

Responsive Behaviours in Dementia

Training guide for care staff

Purpose of this training: To help staff recognise behaviour as communication, identify possible unmet needs, respond calmly and respectfully, and know when to report sudden changes for further assessment.

- **Sundowning**
- **Delirium**
- **Pain**
- **Refusal of Care**
- **Managing Responsive Behaviours**

1. Sundowning

What is Sundowning?

Sundowning is a term used to describe a pattern where some people living with dementia become **more confused, anxious, restless or distressed in the late afternoon or evening**.

As the day progresses, you may notice changes such as:

- Increased confusion or disorientation
- Pacing or wandering
- Wanting to “go home”
- Repeated questioning or calling out
- Anxiety or fear
- Irritability or agitation
- Resistance to care
- Difficulty settling for the evening

Sundowning is not a type of dementia or a separate disease. It describes a **pattern of symptoms that become more noticeable later in the day.**

Important: Not every person living with dementia experiences sundowning, and a sudden change in behaviour should never automatically be assumed to be sundowning.

Why Does Sundowning Happen?

Our brain has an **internal body clock** that helps us recognise when it is daytime and when it is time to sleep.

In dementia, changes in the brain can interfere with this body clock. As **daylight fades and the person becomes more tired**, it may become harder for them to understand:

- Where they are
- What time of day it is
- What is happening around them

Less daylight + tiredness + dementia-related brain changes can lead to increased confusion, anxiety, restlessness or agitation.

Other factors such as **pain, hunger, needing the toilet, noise, unfamiliar surroundings or changes in routine** can make this worse.

Sundowning isn't the person being difficult — their brain may be having greater difficulty making sense of their surroundings as the day progresses.

How Can We Reduce Sundowning?

The aim is to **reduce triggers, meet the person's needs and create a calm, familiar environment.**

- **Maintain a familiar routine** – consistency can reduce confusion and anxiety.
- **Encourage daylight during the day** – open curtains and encourage appropriate daytime activity.
- **Reduce evening stimulation** – lower noise levels, avoid busy environments and create a calmer atmosphere.
- **Use appropriate lighting** – as daylight fades, turn lights on to reduce shadows and changes in the environment.
- **Avoid overtiredness** – consider whether activities or personal care can take place earlier in the day.

- **Check basic needs** – pain, hunger, thirst, toileting, constipation, temperature and general discomfort.
- **Use reassurance and validation** – acknowledge how the person is feeling rather than arguing or repeatedly correcting them.
- **Use familiar activities** – music, photographs, reminiscence or another activity the person finds comforting.
- **Know the person's life story** – evening behaviour may relate to previous routines, such as collecting children, preparing dinner or returning home from work.
- **Look for patterns** – document when the distress occurs, what happens beforehand and what helps.

Key message

Don't just try to stop the behaviour — ask what may be causing the distress and what the person needs.

2. Delirium – A Sudden Change in Confusion

What is Delirium?

Delirium is a sudden change in a person's thinking, attention and awareness.

It usually develops **over hours or days** and symptoms may **fluctuate throughout the day**.

A person living with dementia can also develop delirium.

Dementia or Delirium?

Dementia	Delirium
Usually develops gradually	Sudden onset
Progressive over time	Develops over hours or days
Symptoms may be relatively consistent	Symptoms fluctuate

Dementia	Delirium
Attention may be preserved earlier	Attention is often impaired
Usually related to underlying brain disease	Often triggered by acute illness or another physical cause

What Can Cause Delirium?

Think about:

INFECTION – UTI, chest infection

PAIN – including pain the person cannot communicate

DEHYDRATION – not drinking enough

CONSTIPATION – or urinary retention

MEDICATION – new medication, changes or side effects

ILLNESS – acute deterioration or metabolic disturbance

ENVIRONMENT – unfamiliar surroundings, poor sleep or sensory difficulties

These overlap with the physical causes the Joymac material already asks staff to assess when behaviour changes.

What Might Staff Notice?

The resident may suddenly:

- Become much more confused
- Struggle to concentrate or follow conversation
- Become restless or agitated
- Become unusually sleepy or withdrawn
- Experience hallucinations
- Have disturbed sleep
- Behave very differently from their **usual baseline**

A sudden change in behaviour or confusion should never automatically be put down to dementia.

Know the person's normal baseline → recognise the change → report it → investigate the cause.

“Mary, who normally walks to the dining room independently and chats with staff, is suddenly very sleepy, confused and refusing her breakfast this morning. Is this her dementia progressing?”

That should get them thinking **NO — this is a change from baseline and needs assessment.**

Dementia → Sundowning → Delirium → Behaviour as communication/unmet need.

Treatment & Management of Delirium

The key principle is:

Delirium is treated by identifying and treating the underlying cause.

