

## FACILITATOR GUIDE

### Overview

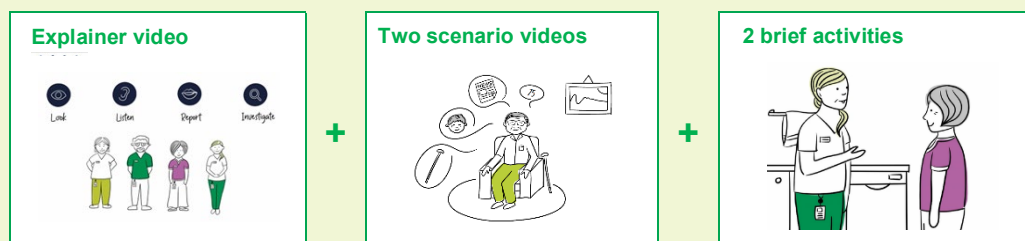
**i** What to do

**o** What to say

#### **i** Key information

##### **This session:**

- can be completed in 20 minutes
- will help participants be more alert to pain as a possible underlying cause of changed behaviour for persons living with dementia
- consists of:



##### **You will need:**

- an internet-connected tablet or computer with a screen that can be viewed by everyone in the group (for example, you may need a projector and screen for a larger group)
- pens and paper (for participants to take notes) and a whiteboard or butcher's paper (optional).

#### **i** Learning objectives

At the end of this session, participants will be more aware:

- that pain might be the underlying cause of behaviour change for a person living with dementia
- of how to recognise non-verbal signs of pain
- of the need to act on their concerns about pain or sudden behaviour change by telling someone who can investigate and take action (such as a registered nurse [RN], shift coordinator, team leader or general practitioner [GP])
- of the need to listen, respect and take action if someone is concerned about a person living with dementia (such as family or friends, personal care workers and others who spend regular time with them and know them best).

## Introduction

**i** Introduce the session and explain what will be covered. [1 min]

- 💬** In this session we'll look at the most common reason a person living with dementia has changed behaviour – they are experiencing pain. Although up to two-thirds of cases of changed behaviour are caused by pain, it's often unrecognised and undermanaged. We'll work together to understand why this happens and what we can do to make sure pain is always considered as a possible cause of changed behaviour.

## Video 1: Pain and changed behaviour

- 💬** We're going to watch a short video about the relationship between pain and changed behaviour. The video focuses on what pain can be like for a person living with dementia and how they might express pain.

**i** Play **Video 1**. [3 min 25 sec]



## Activity 1: Group discussion – Recognising the signs of pain

**i** Lead a group discussion to unpack the content of the video and reinforce learning. Use the questions below as prompts. [2 min]


- 💬** From the video, we saw that pain is a common reason for changed behaviour in a person living with dementia but is often missed.

This is partly because pain can sometimes be difficult to see (recognise).

As a group, let's think about our own experiences of recognising the signs of pain in the people you care for:

- What can pain look or sound like?
- What in this person's life history could be clues as to why they might be in pain. For example, have they had a physically demanding job, or do they have painful medical conditions?
- How have you seen pain expressed by someone who couldn't communicate it to you? If you can, use examples from your practice.

## Video 2: Vince's story – Part 1

 In this video, we'll meet Mr Vince Phan. We'll see from his interactions with care staff and family that he's behaving differently from usual, but it isn't clear why.

**i** Play Video 2 [2 min 52 sec]




### Activity 2: Group discussion – Unpacking Vince's changed behaviour

**i** Ask participants to think about the changes in Vince's behaviour that the carers and his son observed during their interactions with him.

Use the guiding questions below to explore the relationship between changed behaviour and pain. Possible answers are provided but your group may find more.


If you have time, record responses on a whiteboard or butcher's paper. [3 min]


 In these three scenes, we saw that Vince wasn't acting like himself. Each of the people interacting with Vince noticed he was behaving differently. Let's talk about what that might mean.

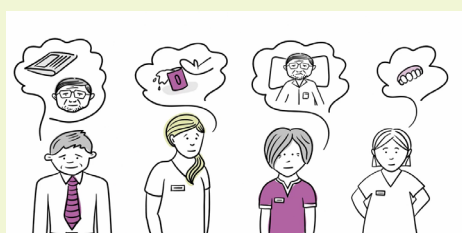
Guiding questions	Possible responses
Has Vince's behaviour changed? If so, how?	<ul style="list-style-type: none"> <li>• He didn't eat much dinner.</li> <li>• He pushed over his cup of tea.</li> <li>• He was short-tempered and rude with staff.</li> <li>• He didn't read the newspaper.</li> <li>• He hadn't shaved.</li> <li>• He didn't engage with his son when he visited.</li> <li>• He wasn't interested in Travel Club.</li> </ul>
What could be some reasons for these behaviour changes?	<ul style="list-style-type: none"> <li>• He could be having a bad day.</li> <li>• He might be tired and grumpy from poor sleep.</li> <li>• He could be getting sick.</li> <li>• The dementia may be progressing. Dementia can affect a person's:                             <ul style="list-style-type: none"> <li>○ function</li> <li>○ mood, memory or usual behaviour</li> <li>○ ability to communicate (challenges with word finding or understanding instructions).</li> </ul> </li> </ul>

