Distressed behaviour

All behaviour has a reason. It can be a way for people to communicate difficult emotions, such as frustration or distress, or get a need met.

A person can feel a sense of distress for many reasons, including their environment, past experiences, discomfort, or physical or emotional pain. This can trigger behaviour which matches the level of distress they feel.

Finding yourself in an unfamiliar place or with unfamiliar people can be deeply unsettling, especially when memory or cognition is affected.

Understanding the feelings that are causing a person's distressed behaviour is incredibly important, and can allow you to respond thoughtfully and compassionately to reduce their distress and improve wellbeing.

The term "challenging behaviour" implies that a person is being difficult. While acknowledging that the situation may be challenging for someone, a better term is "distressed behaviour" which is preferred by people living with dementia and helps us focus on the feelings of the person.

This guide provides practical tips, tools, and examples to help carers to respond with compassion, respect and confidence.

Dementia and distress

- Dementia is an umbrella term that is used for many different types of diseases which affect the brain — including Alzheimer's Disease, Vascular Dementia, Lewy Body Dementia and Frontotemporal dementia.
- Dementia damages the brain over time, so it gets worse (progressive). Cognition and capacity can fluctuate, with natural 'good' and 'bad' days.
- Everyone experiences dementia differently — no two people are the same.
- People with dementia are trying to make sense of the world, which can lead to frustration or distress. This can affect how they behave.
- All behaviour has a reason. It's our job to be curious and find out why.

Stress vs distress

Stress is a build-up of everyday pressures that affect the mind and body. Over time, it can impact how we feel, causing low mood, anxiety, or changes in behaviour.

When stress becomes too much, it turns into **distress**, and this can happen to anyone, not just people with dementia.

Triggers of distress

Triggers can suddenly cause strong reactions like anxiety, fear, or anger by activating our natural fight, flight, or freeze response. Common distress triggers include:

- a busy, noisy, or unfamiliar environment (sensory overload)
- reminders of past trauma, like familiar faces, smells, music, food, or certain situations.

Be aware of the impact of pain, delirium, UTI, infections, hydration, constipation, medication, depression, environment, your own behaviour, other long-term health conditions, and medication on a person's behaviour.

Understanding the triggers of distress and what comforts someone, along with knowing their life story, is essential for making sense of their behaviour and providing truly person-centred care.

Common signs of distress

Appearing to react to things that other people can't see or hear

Shouting, swearing, screaming or banging things

Not looking after personal hygiene

Inappropriate or risky behaviour

Crying, groaning, or complaining

Changes in eating or drinking

Low mood or depression

Lack of interest or motivation (apathy)

Signs of anxiety, including:

- tapping, rubbing
- restlessness or needing to leave
- repeating "help me" or similar phrases
- feeling alone, lost, or scared
- saying they're being treated badly
- pacing or walking around
- repeating questions
- picking at hair, skin, or clothes

Difficulty communicating

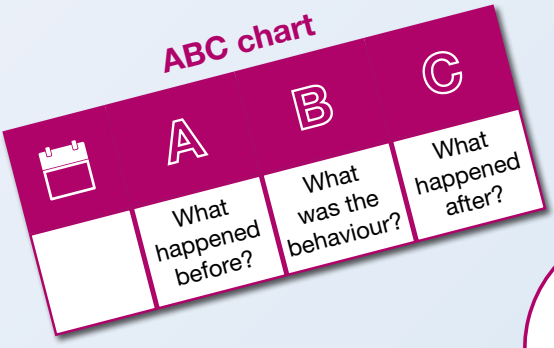
Trouble sleeping at night

If we don't respond to a person's distress, it can lead to:

- exclusion and stigma
- poor care and a negative care environment
- more use of medication or removing people from settings
- stress and burnout for carers and staff
- injuries, like falls
- tension and conflict in families
- complaints
- lower quality of life and wellbeing

How to support someone in distress

- Stay calm – be aware of your body language and tone of voice
- Pause and take a breath before responding
- Keep communication simple – use short statements and visual cues, don't ask too many questions
- Don't argue, correct, or criticise
- Offer a distraction or a quiet space
- Help calm the situation – spend time with the person and ask gentle questions like: "What's happening?" or "How can I help?"
- Listen and accept how they feel – even if it's not true for you, it feels real to them
- Learn about their life story
- Talk to colleagues or family to better understand their behaviour.



Helps explore what the person might be seeing, hearing, feeling, or needing

Use tools like an ABC chart or Empathy map. **See appendix for more info.**

Top tip Be curious

What might be going on for the person living with dementia? Are they acting differently? How would they usually respond to difficult feelings? Try to understand what they might be feeling, and why.