Delirium itself is a **sign that something has changed**. Treatment therefore depends on what is causing it.

Examples include:

- **Infection** → medical assessment and appropriate treatment
- **Dehydration** → encourage/restore fluids as clinically appropriate
- **Pain** → assess and manage pain
- **Constipation or urinary retention** → identify and treat
- **Medication** → review recent changes and possible side effects
- **Poor nutrition** → assess food and nutritional intake
- **Low oxygen/acute illness** → urgent clinical assessment where indicated

The Joymac material already identifies infection, pain, dehydration, constipation and medication changes as physical factors that should be considered when behaviour changes.

While the Cause is Being Treated

Staff can also help by:

- Providing **calm reassurance**
- Keeping the environment **quiet and familiar**
- Ensuring appropriate **lighting**
- Using clocks, calendars and familiar objects to aid orientation
- Encouraging appropriate **food and fluids**
- Making sure glasses and hearing aids are available

- Supporting normal **sleep and daytime activity**
- Avoiding unnecessary moves or environmental changes
- Involving familiar staff and family where appropriate
- Monitoring and reporting changes

Important

Don't simply treat the agitation — find the cause of the delirium.

SUDDEN CONFUSION = THINK DELIRIUM → REPORT → ASSESS → IDENTIFY & TREAT THE CAUSE

3. Pain in a Person Living with Dementia

A person living with dementia may experience pain but may be **unable to recognise, remember or communicate it clearly.**

Instead of saying “**I'm in pain,**” they may communicate their discomfort through a **change in behaviour.**

Signs That May Indicate Pain

- Facial grimacing, frowning or looking distressed
- Moaning, groaning, calling out or crying
- Guarding or rubbing an area of the body
- Changes in walking or mobility
- Restlessness or agitation
- Becoming withdrawn or unusually quiet
- Resistance during personal care or movement
- Changes in sleep or appetite
- Increased confusion
- Sudden aggression or distress

Think About When It Happens

During personal care? → Could movement or positioning be painful?

When standing or walking? → Consider joint, muscular or other pain.

At mealtimes? → Consider dental or mouth pain.

When passing urine? → Consider urinary symptoms.

When opening bowels? → Consider constipation or discomfort.

What Should Staff Do?

OBSERVE → ASK → ASSESS → REPORT → RESPOND → REASSESS

Know the person's **usual behaviour and baseline**. If something changes, ask “**Could this person be in pain?**”

Key Message

Behaviour may be the person's way of communicating pain. Treat the possible cause — don't simply react to the behaviour.

Pain Assessment in Dementia

Pain should **never be dismissed** because a person cannot clearly tell us they are in pain.

1. Ask the Person

Where possible, **self-report is still the preferred method**.

Use simple questions:

- “Are you sore?”
- “Where does it hurt?”
- “Is it sore when you move?”
- “Is it a little sore or very sore?”

If the person can use one, consider a **numerical rating scale (0–10)** or a simple verbal scale such as **no pain / mild / moderate / severe**.

2. When the Person Cannot Reliably Self-Report

Use an appropriate **observational pain assessment tool** in accordance with the person's care plan and local policy.

For example, **Abbey Pain Scale** is designed to assist assessment of pain in people who have difficulty communicating.

It looks at areas such as:

Vocalisation – moaning, crying, calling out

Facial expression – grimacing, frowning

Body language – guarding, rocking, resisting movement

Behavioural change – increased confusion, distress or withdrawal

Physical changes – changes that may accompany pain

3. Look for the Cause

Don't stop at recording a pain score.

Consider:

Could it be arthritis? A wound? Constipation? Dental pain? Infection? A fall or injury? Poor positioning?

Also ask **when** the behaviour occurs. A resident who becomes distressed only when being transferred may be communicating something very different from a resident who becomes distressed throughout the day.

Treatment & Management

Treatment should be **individualised and based on the suspected cause, assessment and prescribed care plan.**

This may include:

- Prescribed analgesia
- Repositioning and pressure relief
- Comfortable seating and positioning
- Appropriate movement or mobility
- Addressing constipation or other underlying causes
- Heat/cold or other measures where clinically appropriate and permitted
- Rest and comfort measures
- Medical/nursing review where required

Don't Forget to Reassess

Giving pain relief isn't the end of the process.

ASSESS → INTERVENE → REASSESS → DOCUMENT

Did the pain score reduce?

Did the person's facial expression change?

Are they moving more comfortably?

Did the agitation or resistance reduce?

Important Teaching Point

If a resident who normally accepts personal care suddenly begins shouting or hitting out when being moved, don't immediately document “aggressive behaviour.” Assess whether movement is causing pain.

4. Refusal of Care in Dementia

“What do we do when a resident says NO?”

