

# Observe a Change Consider Pain

5 steps to manage pain  
in people with dementia



Up to **93%** of people in residential aged care experience **pain**.

**Pain** is a contributor of up to 80% of behavioural changes in people living with **dementia**.

# Intervene Pain Management Resource

## Notes for Trainers & Educators

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### Introduction

This resource has been designed as an educational intervention for aged care staff to provide a person-centric, pain management plan for people living with dementia. The resource can be used for independent reading, however, we recommend that it be used as part of a professional development program to improve staff's capacity to identify and optimally manage pain. Detailed information and additional video, poster, educational booklet and pocket reference-card resources, are available as free downloads at the Dementia Centre website ([www.dementiacentre.com](http://www.dementiacentre.com)). These resources were co-developed with aged care staff during the Intervene Phase 2 research project, a collaborative project designed to improve staff's ability to Identify, Assess, Manage, Reassess and Monitor pain. This work was based on the premise that care staff spend the most time with residents and are best placed to notice changes in residents that may indicate pain.

### About the Resource

The resource provides an evidence informed, 5-step approach to Identify, Assess, Manage, Reassess and Monitor pain for residents living in aged care. Each step is clearly outlined in the resource. The resource also presents four case studies where the 5-step approach is used to create a personalised pain management plan.

### Suggestions for using the Resource

- 1. Independent Reading:** The resource outlines a 5-step approach to managing pain and the case studies offer suggestions for implementation.
- 2. Education Sessions:** The resource can be used as a basis for one or more educational sessions. Sections of the resource could be used as handouts and session notes. Additionally, case studies could form the basis of group discussions and associated resources (videos, etc.) could be used to give depth of skill in applying the pain management process. Within the session, staff should be encouraged to consider:
  - Specific relevance to certain residents within the service who may be experiencing pain;
  - Non-pharmacological interventions which may be of benefit to residents;
  - Review the service's existing pain management processes and create pathways to optimise the delivery of multidisciplinary care.

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# Pain is everyone's business

## The Challenge of Pain Management

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### So, what is pain?

Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage. Pain evokes emotional responses and is influenced by the person's previous experience of pain, the psychological state and social situation they are in.

### Pain is whatever and whenever the person experiencing it says it is.

People with dementia experience pain and it is unique to each person. They may or may not be able to tell you directly that they are in pain, but listen to the person and observe signs of change.

### What is best practice pain management?

- Knowing the person.
- A whole team effort and including the person and their family.
- Review for possible causes of undetected or new pain.
- Non-medication measures such as comfort care, diversional strategies and exercise should be considered.
- Evidence-informed assessment, monitoring and documentation.
- Taking time for your own well-being and reflection on your care practice.

**In residential care, managing pain is everyone's business.**

This resource takes you through an efficient, proven-in-practice series of 5 steps to assist you in reducing and managing pain in your residents.

Pain is everyone's business. Observe a change, consider pain.

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# 5 Steps of Pain Management

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Identify

Assess

Manage

Re-assess

Monitor



Pain not improved

# Step 1: IDENTIFY

## Identify

Assess

Manage

Re-assess

Monitor

## Is pain a possibility?

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### Ask the person if they are in pain

Use different approaches:

- Prompt (e.g. “You appear to be in pain.”)
- Use different terms (e.g. “Does it hurt?” “Are you sore?”)
- Use the person’s first language wherever possible

### Listen to

- What they say
- How they say it
- Vocalisations (e.g. groaning, crying, yelling)

### Look at

- Facial expressions (e.g. frowning, grimacing, clenching teeth)
- Movement and behaviours (e.g. reluctant to move, rubbing or protecting a body part, resistiveness to care, pacing, agitation)
- What has changed (e.g. sleep, appetite)

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# Step 2: ASSESS

Identify

**Assess**

Manage

Re-assess

Monitor

People with dementia may no longer be able to tell you they are in pain.