Here are some common behaviours and what could be behind them:

- Touching, moving, or staring at things – they may be confused about who they are or where they are, trying to make sense of their surroundings.
- Wanting to leave the house or asking for mum/dad/work – they might feel lost or think they're in the wrong place, looking for safety or comfort.
- Asking the same questions over and over – this could come from fear, confusion, boredom, or wanting to connect with others.
- Lack of motivation – they might be feeling low, sad, or helpless.
- Being suspicious or accusing others – this can be caused by confusion, mistrust, or feeling lonely.

Should we lie to people living with dementia?

This is a personal and sometimes tricky question, and there is no 'one answer'. The best response to difficult questions depends on the person and the situation.

Sometimes all those involved in someone's care decide that it's best to use 'therapeutic lying' by not confronting them with a truth that may be distressing to them. As an individual worker you should follow the care plan for each person.

In social care, the focus is on kindness, dignity, and reducing distress. We should always focus on those priorities.

Alternatives to lying

You don't always have to either lie or fully agree with a person whose reality has been impacted by dementia — there are often kinder ways to respond that sit in the middle.

Here are some helpful approaches:

- **Validation:** Acknowledge how they're feeling.

  Example: ***"You miss your mum. She was very special to you."***

- **Distraction:** Gently change the focus to something calming or familiar.

  Example: ***"Let's have a cup of tea"*** or ***"I wonder what's on TV."***

- **Reframing:** Use gentle, supportive language that fits their world.

  Examples: ***"Let's wait here together until she arrives."***

  Neutral comments can help such as ***"it's always nice to be with good friends."***

These approaches help reduce distress while still being respectful and kind.

When avoiding the truth can be helpful

Sometimes, gently changing the truth can avoid upsetting the person or reducing confusion and risk if their understanding of reality has been affected by dementia.

For example, if a person is distressed because they want to go for a drive, saying ***"the car is at the garage"*** instead of ***"you can't drive anymore"*** can help to avoid distress.

But be careful: sometimes, the person might realise you're not being fully honest. They may go along with it but feel unsure if they can trust you, which can make care harder later on.

It's all about balance:

- Telling the full truth can sometimes cause pain or confusion
- Gentle fibs or redirection can protect their emotional wellbeing

What matters most is your intention: support the person, not just ease your task. If one response doesn't help, try a different approach.

Be kind to yourself

- Ask for help when you need it
- Take a moment to check in with yourself – How am I feeling today?
- Think about how you're spending your time – is it helping you? Maybe swap some screen time for a walk
- Speak to yourself the way you would to a friend
- Stay connected with others
- Take care of your body. Eat well, drink water, move your body, and get enough sleep
- Try to see things differently – We might not be able to do XYZ, but we can still...

Possible scenario or storytelling

You're supporting a lady living with dementia at home. During your visit, she makes frequent comments to you. How should you reply? Think of the feelings behind what she is saying. What might her need be?

"Have you seen my mother? She doesn't know I'm here — she'll be worried about me."

Possible feelings

- Fear or anxiety
- Loneliness
- Need for safety and reassurance
- Confusion about time/ place
- Desire for connection and familiarity

Possible replies

"It sounds like you're missing your mum. You're safe here with me. Tell me more about her?"

Why this works

It validates the emotion (worry, longing), reassures safety, and invites connection through reminiscence.

“We’re good friends, aren’t we? We used to work together.”

Possible feelings

- Desire for companionship
- Need for validation and belonging
- Searching for identity and purpose
- Comfort in familiar roles or memories

Possible replies

“Yes, we’ve spent time together. I’d love to hear more about your work — what did you enjoy most?”

Why this works

It affirms the relationship, supports identity, and encourages storytelling, which can be comforting.

“Call the police, I don’t live here – I’ve been kidnapped, I need to get home”

Possible feelings

- Confusion or disorientation
- Loss of agency and control
- Wrongdoing
- Need for safety and reassurance
- Feeling trapped or misunderstood.

Possible replies

“That sounds really frightening. You’re safe now, and I’m here to help. Let’s sit down together and talk about what’s worrying you.”

“How scary for you. How can we make this better?”

Why this works

It acknowledges fear without confrontation, reassures safety, gently redirects and offers connectivity.

“I can’t talk right now, I’m a teacher and they will be expecting me at school.”