Guiding questions	Possible responses
Were there any signs that Vince may have been in pain?	Even though Vince said he was 'fine' when asked if he was feeling OK, he was agitated and withdrawn which could be an expression of underlying pain. Therefore, pain should be considered.
Would these scenes on their own indicate anything to be particularly concerned about?	Each individual interaction could have other causes aside from pain (such as having a bad day or feeling tired from poor sleep). If this is not his 'normal', something may be wrong.
What if we put all the scenes together? Does this picture change?	If we consider all these interactions together, we can see a pattern of changed behaviour.


## Video 3: Vince's story – Part 2


 Let's see what happens next. Look out for the ways that information about Vince is shared between the people who care for him.

 **Play Video 3** [3 min 18 sec]



## Activity 3: Group discussion – Apply the learning to our workplace

 Lead a discussion using the guiding questions and possible answers. [3 min]

 In this video, we saw that **communication** was the key to connecting the pieces of information that pointed to pain as the reason for Vince's changed behaviour.

This shows how important it is that everyone expresses their concerns to the appropriate person. While small interactions on their own may not be enough to indicate that pain was the cause, when we consider them together, we can see the bigger picture.

We can also see that everyone had a part to play in recognising and managing Vince's pain.

*See the guiding questions on the next page.*

Guiding questions	Possible responses
<p>What could have happened if Vince's son Tuan and the care staff hadn't expressed their concerns?</p>	<ul style="list-style-type: none"> <li>• The mouth ulcer may have progressed, leading to more symptoms, illness, increased pain and medical interventions for Vince.</li> <li>• Vince may have withdrawn further, or his behaviour changes may have become more pronounced.</li> <li>• If the behaviour worsens, Vince may be medicated to manage the behaviour.</li> <li>• Staff may have started avoiding Vince, given his changed mood and behaviour.</li> <li>• Vince's level of activity and quality of life may have decreased.</li> </ul>
<p>Why is it important for the RN to listen to each person and then act on their concerns?</p>	<ul style="list-style-type: none"> <li>• Because if they hadn't, they may have missed a chance to identify an injury at an early stage – before it became worse and caused more pain for Vince.</li> <li>• Pain is a common cause of delirium which can exacerbate symptoms of dementia including changed behaviour.</li> <li>• Because the people who spend time with a person living with dementia know them best and they'll be the ones who notice when someone is 'not quite themselves'.</li> <li>• Because it's important not to dismiss changes in behaviour as being caused by their dementia – which we can't impact. While it is possible, it's important to consider that there may be other treatable underlying causes that we can't immediately see.</li> </ul>





Let's discuss what this means for our workplace. How can we improve the way we currently assess for pain and share and value the observations of others, regardless of their role?

Guiding questions	Possible responses
<p>How do you communicate your concerns to others that a person living with dementia might not seem themselves?</p>	<ul style="list-style-type: none"> <li>• Report it to someone who can investigate such as an RN, team leader, shift coordinator or similar.</li> <li>• Document your concerns in the person's progress notes.</li> <li>• Know the person well enough that you can describe the differences you've noticed.</li> </ul>
<p>How can we improve this process of communicating concerns about a person in our care?</p>	<ul style="list-style-type: none"> <li>• Value input from everyone in the workplace, regardless of their role</li> <li>• Be responsive to a report regardless of who has reported it.</li> </ul>

Guiding questions	Possible responses
	<ul style="list-style-type: none"> <li>• Make sure staff feel confident that if they raise a concern that it will be listened to and acted on.</li> </ul>
How can we stress to families, other staff and visitors that it is important for them to tell staff if they notice changes?	<ul style="list-style-type: none"> <li>• Recognise that the person who notices a change in behaviour could be anyone (for example, a relative, volunteer, kitchen staff or cleaner). Encourage everyone to communicate any concerns.</li> <li>• See everyone as being part of the team that contributes to person-centred care.</li> </ul>
How do we make them feel safe to share their concerns and not like they are interrupting or being annoying?	<ul style="list-style-type: none"> <li>• Give your full attention, listen and respond appropriately when families and visitors' express concerns.</li> <li>• Respond promptly to a report and provide feedback about any assessment you conduct and the actions you take.</li> </ul>

## Take-home messages

 End the session with take-home messages. (1 min)

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  - If a person's behaviour changes, first consider that they might be in pain. **See change. Think pain.**
  - Remember:
    - **Look:** Notice changes in a person's:
      - usual behaviour or interactions with others
      - body movements and facial expressions
      - level of activity
    - **Listen:**
      - to what the person living with dementia verbalises
      - to their family and other staff who may have expressed concerns
    - **Report:** Tell someone who can investigate further
    - **Investigate:** Find out what's going on.
  - It's important to regularly evaluate a pain management plan, especially if medications are included. Is the medication being dispensed as prescribed? Is it working? Be alert to side-effects and polypharmacy.
  - If pain is identified and addressed (or pain is ruled out) and the behaviour continues, ensure other possible reasons for the changed behaviour are investigated.

