National Alzheimer's Project Act (NAPA)

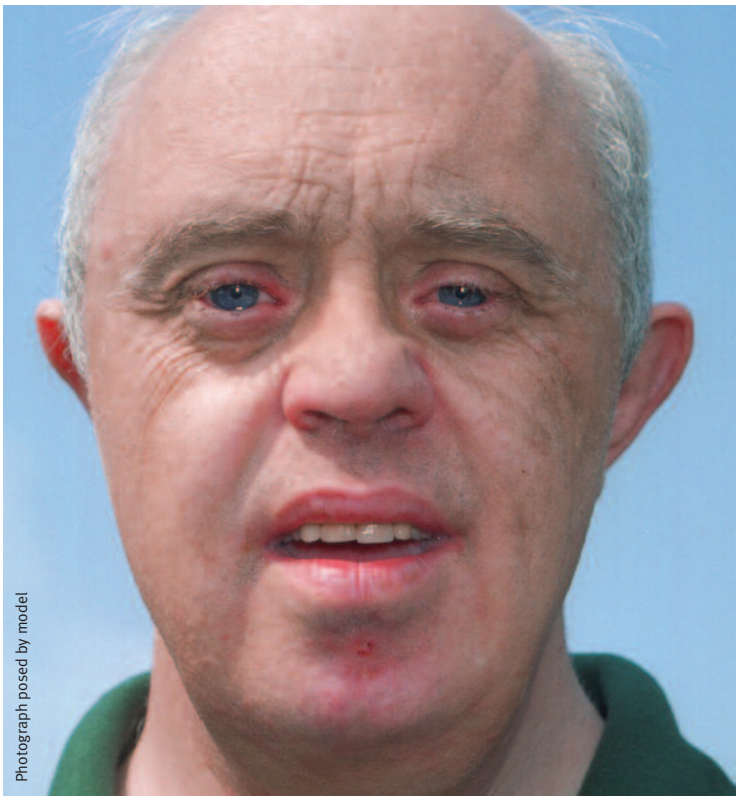
The information that follows was included as an attachment to an email submitted by the public.

For more information about NAPA, visit the NAPA website at:

http://aspe.hhs.gov/national-alzheimers-project-act

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

A guide for GPs

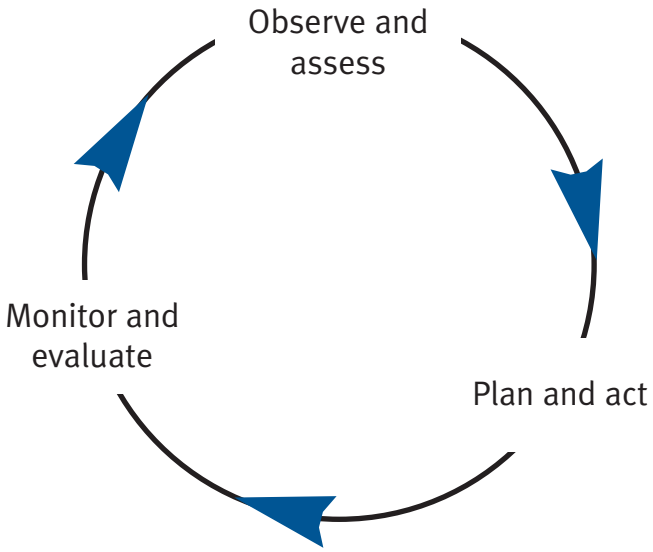


Photograph posed by model

Your patient 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 the lives of people with a learning difficulty and dementia and those around them.

What can you do?



OLM-Pavilion

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Observe and assess: do you have all the information?

Listen to the person and observe them

Showing respect for the person – ensuring that you acknowledge, speak to and listen to them – will help to make sure you get good information so you can make an accurate diagnosis.

It is important to combine this with a full examination, especially if the patient has trouble communicating.

Listen to the views of people who know them well

Remember to talk to the person's carer, who can provide essential information when assessing pain. They know the person best as they are in constant and intimate contact with them. They will have observed subtle behavioural or physical changes and signs that would not be evident during a short consultation.

When carers know that their concerns are taken seriously, they will be more likely to return to the GP with any other concerns in the future.

Use an appropriate assessment tool

When someone has difficulty communicating it is important to use a pain assessment tool that looks for non-verbal signs of pain and how the person has shown they are in pain in the past. Any pain assessment tool should cover six key areas:

- facial expression
- verbalisation
- body movement
- changes in interpersonal interaction
- changes in activity patterns or routines
- mental status changes.

