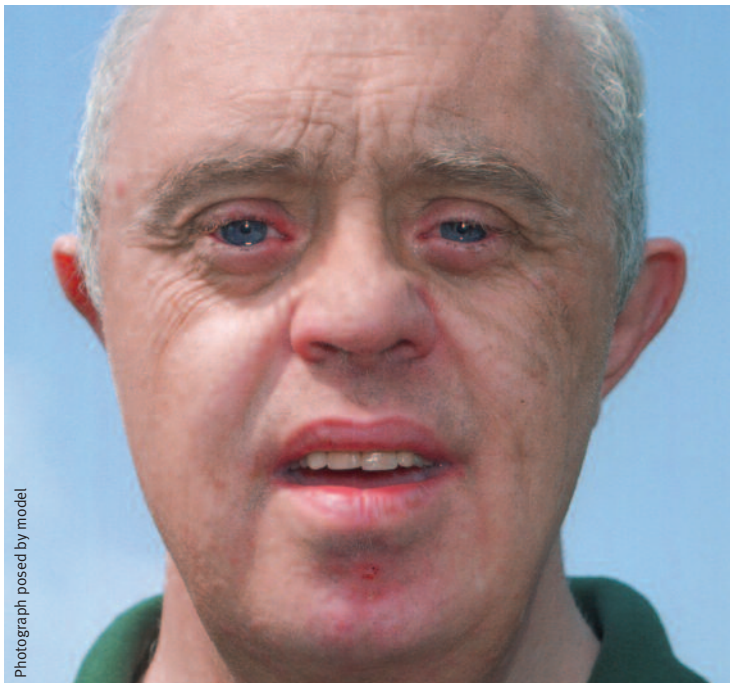


Do you recognise pain in someone with a learning difficulty and dementia?

Responding to the pain experiences of people with a learning difficulty and dementia (2006)

Diana Kerr, Colm Cunningham and Heather Wilkinson

A factsheet for care staff and carers



People with learning difficulties are living longer and this means they are more likely to develop the conditions of older age, such as dementia. When people with dementia are in pain it is often mistaken for challenging behaviour, or ignored. Research was carried out to look at people's experiences of pain, staff and GPs' understanding of pain, good practice in treating people, and recommendations for practitioners and service providers. This is a summary of the key findings of the report.

For more information, including a guide for GPs and a guide for care staff and carers, 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/

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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Experiences and views of people with a learning difficulty

'I have to put up with it when I am in bed, but I can't sleep.' (Man with dementia)

- Staff need to help people with a learning difficulty and dementia to show when they are in pain.
- Pain management should be regular and not given only when staff think someone needs it.
- Staff should remember that people may wake up in the night because they are in pain and not just because they have dementia. They should think about using a painkiller at night-time.
- It is important to make sure people have the right sort of seat. Special seating adapted to the individual's needs should be considered.

Problems with pain recognition

'We used to know him quite well... he would let you know his immediate needs... now he has dementia it's really hard to know when he is in pain.' (Staff)

- All staff who care, support and treat people with a learning difficulty and dementia need to be trained about knowing when someone is in pain. The training should look at:
 - how pain can be affected by different things and how only the person in pain knows how bad it is and how they feel
 - why people with dementia find it more difficult to communicate
 - how different behaviour could show that someone is in pain.
- Staff should have training about challenging behaviour, which looks at how dementia affects people and why this might change their behaviour.
- Staff should be trained to know that someone might display challenging behaviour because they are in pain.
- It is better not to use agency or bank staff because they will not know the person so well. If agency or bank staff are used they need the same training as other staff.
- Life-story work (talking to someone about their past and recording their thoughts with mementos and photos) helps staff to understand why someone behaves in a certain way. It is most useful to do this before the person develops dementia.

Knowledge, experience, role and views of staff

'Since we have taken part in your research we are offering pain relief to our residents... then we discovered that this [pain] was her problem.' (Manager)

- Support staff need training about what people with a learning difficulty and dementia need if they are in pain.
- All staff should use the same, simple system to record any information about the person's pain and treatment.

- Staff should develop a relationship with a GP who understands what people with a learning difficulty and dementia need.
- Organisations need to have clear and simple instructions for staff to use when they need to contact GPs.
- There are guidelines that staff and GPs should follow when using painkillers, for example NICE (2004) *Improving Supportive and Palliative Care for Adults with Cancer, Recommendation (2)*. London: NICE. Available at: www.nice.org.uk/Guidance/CSGSP [accessed September 2008].
- Staff should think about treatment that doesn't use drugs, for example aromatherapy oil and massage, music, warm baths, special comfort chairs etc.

GPs

'He will listen to staff and he will book double appointments, the last one we had we were with him for 20 minutes, he does listen.' (Staff)

- GPs should study learning difficulties when they are training.
- GPs should be encouraged to specialise in learning difficulty and dementia.
- There needs to be a tool to help GPs find out why someone has pain and how much they have.

The community learning disability team

'Since receiving the leaflet about the pain study, two of the people with a learning disability and dementia who had challenging behaviour were treated for pain and their behaviour has significantly changed for the better. We did not think that it might have been pain, I feel really bad that we didn't think about pain first.' (Community nurse)

- Members of the community learning disability team (CLDT) need to know more about the effects that age and dementia have on people with a learning difficulty.
- Pain should be a bigger part of the CLDT assessment of people with a learning difficulty and dementia.
- There needs to be a tool to find out why someone has pain and how much they have.
- CLDT members and support staff should regularly look at the pain and treatment of people with a learning difficulty and dementia who might be in pain.

Common painful conditions

'She had slept in an upright position for some time. On the fourth day after she came here we discovered that she was quite constipated. We gave her an enema and since then she has slept comfortably back on her pillows.' (Matron)

- Staff should know about the different conditions that might cause pain as people with a learning difficulty and dementia get older.
- The needs of people with a learning difficulty and dementia should be looked at in policy and planning.