DOWN'S SYNDROME ASSOCIATION

Pain and people who have Down's syndrome

December 2024

Introduction

People who have Down's syndrome experience the same chronic conditions as the general population, although they are at a higher risk of having health conditions that mean pain is more likely.

Common Causes of Pain

The following list isn't exhaustive, but these are some of the more common reasons why someone may be in pain:

- Dental problems
- Gastroesophageal reflux
- Bladder problems
- Ear infections
- Gastrointestinal discomfort (could be Coeliac disease /constipation)
- Arthritis
- Subluxation of the joints especially in the cervical spine
- Emotional distress
- Injury

People with verbal skills and a wide vocabulary may still have difficulty expressing the extent of their pain and the location.

Where people have communication challenges, pain may be harder to identify. Research indicates that people who have learning disabilities are less likely to receive appropriate intervention and treatment and therefore have poorer health outcomes.

People who have Down's syndrome and pain

For those supporting people who have Down's syndrome it is important to know that pain may not be communicated as pain, but as another feeling such as discomfort or worry. If the person is finding it hard to express their pain, they may feel upset, anxious or low in mood.

It may be necessary to look for non-verbal clues that someone is unwell or feeling uncomfortable. Any changes in mood, routine, appetite or behaviour may indicate that there is something wrong. Any sudden change in behaviour should be investigated.

Other indicators of pain could include:

- Difficulty sleeping
- Lack of engagement
- Restlessness
- Anger
- Apathy
- Tearfulness
- Grimacing
- Pointing to a body part
- Using a spoken phrase that is not typical
- Sweating for no apparent reason
- Holding a limb differently

People who have Down's syndrome and pain

There may be times when a person is obviously in pain but unable to communicate that fact to others. Some people may not tell you about a painful condition to avoid further medical treatment. Pain that is left untreated can lead to further complications.

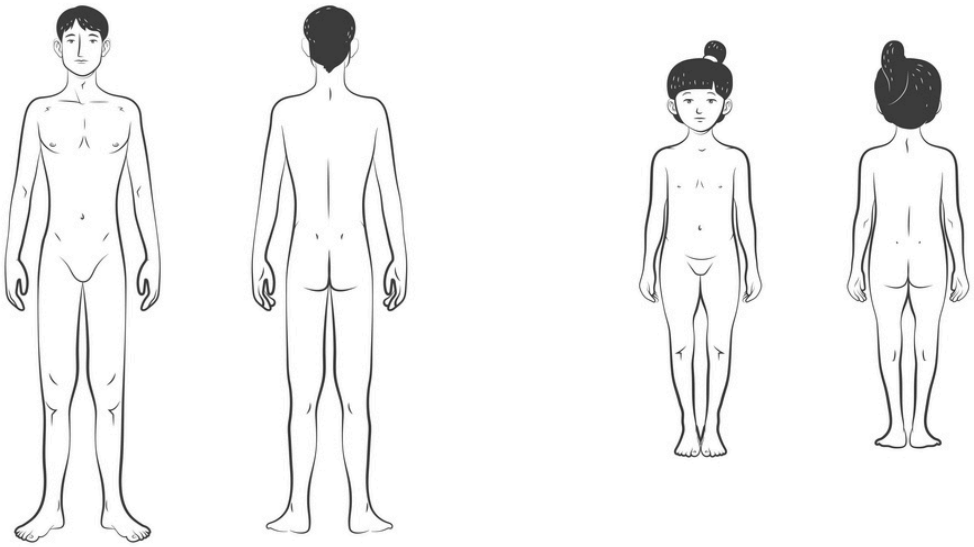
According to Chicoine and McGuire (2021), many people who have Down's syndrome seem to have reduced and delayed pain responses. This is not necessarily an insensitivity to pain but that their expression of pain is delayed and less precise. They go on to suggest that it is hard to tell if people have a decreased ability to sense or localise pain, a higher pain tolerance, or if the reaction to pain is delayed. A higher pain tolerance would reduce the drive to seek help or treatment for the pain.

Non-communication of pain does not necessarily mean that the person is not in pain. It is important to understand that people may demonstrate different pain responses.