Possible feelings

- Sense of duty, purpose or responsibility
- Need for routine and structure
- Holding onto identity, occupation and self-worth
- Confusion about current reality
- Desire to be useful and recognised

Possible replies

“It sounds like being a teacher means a lot to you. What was your favourite part of the school day?”

“I used to love school, especially PE and the dinners”

Why this works

It honours their identity and role, validates their sense of purpose, redirects with dignity and opens the invitation to reminiscence/life story.

Terminology

The words we use matter. Negative language can lead to unfair judgments, stigma, and even rushed decisions about care or medication. Using respectful, accurate terms helps promote understanding and better support.

Words commonly used	Alternatives and thoughts to consider
Non-compliant	Unable to participate at this time. Are they expressing a preference? Finding it difficult to communicate? Need more time or support? Showing signs of discomfort or uncertainty?
Resistant	Preferring not to... Expressed signs of discomfort, overwhelm or uncertainty about... Are they seeking autonomy, reassurance, protecting their boundaries, preferring a different approach? Maybe they aren't ready to engage or it's a sign of emotional distress or concern?
Refused	Chose not to Expressed a preference for [example] instead Did not wish to Was not comfortable with... Needed more time with... Responded differently to...

Words commonly used	Alternatives and thoughts to consider
Challenging	X showed signs of [shouting, agitation, picking hair/skin, being withdrawn, wanting to go home] Emotionally driven when [spoken to, getting dressed, having a bath] Could it be behaviour that is communicating a need? Signals discomfort? Invites curiosity? Reflects unmet needs? Requires deeper understanding?
Aggressive	Frustrated/distressed X became emotionally overwhelmed when Y happened Communicating discomfort, reacting to unmet needs, was seeking safety or control, responding to confusion or fear, displaying protective behaviour, experiencing heightened emotions or expressing themselves strongly

Words commonly used	Alternatives and thoughts to consider
Sufferer	Can imply passivity, victimhood, or a lack of agency. Use the person's name if you know it. If referring to a group of people: ■ Person living with dementia ■ Individual affected by dementia ■ Person experiencing dementia ■ Person with a diagnosis of dementia ■ Individual navigating dementia ■ Person supported through dementia ■ Someone on a dementia journey ■ Person with dementia (if preferred by the individual)
Burden	Can be emotionally charged and imply that someone is a problem or an inconvenience Taking care of or supporting X with... Care commitment or responsible for Shared journey with family/care workers Emotional impact Life adjustment Ongoing support requirement Part of the caring relationship A role that requires compassion and resilience

Words commonly used	Alternatives and thoughts to consider
Argumentative	Can imply confrontational or difficult behaviour X was expressing strong opinions on/when... Feeling misunderstood or unheard Responding with emotion Expressing a need for control or clarity Demonstrating assertiveness Reacting to confusion or distress Engaging in a protective response Attempting to make sense of the situation
Sundowning	Can describe increased confusion, agitation, or distress that often occurs in the late afternoon or evening – although distress can happen any time of day. Late-day distress/tiredness End-of-day or (time of day) anxiety or overwhelm. Evening behavioural changes – due to lack of light/vulnerability. Circadian rhythm (body clock) or routine disruption

Appendix

Empathy map

An empathy map is a visual and practical tool that can support people to reflect and become curious about what could be happening for another person. It could be used for individuals to complete or in reflective group setting.

As you populate the map, ask yourself:

Who are we empathising with?

- Who is the person we want to understand? What is the situation? What is their role in the situation?

What do they need to do?

- What do they need to do differently? What job do they want to get done? How will be know they were successful?

What do they hear?

- What are they hearing others say? What are they hearing from friends or colleagues?

What do they think and feel?

- What are their pains (frustrations, anxieties of fears)? What are their gains (hopes, dreams, wants or needs)?

What do they see?

- What do they see in the market, in their environment? What are they watching or reading? What are others doing?

