



How social care staff can recognise and manage pain in people with learning disabilities

Pain management



It can be hard to recognise if some people with learning disabilities are in pain.

People with learning disabilities may not say they are in pain. They may not act in a way that you would expect people in pain to act.



It is particularly difficult to know if someone is in pain if they do not communicate verbally.

People who have additional health needs, especially those who are immobile or wheelchair dependent, are likely to suffer from long-term pain.



Sometimes when people are in pain they may display challenging behaviour – this might include trying to hurt themselves or others.

Other people may become quiet or withdrawn or they may show unusual behaviours like laughing or crying.

This sort of change in behaviour should not just be assumed to be because they have a learning disability. They might be showing that they are in pain.



Many people with learning disabilities will not ask for medication for their pain. So, it is important that support workers notice if someone may be in pain.

If you think someone is in pain but pain medication does not seem to be helping then seek medical advice.



Some people believe that people with learning disabilities can tolerate more pain than the general population. This is not true.

People with learning disabilities, like non-disabled people, will have individual and different responses to pain.



It is important not to treat everybody with learning disabilities as though they can cope with a lot of pain.



It is important to think of when people might be in pain:

- someone with epilepsy might have a headache after a seizure
- women may have pain when they have a period
- when people are dying they are often in pain but we know that people with learning disabilities are less likely to have their pain well controlled when they are dying



Signs and symptoms that a person may be in pain include:



Aggression directed towards themselves or others

Changes to how the person holds or moves their body, including altered facial expression



Changes to mobility or balance

Change in behaviour, such as tearfulness, irritability or withdrawal



Changes to appetite or vocalisation



Confusion

Restlessness or changes in their sleep patterns

What social care staff can do



Ask yourself if the person you support is showing any of the signs or symptoms that might be because they are in pain.

Do not assume they are pretending to be in pain to get out of doing something or to get attention.

Take their temperature.

Check whether they are constipated.

Communicate with their GP or other medical professionals.





Use pictures to help the person you support to communicate if they are in pain and to find out where the pain is.



There are tools that can be used to help to recognise pain or distress in people with learning disabilities. (see below)

If you are not sure if a person is in pain it is better to assume they are than to ignore it.



Have a plan about what to do when someone is in pain. This may include giving them medicine such as paracetamol, indigestion tablets or cough medicine.



There are other things that might help people to cope with pain. These include:

- massage
- a hot bath
- a quiet place
- heat treatment



The Royal College of Nursing has easy-read leaflets about pain control in hospital and at home¹.

Tools to help identify pain



My Pain Profile² can be used. This helps supporters to think about the signs that someone is in pain and what to do if they are.



A person-centred pain picture can be used. This is developed with those who know the person best. A traffic light system is used to note how the person will appear when they are well and when they are pain. There is more information about this [here](#).³



The Disability Distress Assessment Tool⁴ (DisDAT) is based on the idea that each person has their own 'vocabulary' of distress signs and behaviours. The tool builds on the ability of family and supporters to identify different signs of distress in individuals. It can be used to record the signs and behaviours of the person when they are content or distressed.



There is an 18 item checklist called Non-Communicating Adults Pain Checklist⁵ (NCAPC). This can help assess chronic pain in non-communicating adults.



Wong and Baker's FACES Pain Rating Scale.⁶ This uses pictures of faces to help people to communicate the intensity of pain from 'no hurt' to 'hurts worst'.

Key messages:

- recognising and managing pain is an important part of health and social care for people with learning disabilities
- people with learning disabilities have individual responses to pain
- unrecognised pain may present as challenging behaviour
- changes in behaviour may be a sign that someone is in pain
- there are tools that can be used to help identify and monitor pain

This is the tenth in a series of health factsheets for social care staff. You can find others and more **guidance** for social care providers.

There is a **supporting set of slides** for this document that can be used by social care staff as a training resource.

The pictures in this factsheet are from Photosymbols: www.photosymbols.co.uk

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PHE supports the UN
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¹ <https://www.rcn.org.uk/professional-development/publications/pub-005600> and <https://www.rcn.org.uk/professional-development/publications/pub-005591>

² <http://www.dyingmatters.org/sites/default/files/user/images/pain%20assessment%20tool%20Notts%20final%20doc.pdf>

³

<https://books.google.co.uk/books?id=XO3sBQAAQBAJ&pg=PA92&lpg=PA92&dq=Pian+pictures+Gwen+Moulster&source=bl&ots=qODSnuxVNY&sig=18YyBM8wTdTXyknmTVjaJZvLFW&hl=en&sa=X&ved=0ahUKEwi7rKnGvvzWAhWLuhoKHW4CkwQ6AEIRTAI#v=onepage&q=Pian%20pictures%20Gwen%20Moulster&f=false>

⁴ <http://www.stoswaldsuk.org/how-we-help/we-educate/resources/disdat.aspx>

⁵ <https://www.painbc.ca/sites/default/files/Non-Communicating%20Adult%20Pain%20Checklist.pdf>

⁶ <http://wongbakerfaces.org/instructions-use/>