What Might Help

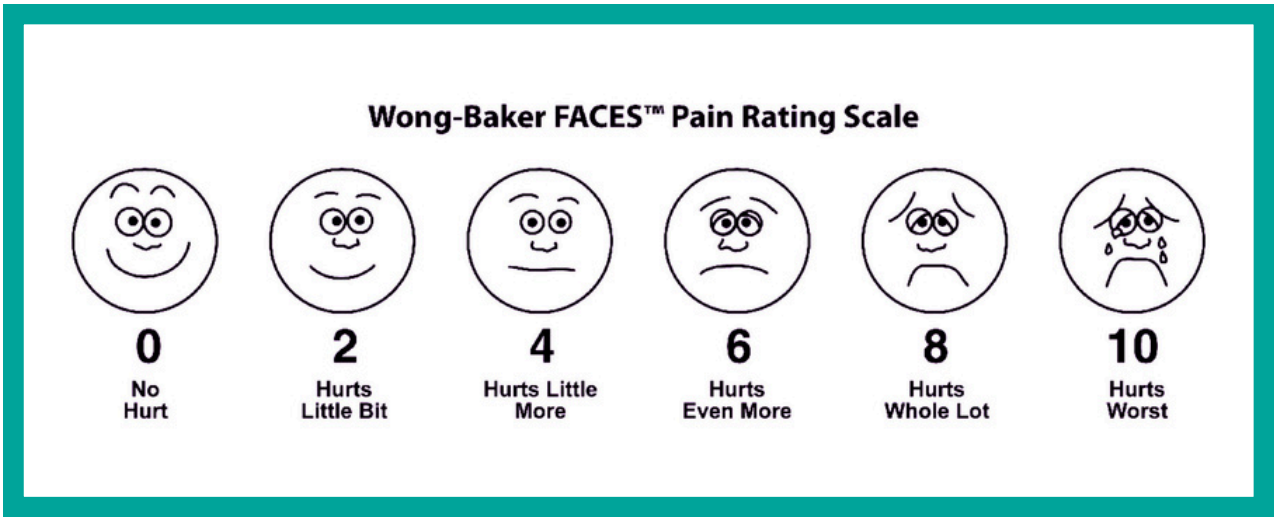
It may be necessary to use visual supports to help people identify pain and the degree of pain. Body maps can be helpful as the person can point to the place where they are feeling the pain.

Below are some examples, others can be found online:



Some people may be able to identify pain by pointing to parts of their own body or by pointing at a doll or cuddly toy.

The use of symbols, signs, pictures, photos and simple visual pain scales can also be helpful. A commonly used tool is the Wong and Baker's FACES Pain Rating Scale. This uses pictures of faces to help people to communicate the intensity of pain from 'no hurt' to 'hurts worst'.



DisDAT (Distress and Discomfort Assessment Tool)

The DisDAT is an assessment tool to help identify and document the signs and behaviours of people who have limited verbal communication.

It can be used to record behaviours when a person is calm and when they are distressed. It may take a while to complete but it is a useful tool if the person is admitted to hospital or staying away from home. The distress may be caused by several factors in the checklist including pain.

A free download of the DisDAT is available here.

In addition to those already mentioned, there are other tools such as the 18 point Non-Communicating Adults Pain Checklist (NCAPC).

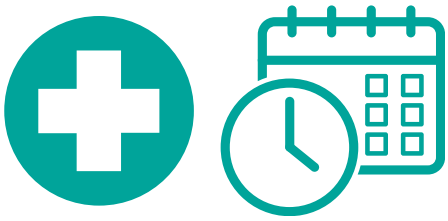
Any assessment of pain should always include the input of others who know the person well. If it is difficult to ascertain whether the person is in pain, it is better to assume and treat as if they are.

What To Do

If you know the cause of the pain and it does not require further investigation then the person may benefit from relaxing activities such as a warm bath, slow deep breathing and gentle movement.

If there are no contraindications (can be checked with a pharmacist), you may decide to provide over the counter pain relief.

If you suspect that the person is in pain and you are unable to ascertain the cause, please make appointment with your GP and explain your concerns.



If you feel there needs to be an urgent response, take the person to A&E.
It may be worth making a dental appointment to rule out dental pain.

The information contained in this document is up to date as of 19 December 2024 and is subject to change. To find the latest version go to downs-syndrome.org.uk

References

Mental Wellness in Adults (Chicoine & Mcguire, 2021)

Learning Disabilities Toolkit (Royal College of Emergency Medicine, 2024)

Wong-Baker Faces

Resources

Pain Scale - Example - Mencap

My Pain Communication Kit - Leeds & York NHS

How social care staff can recognise and manage pain in people with learning disabilities - Public Health England

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