For more information see: American Geriatrics Society Panel on Persistent Pain in Older Persons (2002) The management of persistent pain in older persons. *Journal of the American Geriatrics Society* **50** (6) (supplement) available at: www.americangeriatrics.org/products/positionpapers/JGS5071.pdf [accessed September 2008].

Make sure that there is an effective recording process about pain in place for carers. Clear and effective communication between all the various people involved in supporting the person is essential.

Plan and act: what action can you take?

Consider the use of non-pharmacological interventions

Check the patient'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 for carers to manage the individual's 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
- sitting with the person, 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 patient 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 patients, ideally before they develop dementia, will help those around them to understand their past, which will help to explain their present behaviour.

Use the analgesic ladder

The analgesic ladder is a common framework originally proposed by the World Health Organization (WHO) for prescribing analgesia in a logical, step-by-step approach.

The analgesic ladder (Adapted from WHO, 1996)

Step 3
Administer opioid for moderate to severe pain
+ non-opioid
+ adjuvant

Step 2
Administer opioid for mild to moderate pain
+ non-opioid
+ adjuvant

Step 1
Administer non-opioid medication
+ adjuvant

WHO (1996) *Cancer Pain Relief* (2nd edition). Geneva: WHO.

Caution with the use of 'as required' analgesia

As people with dementia and a learning difficulty may find it hard to indicate that they are in pain, regular analgesia instead of 'as required' (PRN) analgesia is a more effective way of treating pain.

Avoid the use of sedative medication as a first response

Look at pain relief instead of sedatives to control 'challenging behaviour' caused by pain.

Monitor and evaluate: ensure that the pain is managed

Set a date to review the pain management interventions

Regular checks need to be made to ensure that pain relief is effective and that side effects are being controlled.

Monitor the impact of the pain interventions

Make sure that a suitable tool is being used to record the impact and effectiveness of pain interventions and encourage carers to support this.

Identify and record information from medication administration documents

Ensure that any important details are kept with the pain management plan and communicated to everyone involved with the patient, such as:

- Does the person have difficulty swallowing tablets?
- What time of day do they receive medication?

Update the pain management plan

Important information will include:

- When and how does the patient take the medication?
- What non-pharmacological interventions help with pain?
- What helps the patient feel relaxed?

What could be causing the pain?

The conditions listed here are common in older people and attention should be given to whether they are causing pain. It is not a complete list and all the other pains that people may have because of their individual circumstances and conditions, will still be there.

Musculoskeletal disease

- Musculoskeletal disease increases in frequency with age.
- It has been found to be more likely in women and is thought to be attributable to high frequencies of osteoarthritis and osteoporosis.

Dental problems

- Ageing leads to a general deterioration in dental health and people with a learning difficulty are much more susceptible to dental decay and gum disease.
- The impact of poor or inconsistent dental care earlier in life has a major impact in older age.
- Many people with a learning difficulty have not been able to take adequate care of their teeth.
- Some may have had experiences of the dentist that have made them reluctant to seek further help.

Impacted earwax

- This can cause pain, discomfort, dizziness, noises in the ear and hearing loss. It can also lead to ear infection and, therefore, additional pain.
- People with a learning difficulty are twice as likely to have impacted earwax as the general population.
- It is worth considering that people with dementia also have problems with chewing. It may be that this also increases their susceptibility to impacted earwax.

Eye infections

- People with Down's syndrome are particularly susceptible to dry and infected eyes.
- Blepharitis causes dryness and redness of the eyelid margins and increases the risk of infection. It is particularly uncomfortable and irritating during the morning.

Urinary tract infection

- Older people with a learning difficulty can experience higher levels of recurrent urinary tract infection than the general population.
- It should be noted that many of the underlying causes of urinary tract infection are easily treated, for example, urethral stenosis, benign prostate enlargement and bladder stones.
- The higher incidence of diabetes in people with a learning difficulty, coupled with the reduced food and fluid intake as a consequence of dementia, also increase risk of a urinary tract infection.

Constipation

- The general slowing down of the gastrointestinal system in older age can lead to constipation as well as diarrhoea and irritable bowel syndrome.
- The pain associated with constipation can be severe and lead to behaviour that can easily be misinterpreted and, therefore, mistreated.
- People with dementia, unless monitored and supported, will not drink sufficient quantities of water which increases susceptibility to becoming constipated.

For more information, including a factsheet 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/

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