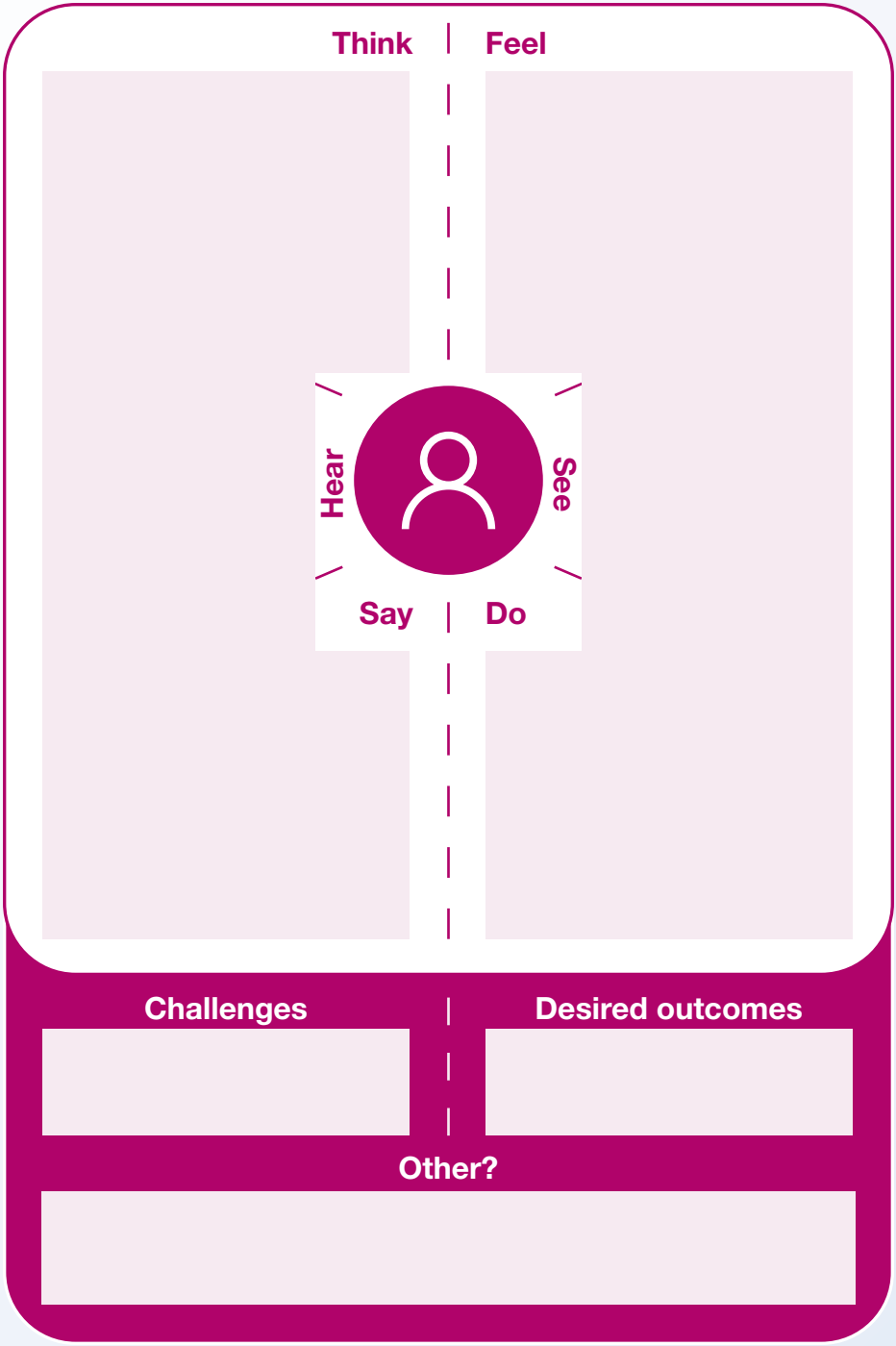
What do they do?

- What behaviour do we observe? What can we imagine them doing?

What do they say?

- What have you heard them say, or imagine saying?

Other feelings/thoughts that may motivate their behaviour?


Think
Feel
Hear
See
Say
Do
Challenges
Desired outcomes
Other?

ABC (Antecedent, Behaviour, Consequence) Chart

An ABC chart for dementia is a tool used by caregivers to track and analyse behavioural and psychological symptoms of dementia by recording the Antecedent (what happened before), the Behaviour (what occurred), and the Consequence (the outcome) of an event.

By observing these patterns, caregivers can identify triggers for challenging behaviours and develop effective, person-centred strategies to improve well-being and manage distress.

In the behaviour log, fill in:

A – Antecedent (triggers)

What happened immediately before the change in behaviour?

- Who was involved? What activity was going on? When did the behaviour occur? How (in what way or manner)?

(Consider any potential unmet needs)

B – Behaviour

What was the behaviour you would like to change?

- Describe the behaviour observed i.e. yelling, kicking, swearing. What happened? How long did it last?

(Consider any potential unmet needs)

C – Consequences (Responses)

What happened after the behaviour occurred?

- How did the person living with dementia respond?
  How did others around the person respond?
  Who else was involved?

Date and time	A Antecedent	B Behaviour	C Consequences

Visit skillsforcare.org.uk/dementia to download the resources and find more support on dementia.