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## Use validated pain assessment tools

- Observational Pain Scale (e.g. Abbey Pain Scale, PAIN-AD)
- Pain Intensity Scale (e.g. Faces Pain Scale, Numerical/Verbal Rating)

## Assess

- Physical aspects (e.g. movement, function, sleep)
- Psychological aspects (e.g. mood, fear, emotions)
- Social & Cultural aspects
- Existential aspects (e.g. spirituality, purpose, hope)
- Environmental aspects (e.g. review bedding, room temperature and suitable clothing)
- Medication review

## Seek additional information

- Family may help you interpret changes
- From clinical staff (e.g. care staff, allied health, nursing, doctors)
- Check previous hospital and/or medical records

## Document clearly

- Why you suspect the person is in pain
- Where and how severe the pain is
- Results of your pain assessment (body part, resistiveness to care, pacing, agitation)
- What has changed (e.g. sleep, appetite)

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# Step 2: ASSESS

Identify

**Assess**

Manage

Re-assess

Monitor

People with dementia may no longer be able to tell you they are in pain.

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## Pain Assessment Tools

There are over 30 pain assessment tools for people living with dementia when verbal or cognitive ability are limited. Using a pain assessment tool can help to provide an objective measure of pain, clear communication among staff, and ensure that pain management is optimal.

**One validated pain assessment tool is the Abbey Pain Scale.**

### Remember

- Take time to carefully observe the person – Ask, Listen and Look
- Observe the resident during activities of daily living
- If unsure, don't score zero. Document your observations
- The Abbey Pain Scale does not differentiate between pain and distress
- It is a part of the whole person assessment

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# Abbey Pain Scale

## Abbey Pain Scale\*

Absent – 0 Mild – 1 Moderate – 2 Severe – 3

### For measurement of pain in people with dementia who cannot verbalise

- Q1.** Vocalisation (e.g. whimpering, groaning, crying)
- Q2.** Facial Expressions (e.g. looking tense, frowning, grimacing, looking frightened)
- Q3.** Changes in body language (e.g. fidgeting, rocking, guarding part of the body, withdrawn)
- Q4.** Behavioural changes (e.g. increased confusion, refusing to eat, alteration in usual patterns)
- Q5.** Physiological changes (e.g. temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor)
- Q6.** Physical changes (e.g. skin tears, pressure areas, arthritis, contractures, previous injuries)

### Add scores for Q1-Q6 and record total

**0-2**  
No pain

**3-7**  
Mild

**8-13**  
Moderate

**14+**  
Severe

\*Adapted with the permission of Jennifer Abbey for the Invervene phase 2

# Step 3: MANAGE

Identify

Assess

**Manage**

Re-assess

Monitor

## What can I do?

### Pain management is not always a pill or a procedure.

Pain management is more than just lessening the severity of the pain. Rather, good pain management is about knowing the person and understanding the factors influencing their pain. Good pain management is about tailoring the plan to the individual and delivering it appropriately.

### Comfort measures

- Often most effective with fewer side effects (e.g. reassurance, repositioning)

### Non-medication measures

- Review the approach to personal care
- Exercise (e.g. stretches, walking, dancing, yoga, Tai Chi)
- Touch Therapy (e.g. massage, heat)
- Diversion/Distraction (e.g. music, art, gardening, pet therapy)
- Physical adjustments (e.g. appropriate seating, pressure care)
- Review supportive aids (e.g. walking frame, brace, hoist/lifter)
- Spiritual care (e.g. meditation, prayer, chapel services)

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# Step 3: MANAGE

## Medications

- Check what is prescribed
- Ensure adequate time between taking medication and activity

### If treatment strategies are not effective, inform clinical staff.

The focus of pain management often shifts from fixing or curing the pain to managing the pain with the aim to enhance quality of life, optimise physical function and reduce distress.



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# Step 4: RE-ASSESS

Identify

Assess

Manage

**Re-assess**

Monitor

## Is pain still there?

### Why is re-assessment of pain important?

- Re-assessment is the only way to know if we have managed pain effectively.
- Use the same validated tool, completed by the same person, in a timely manner:
  - After administering medication: 30 minutes
  - After non-medication intervention: 60 minutes
- Observe for any other changes: Ask, Listen and Look

### Document interventions & outcomes – Consult with or inform clinical staff

#### If interventions are ineffective

- Consult clinical staff and family for more insights.
- Ask if this is the appropriate intervention for the condition.
- Review other possibilities and reconsider the intervention.
- Think outside the box (e.g. could it be a tooth infection or ingrown toe nail?)
- Could it be something more serious like a broken rib or heart attack?

