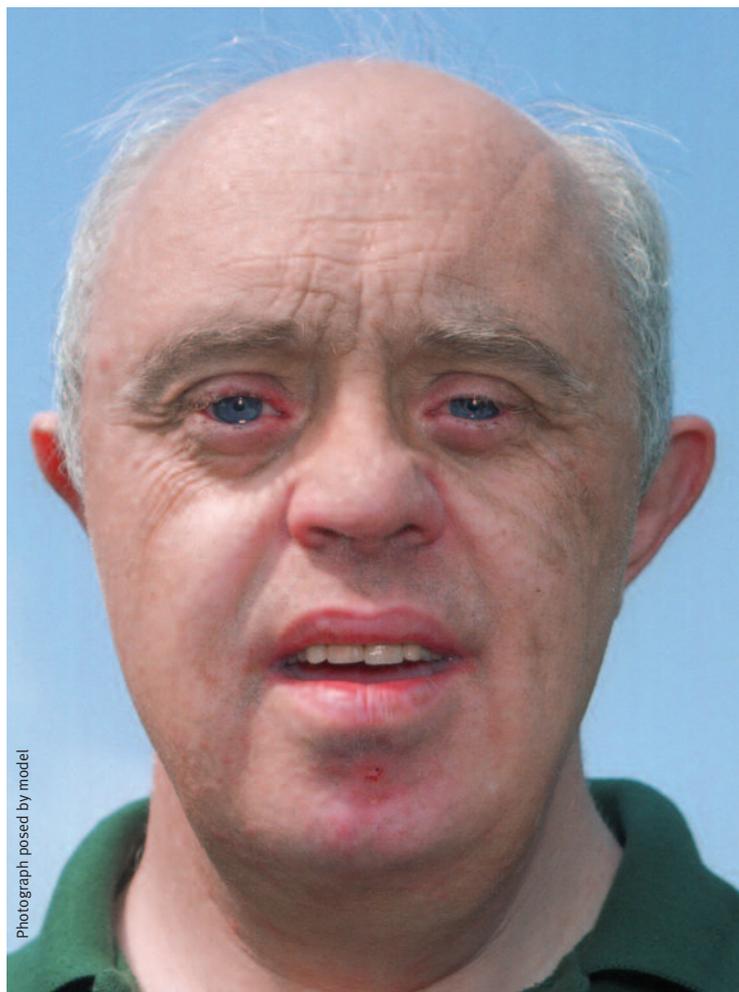


Do you recognise pain in someone with a learning difficulty and dementia?

A guide for care staff and carers



Photograph posed by model

What is the problem?

Someone with a learning difficulty and dementia may not be able to tell you they are in pain. Their pain is often ignored, not noticed, or mistaken for challenging behaviour. Recognising and treating this pain can vastly improve their lives and the lives of those around them.

Signs that someone is in pain

- Withdrawal
- Hitting out
- Night-time disturbance
- Shouting
- Pacing
- Problems eating
- Screaming
- Crying
- Aggression
- Confusion

Common causes of pain

- Musculoskeletal disease
- Dental problems
- Impacted earwax
- Eye infections
- Urinary tract infections
- Constipation

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Why does it happen?

People are generally living longer, which means that more people with a learning difficulty are experiencing conditions and illnesses that come with old age.

People with dementia, and people with a learning difficulty, often have problems communicating. This can make describing pain very difficult – especially if someone has both dementia *and* a learning difficulty.

If someone has been diagnosed with dementia or a learning difficulty, any challenging behaviour is likely to be seen as part of these conditions, without considering whether anything else, like pain, could be having an effect. This is called ‘diagnostic overshadowing’.

Past experiences, particularly of unpleasant or scary medical situations, mean that some people don’t want to admit that they are in pain because they are scared of what will happen to them.

Temporary carers from agencies won’t be familiar with the subtle changes in someone’s behaviour that might show they are in pain.

Dementia can mean that the part of the brain that understands the ‘geography’ of the body is damaged, so people can not show where they are experiencing pain.

It is often (wrongly) believed that people with a learning difficulty have a high pain threshold, so members of staff do not consider that someone could be in pain.

What can you do?

Arrange for the person to see their GP as soon as possible for appropriate pain management. Record the person’s behaviour and what you consider to be signs of pain to help the GP. Remember that your knowledge of the person can help the GP.

Ask for advice from your manager if you need support in making decisions around pain assessment.

Check the person’s posture and seating. Are they sitting upright and can they put their feet flat on the ground? Are they well supported in their seat?

Look at ways to manage pain that don’t involve taking medicine (non-pharmacological pain management), such as:

- aromatherapy oil and massage
- massage mattress
- music that the person likes
- whirlpool, bubbles, peace and quiet, warm bath
- calmly asking about the pain
- being slow and relaxed when moving people
- pressure sore cushion
- special comfort chairs
- comfort at night – blankets, warmth etc.

Helping the person to relax tense muscles will make the pain more bearable.

Life-story work (talking to someone about their past and recording their thoughts with mementos and photos) with people, ideally before they develop dementia, will help those around them to understand their past, which will help to explain their present behaviour.

For more information, including a factsheet and a guide for GPs, go to: www.jrf.org.uk/dementia/

For the full report, *Responding to the pain experiences of people with a learning difficulty and dementia* by Diana Kerr, Colm Cunningham and Heather Wilkinson, go to: www.jrf.org.uk/painexperiences/