste Care program (1 hour) experiential session

Learning objectives:

1. Recognise the importance of sensory-based activities, sense memories and person-centred care.
2. Develop loving touch strategies to enhance comfort and well-being.

Facilitator resources:

- Equipment & resources to set up room for experiential session: oil diffuser(s) and essential oils – e.g., Springfields aromatherapy or Oil Garden blends: balance & harmony, tranquil and calm; soft furnishings, rugs, cushions; fabrics/fun & furry; Garden items: flowers, foliage, herbs; lollipops; CD player and CDs – familiar, relaxing music & upbeat, rousing music.
- When sharing touch in paired activity, full hand wash required – access to wash basin.

The purpose of this session is to simulate the experience of the Namaste Care program and for participants to 'get a feel' for activities that can be offered to people in the program.

Simulation activities:

1. Welcome participants into the 'Namaste Care' room and greet each person individually, making eye contact and wearing a smile.
2. Escort person to chair and make comfortable with a rug/cushion – check for comfort!
3. Once everyone is settled, ask them to look around and notice what senses are being stimulated. Ask participants to name each sense:
   Identify each one: visual, auditory, olfactory, tactile, gustatory, and Kinaesthetic.
4. Explain before the demonstration of a short hand massage, participants will need to prepare themselves so they can offer touch with a sense of quiet and calm. The mind needs to be cleared of ordinary concerns, a process known as 'centering' or 'grounding'. One way to do this, is to focus on physical sensations, instead of thoughts and by paying attention to the breath [13]. Participants will also need to be aware of cautions, contraindications and adjustments when providing hand (or foot) massage for a person with dementia [13] e.g. pain, contractures, masses and swellings.
5. Demonstrate the five-minutes therapeutic hand massage for Seniors[2] as follows:

    - Greet and use person's name

[2] Adapted from Elliot, G., DementiAbility Enterprises Inc. YouTube 5 Minute Therapeutic Hand Massage for Seniors

- Be seated in chair facing the person at eye level (let the person see you as much as possible)
- Always start on the hands of a person with dementia rather than the feet
- Start with some gentle stroking of the hands to allow the person to become acquainted with you
- When you understand that the person accepts your touch and there is no agitation, you can begin
    - ✓ Be mindful of rhythm, touch, and repetition
    - ✓ Can use a little moisturiser (not too slippery)

1. Rest arm on a pillow, support the forearm, interlock fingers, and begin gentle range of movement in the wrist.
2. Rotate the wrist in gentle circles, and then commence technique of 'breaking the bread'. Place the hand and arm flat on the pillow and open the palm.
3. Start at the bottom of the hand and work out to the sides – Bottom to sides for several minutes. There are a few acupressure points below the wrist.
4. Apply gentle massage to these points very gently under the wrist area.
5. Go back to 'breaking the bread'. Use the tendons and bones as a guide to work the muscles in the hand. Run fingers very softly between the muscles of the hand – especially the thumb area.
6. Turn hand over and can gently stimulate the acupressure point on top of the mound of the thumb (bring fingers together). Gently massage in small circles.
7. Turn the hand over again and go back to 'breaking the bread'.
8. Commence work around the fingers, one at a time: Start with a wiggle each side of the finger – softly caterpillar walking up the sides of each finger. Ensure pressing on both sides of the finger. Doing this to the thumb, promotes relaxation.
9. After doing the sides, do each finger top to bottom, using the same caterpillar walking up and down the fingers. Do this very gently, no traction or pulling.
10. Come back one last time to 'breaking the bread'.
11. Finish by pulling up the hand, resting elbow on the pillow and support the wrist. Massage into the sides of the hand, starting with the 'pinky' side. This activates more acupressure points as you move down the side of the hand with your fingertips.
12. Put the hand down and repeat along the thumb side, softly and gently, working the soft tissue.
13. Rest arm/hand face up (looks like cradling of the arm) and finish with soft stroking up the arm in the heart direction. Do this for a minute or two.
14. When finished, rest hand in yours (ham sandwich for a moment or two). Ask the person if they enjoyed this and if they would like to do this again another time.

REPEAT other side, time permitting

Wrap up session by asking staff how they feel and affirm that while sharing touch can feel awkward at first, it becomes more natural with practice and can become almost an artform over time.

Thank staff for their participation in the activity.

Session Guide 4: Evaluation

Workshop Evaluation Form

Please rate the following agree, neutral, disagree.

Presenters

1. The presenters began on time and used the time well.	Agree	Neutral	Disagree
2. The presenters were well organised.	Agree	Neutral	Disagree
3. The presenters presented the content so that it was easy to follow and understand.	Agree	Neutral	Disagree
4. The presenters held the attention of the audience.	Agree	Neutral	Disagree
5. The presenters were responsive to questions.	Agree	Neutral	Disagree
6. The presenters were knowledgeable about the workshop topic.	Agree	Neutral	Disagree
7. Interaction between presenters and participants interaction was sufficient.	Agree	Neutral	Disagree
8. This workshop was well tailored to the audience.	Agree	Neutral	Disagree

Workshop

1. What did you find most helpful about the workshop topic?

2. List any suggestions to improve the workshop.

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13. Goldschmidt, B. and N. van Meines, *Comforting touch in dementia and end of life care: Take my hand*. 2012, London: Jessica Kingsley Publishers.