For people from Aboriginal/ Torres Strait Islander or culturally and linguistically diverse backgrounds consider:

- a culturally appropriate approach to care
- multicultural and language appropriate pain assessment tools
- interpreter services and ethnic specific assistance

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# Step 5: MONITOR

Identify

Assess

Manage

Re-assess

**Monitor**

## What is your plan?

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Ongoing monitoring of pain for people living with dementia is important to ensure that the interventions continue to work effectively and to recognise any new pain or changes to existing pain.

### Monitor

- At least once per shift for the next 24 hours until settled.
- Ask, Listen and Look – using the same validated tool.

### Document

- What signs indicate pain?
- What works and what doesn't?
- Personalise the assessment and intervention strategies
- Review notes from previous shifts and update care plans

**Monitoring may be the only way to know if a person is in pain, when they are unable to communicate effectively with words.**

Remember, all pain assessments and interventions should be implemented keeping in mind the dignity and choices of the person.

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# Pain Management Document



My resident

**What next? Is it pain?**  
Use the 5 Steps

## Identify

How best to identify pain? What to look and listen for?

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## Assess

Know the person. Speak to the family. Use Abbey Pain Scale

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## Manage

What can I do? Ways to comfort. Has it worked or not?

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## Re-assess

Is pain still there? Repeat Abbey Pain Scale

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## Monitor

What is the future plan to prevent and provide care?

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# How do I know if it's pain? What can I do?

## CASE STUDIES

Each of these stories are different, but is it dementia?  
Or, could it be due to unrecognised or under-treated pain?

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**Shirley** kept calling out, "Nurse! Nurse!". When staff asked her what was wrong, she just nodded her head. She has dementia. Is the calling out due to dementia? Is it due to pain? Or, does she just want company?



**Alex** is a big man. Today he hit out and swore at staff when they tried to assist him with personal care. He tends to be verbally aggressive and a bit frightening to work with. Staff wonder if he has always been so difficult or if it is his dementia.



**Maria** has dementia. She used to be quite social. She has lost five kilos in the last three months and is reluctant to eat. She just wants to stay in her room. Staff wonder if this is grieving for her husband or is it just settling in after the move to the care home.



**Giorgio** is very confused about where he is, and shouts in Italian, "dolore". Due to his dementia he has forgotten English and his family are also not able to understand him. He falls frequently. Staff are worried that pain medication will just make him more confused.

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# Shirley

“Shirley kept calling out, “Nurse! Nurse!“. When staff asked her what was wrong, she just nodded her head. She has dementia. Is the calling out due to dementia? Is it due to pain? Or, does she just want company?” – Susan, care staff



**Shirley** is a 93 year old great-grandmother who has severe dementia. She has limited ability to communicate verbally. Staff report that Shirley can be resistive when her clothes are changed. She has begun making loud noises which can go on for a long period of time, particularly after personal care. Each week, her two sons visit their mother. They note their mum’s condition is deteriorating. Shirley is not prescribed any pain medications as her doctor fears risk of adverse effects particularly after she became drowsy the last time pain medications were prescribed.

Discussion with Shirley’s sons indicate they feel their mother’s screaming is a sign of pain, as it is how they remember her reacting when she had a gall stone a few years ago.

Pain is everyone’s business. Observe a change, consider pain.

## Use the 5 Steps

### Identify

Start by asking Shirley, "Are you in pain?". If she is unable to give a meaningful response, observe her verbalisations, posture and facial expression. Pain is a strong possibility.

### Assess

The two staff who did Shirley's personal care completed the Abbey Pain Scale after her shower. She scored 14, which was suggestive of severe pain. The staff noted she was particularly noisy when her left shoulder was moved or while being transferred into the lifter. Susan, care staff, documented and discussed the findings with the RN, who also brought it to the attention of the doctor.

### Manage

Susan offered Shirley a heat pack to be placed on her shoulder and also repositioned her in bed. This settled Shirley. The heat pack is now regularly used when Shirley is starting to get noisy or restless. The physio helped staff change the way they used the lifter with Shirley to make her more comfortable. Susan talked to care staff during handover about being more careful with Shirley's left shoulder. The doctor ordered a mobile x-ray and noted an old fracture which was partially healed. There was no need for surgery. The physio is now using massage and gentle mobilisation of the arm and shoulder to maintain her movement. Topical anti-inflammatory creams are being applied to her shoulder. Shirley now has prescribed pain medication an hour before her morning personal care and before going to sleep at night. Her favourite music is being played in the morning after her care.