A person living with dementia may refuse **personal care, medication, food, assistance with dressing, continence care or other support.**

A diagnosis of dementia does not automatically mean a person cannot make decisions or that their wishes can be ignored.

First Ask – Why?

Refusal may be communicating:

- **Pain or discomfort**
- Fear or anxiety
- Embarrassment
- Not understanding what is happening
- Not recognising the staff member
- Feeling rushed or overwhelmed
- Previous negative experiences
- Desire for privacy or independence
- Tiredness
- Personal or cultural preferences
- Simply **not wanting the care at that particular time**

How Should Staff Respond?

STOP – don't force the situation.

- Remain calm and respectful
- Give the person time and personal space
- Explain simply what you would like to do
- Offer **choices** rather than demands
- Try a different approach
- Consider whether a **familiar staff member** would help
- Step away and **try again later** where safe to do so

- Consider pain, illness or another unmet need
- Maintain the person's privacy and dignity
- Report and document repeated or significant refusal
- Review the care plan if refusal becomes a pattern

Consent & Capacity

Remember:

Capacity is decision-specific and should not be assumed absent simply because a person has dementia.

Support the person to understand and participate in the decision as much as possible.

Mary normally showers every morning. Today she repeatedly says “NO” and pushes the carer's hand away when they try to remove her nightdress.

Do we need to get Mary showered because it's in her care plan — or do we need to understand why Mary is saying no?

Then explore: **pain? fear? cold? embarrassment? unfamiliar staff? doesn't understand? would she prefer a wash? another time?**

KEY MESSAGE

Don't turn refusal of care into a confrontation. Stop, reassess, change the approach and preserve the person's dignity.

5. Managing Responsive Behaviours

What Can I Actually Do?

Responsive behaviours may include **calling out, pacing, repeated questioning, resistance to care, agitation, wandering, verbal aggression or striking out.**

Rather than asking:

“How do I stop this behaviour?”

Ask:

“What is this person trying to communicate?”

1. Stop & Observe

Before immediately intervening, look at what's happening.

- What exactly is the person doing?
- When did it start?
- What happened immediately beforehand?
- Who was present?
- Is this normal for this person?
- Is there an obvious trigger?

Describe what you see rather than labelling it.

✗ *“Mary was aggressive.”*

✓ *“Mary shouted and pushed my hand away when I attempted to assist her with dressing.”*

That gives us information we can actually use.

2. Check for an Unmet Need

Think **physical first**:

PAIN – could something hurt?

TOILET – constipation, urinary urgency or retention?

HUNGER / THIRST

TIREDDNESS

TOO HOT / COLD

INFECTION OR ILLNESS

MEDICATION CHANGES

The Joymac material specifically identifies pain, acute illness, dehydration, constipation and medication changes as things to investigate.

Then think **emotional**:

**Is the person frightened? Lonely? Bored? Overwhelmed? Looking for somebody?
Trying to fulfil an old routine?**

3. Change Your Approach

Sometimes **we are the trigger**.

Ask yourself:

- Am I rushing?
- Am I standing over the person?
- Am I giving too many instructions?
- Have I approached from behind?
- Am I arguing or correcting?
- Does the person understand what I'm asking?
- Would another/familiar staff member get a better response?

Slow down. Lower your voice. Give one instruction at a time. Allow processing time.

4. Change the Environment

Look around.

Reduce:

Noise • crowds • clutter • bright glare • unnecessary stimulation

Increase:

Comfort • familiar objects • appropriate lighting • personal space • calm surroundings

Environmental factors are actually built into the ABC assessment in the Joymac material.

5. Validate – Don't Argue

If John says:

“I need to go home. My wife will be waiting for me.”

Avoid:

 *“John, your wife died ten years ago. This is your home now.”*

Instead acknowledge the emotion:

 **“You sound worried about your wife.”**

Then gently redirect:

“Tell me about her. What was her name?”

You're responding to the **emotion behind the words**, rather than trying to win an argument about reality.

6. Distract & Redirect

If appropriate, gently move attention towards something meaningful:

- Cup of tea
- Favourite music
- Photographs
- Walking
- Folding towels
- Gardening
- Familiar conversation
- Helping with a simple task

But the activity needs to mean something **to that particular person**.

7. Know When to Step Away

If the situation is escalating and there is no immediate danger:

STOP → GIVE SPACE → ALLOW TIME → TRY AGAIN

Particularly with personal care.

Trying harder isn't always better. Sometimes **five or ten minutes and a different approach** completely changes the interaction.

The Joymac material itself recommends personal space, avoiding arguments, calm redirection and non-threatening body language.

8. Afterwards – Learn From It

Don't just write:

“Resident became aggressive.”

Document:

BEFORE → BEHAVIOUR → RESPONSE → OUTCOME

What happened beforehand?

What exactly did the person do?

What did staff try?

What worked?