# Follow-up

**i** To reinforce this learning, gather the group in a week or two to have them reflect on this session. For example, ask them:

- How has your practice changed since you completed this training?
- Have you had an opportunity to consider pain as a reason for changed behaviour in a person living with dementia since you did this training? Describe what happened.
- Are there any things we can do in our workplace to improve how we communicate about changed behaviour? How can we put these changes in place?

# More information

## Resources available on the DTA website

**The pain puzzle: Recognition, assessment and treatment of pain in people living with dementia**

Increase your understanding of pain assessment and management for people with dementia living in a residential environment.

**Suitable for people working in:**  
Residential Aged Care

**Enhanced Practice**

Online course ⌚ 2 hrs

Certificate 💰 Free

View course

**Recognising and acting on pain in people living with dementia for direct care workers**

Learn how to look, listen and investigate pain in people living with dementia who are unable to verbalise their discomfort or pain.

**Suitable for people working in:**  
Residential Aged Care

**Enhanced Practice**

Online course ⌚ 3 hrs

Certificate 💰 Free

View course

## Other resources

Abbey Pain Scale  
(PDF, 65 KB)

**Abbey Pain Scale**  
For measurement of pain in people with dementia who cannot verbalise

Name: \_\_\_\_\_ (person being assessed)  
D.O.B: \_\_\_\_\_  
Completed by: \_\_\_\_\_ (name and designation)  
Date: \_\_\_\_\_ Time: \_\_\_\_\_  
Latest pain relief given was \_\_\_\_\_ at \_\_\_\_\_

Enter pain score for each of the following six areas:  
Absent 0, mild 1, moderate 2, severe 3

1. **Vocalisation** (e.g. whimpering, groaning, crying)

2. **Facial expression** (e.g. looking tense, frowning, grimacing, looking frightened)

3. **Change in body language** (e.g. fidgeting, rocking, guarding part of body, withdrawn)

4. **Behavioural change** (e.g. increased confusion, refusing to eat, alteration in usual patterns)

5. **Physiological change** (e.g. temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor)

6. **Physical changes** (e.g. skin tears, pressure areas, arthritis, contractures, previous injured)

Add scores for 1-6 and record the total pain score

Tick the box that matches the total pain score

0 - no pain  3-7 mild  8-15 moderate  16+ severe

Tick the box that matches the type of pain

Chronic  Acute  Acute on chronic

Abbey, J.A., Piller, N., Dobbie, A., Graham, A., Pines, D., Oles, L., Lacey, B. (2010) The Abbey Pain Scale: A 6-item, validated instrument for people who are unable to verbalise their pain. *International Journal of Palliative Nursing*, 16(1), 1-10. This document may be reproduced with the appropriate permission.

Pain Assessment in Advanced Dementia Scale (PAINAD)  
(PDF, 24 KB)

**Pain Assessment in Advanced Dementia Scale (PAINAD)**

**Instructions:** Observe the patient for five minutes before scoring his or her behaviors. Score the behaviors according to the following chart. Definitions of each item are provided on the following page. The patient can be observed under different conditions (e.g., at rest, during a pleasant activity, during caregiving, after the administration of pain medication).

Behavior	0	1	2	Score
Breathing/Independent of vocalization	• Normal	• Occasional labored breathing • Short period of hypoventilation	• Noisy labored breathing • Long period of hypoventilation • Cheyne-Stokes respirations	
Negative vocalization	• None	• Occasional moan or groan • Low-level speech with a negative or disappointing quality	• Repeated troubled calling out • Loud moaning or groaning • Crying	
Facial expression	• Smiling or inexpressive	• Sad • Frightened • Tense	• Facial grimacing	
Body language	• Relaxed	• Tense • Distressed pacing • Fidgeting	• Rigid • Fists clenched • Arms pulled up • Pushing or pulling away • Struggling	
Comprehibility	• No need to console	• Distracted or reassured by voice or touch	• Unable to console, distract, or reassure	
<b>TOTAL SCORE</b>				


(Warden et al., 2005)

**Scoring:**  
The total score ranges from 0-10 points. A possible interpretation of the score is: 1-3-mild pain; 4-6-moderate pain; 7-10-severe pain. These ranges are based on a standard 0-10 scale of pain, but have not been substantiated in the literature for this tool.

**Source:**  
Warden, V., Husley, AC, Volker, L. Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J Am Med Dir Assoc.* 2003;4(1):9-15.

Observe a Change Consider Pain  
(PDF, 543 KB)

**Observe a Change Consider Pain**  
5 steps to manage pain in people with dementia



Up to 95% of people in residential aged care experience pain. Pain is a contributor of up to 80% of behavioural changes in people living with dementia.