### Re-assess

The Abbey Pain Scale is being done three times daily - after she wakes in the morning, after personal care and in the evening before going to sleep at night. It ranges between 4 and 8. She still calls out, but is more easily settled. The doctor is scheduled to review her in a week to assess her response to the medications.

### Monitor

A pain plan was created for Shirley, looking out for her vocalisation and facial expressions of pain and observing changes in her behaviour. A care plan detailing Shirley's personal care was documented and shared with care staff. Her sons are regularly updated. She has been referred to the palliative care team for other supportive measures.

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# Alex

“Alex is a big man. Today he hit out and swore at staff when they tried to assist him with personal care. He tends to be verbally aggressive and a bit frightening to work with. They wonder if he has always been so difficult or if it is his dementia?”

– Ajit, locum care staff

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**Alex** is a 65 year-old man, ex-carpenter, with advanced fronto-temporal dementia. He has been in residential aged care for two years and is always very active. From early morning until evening, he walks around the home and sometimes into other residents' rooms. Staff report that he can be verbally aggressive when redirected. Alex speaks with jumbled words that are rarely understood. One morning, care staff find Alex still in bed. They ask him if he is okay and he swears at them. Attempts to get him up cause him to pull away and he hits out at the staff. His temperature is slightly elevated and his pulse is 110 bpm.

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## Use the 5 Steps

### Identify

Staff tried asking Alex, “Are you in pain?”. He mumbled, but remained still. He no longer seems himself. Pain is a strong possibility.

### Assess

The staff completed an Abbey Pain Scale while he was lying in bed and scored 6. Staff eventually assisted him up for a shower and noted he was scratching his right thigh and didn't like the water on his thigh. No skin changes were noted. Ajit, locum care staff, documented and informed the RN. While he could move his arms and legs without restriction, Alex didn't want to walk. He plucked at his clothing over his right thigh. Ajit repeated an Abbey at the end of his shift and scored Alex at 15.

### Manage

Ajit offered him both a cold and heat pack to be applied over his thigh, which Alex pushed away. He did not like the sheets touching the skin either. Ajit informed the night staff to monitor him closely. The RN gave him paracetamol which was charted on an as required basis. The following day, a rash appeared over his right thigh. He was diagnosed with shingles and was started on pregabalin, a medication to help with nerve pain. He became more confused and distressed over the following days. He needed more assistance during care, and staff avoided touching his right thigh. He was reviewed by the physiotherapist and offered a walking frame, but Alex forgets to take it along and frequently reminding him is not effective.

### Re-assess

The Abbey Pain Scale is now being done regularly at the end of each nursing shift and when Alex is agitated. His scores range between 4 and 14. He had many medication changes and once the rash settled, a local anesthetic patch was applied over his thigh.

### Monitor

A care plan for pain management was created for Alex, looking out for his vocalisation, facial expressions of pain and observing changes in his mobility. It also detailed the approach towards Alex's care. Three months later, Alex still wanders and can become irritable when he is unable to go out for a smoke. He no longer appears to be in pain and the Abbey Pain Scale is done once a week or “when a change” in his behaviour is noted. He is encouraged to take breaks during his walks by offering him a cup of tea or the chance to do some woodworking, which he enjoys.

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# Maria

“My mum has dementia. She used to be quite social. She has lost five kilos in the last three months and is reluctant to eat. She just wants to stay in her room. Staff wonder if this is grieving for her husband or is it just settling in after the move to the care home?” – Padi, daughter

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**Maria** is 83 years old. She has been in residential aged care for four weeks. She came into the home following the sudden death of her husband. She has moderate dementia. Maria's great love was her garden. She has arthritis in both hips. During the winter months, she feels the cold which makes her arthritis pain worse. What could be done to support Maria's pain management?

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## Use the 5 Steps

### Identify

Staff asked Maria, “Do your hips hurt? Are your knees sore? Are you in pain?”. She shook her head “no”: Pain is still a possibility.

### Assess

The Abbey Pain Scale was completed when Maria was sitting in a chair. She scored 2 but this increased to 9 just after she walked to the bed. She would rub her knees when she sat on a chair. Her daughter noted a decrease in appetite and that she no longer watched her favorite television programs. A RN documented the Abbey Pain Scale and the comments by Maria’s daughter Padi about the change in behaviour.

### Manage

One of the care staff offered Maria a warm cup of tea and took her to the garden. She has joined the weekly chair yoga and Tai Chi groups at the care home, which she enjoys. Her physiotherapist has reviewed her previous exercise plan. Maria’s GP had prescribed PRN pain medications if needed, but these were not being given as she would not complain and told staff she was not in pain. Padi had mentioned that her mother took regular paracetamol at home. The doctor also noted her to be depressed and charted her antidepressants and regular paracetamol. The home had a neglected raised garden bed. The activities staff spoke with Maria and Padi to find out what were familiar herbs and plants and bought some of these for the two women to use to rejuvenate the garden bed. Padi also bought some potted plants for her mother’s room.

### Re-assess

Maria is asked if she is in pain but continues to say “no”. The Abbey Pain Scale is being done once a day after her late afternoon walk. It ranges between 0 to 4. Her eating has not improved. Staff are suspicious Maria may have dental problems. She has an appointment for the next mobile dental clinic visit.

### Monitor

A pain plan was created for Maria, observing changes in her behaviours, mood and movement. Her weight and eating are being monitored. Various activities are being planned for Maria during the day. She is now participating in a few errands at the home and spends time in the garden.

# Giorgio

“Giorgio is very confused about where he is, and shouts in Italian, “dolore”. Due to his dementia he has forgotten English and his family are also not able to understand him. He falls frequently. Staff are worried that pain medication will just make him more confused.” – **Gina, registered nurse**

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**Giorgio** is a 91 year old widower, living in a residential care home. He has no family living close by, very few friends, and is forgetting the English learnt after he migrated to Australia from Italy. Giorgio has had a very hard life, working as a labourer. He does not open up to strangers, and spends a lot of time in his room. He enjoys listening to Italian music and looks forward to visits from a volunteer called Maria, who speaks his local Italian dialect. Maria visits him once a fortnight through the Italian Association volunteer visitors scheme. Lately, he has been unable to find the toilet in time and has been holding his stomach. His body language indicates pain and possibly fear.

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## Use the 5 Steps

### Identify

Staff tried asking Giorgio, “Are you in pain?”. He pointed to his back and curled up in bed. Pain is a possibility.

### Assess

After his personal care, on the Abbey Pain Scale, Giorgio scored 4, which is suggestive of mild pain. He has had two recent falls, resulting in a few bruises, but no fractures were found. In the past few days, he has been frequently holding his back and sometimes his abdomen. He is prone to being constipated and opens his bowels once every four days. The RN noted swelling over his lower abdomen. He has a pain patch prescribed which is changed every seven days. It was started in the hospital after a fall twelve months ago.

### Manage

Giorgio was offered a back massage with his prescribed medicated cream. The position of the pain patch was checked. The occupational therapist reviewed his chair where he spends most of his day. He was given an iPod which has some of his favorite Italian music. He spends time with the therapy dog which visits the home twice a week. The doctor examined him and stopped his pain patch. His bowel regimen was revised with laxatives and a regular suppository every second day. An ultrasound of his abdomen was arranged.

### Re-assess

Following these changes, staff completed an Abbey Pain Scale twice daily – morning and evening. Giorgio’s pain scores ranged between 8 and 12. He spends more time in bed and is more agitated and frequently cries out. The ultrasound showed he has urinary retention due to an enlarged prostate. A urine dipstick test was positive, so a sample was obtained for the laboratory. The urine culture showed an infection and antibiotics were prescribed. The doctor has started medications for his enlarged prostate.

### Monitor

A pain plan was created for Giorgio, looking for facial expressions of pain, verbalising “dolore” and observing changes in his behaviours. Regular bowel and bladder charts are being kept. He has also been charted different pain medications. He is more comfortable, but regular re-assessment will be continued to monitor the success of the various treatments.

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## Additional Resources

This resource is an output of the Intervene Project (Phase 2). Results from Intervene, as well as other project outputs can be downloaded for free at: [www.dementiacentre.com/programs/intervene](http://www.dementiacentre.com/programs/intervene)

The Australian Pain Society Guidelines can be found at: [www.apsoc.org.au/publications](http://www.apsoc.org.au/publications)

The Pain Australia Website contains further information: [www.painaustralia.org.au](http://www.painaustralia.org.au)

### Contact Us

**Phone** +61 2 8437 7355

**Email** [hello@dementiacentre.com](mailto:hello@dementiacentre.com)

**Web** [dementiacentre.com](http://dementiacentre.com)



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