

# PAIN

## in people with Down's syndrome

### Information for Parents and Carers

**People with Down's syndrome have similar pain tolerance levels to the general population.**

The difference is that not everyone with Down's syndrome will recognise pain or know how to get help. Those who do understand and recognise pain may lack the skills to tell other people. Don't assume the person you care for knows about their body or what it feels like to be healthy.

Down's Syndrome Scotland has a range of publications about health, written for people with a learning disability. Look at these with the person you care for and encourage them to ask questions about health and illness, using appropriate communication methods.

Medical screening has shown that people with Down's syndrome can have a number of undiagnosed painful medical conditions. A change in behaviour in people with learning disabilities could be due to undiagnosed conditions such as arthritis and chronic respiratory conditions. It is important that carers are aware of any signs of pain.

#### **Changes that may indicate signs of pain in a person with Down's syndrome:**

- Loss of interest in activities
- Social withdrawal
- Guarding or protecting areas of the body
- Shouting and screaming
- Loss of concentration
- Increase in aggression or destructiveness
- Rigid, tense body posture
- Loss of appetite or refusing food
- Distress
- Increased pacing or rocking
- Facial grimacing
- Increase in levels of self-harm or targeting one area of the body
- Increased vocalisations such as sighing, moaning or groaning
- Changes in skin colour

#### **REMEMBER**

- Each person will have their own unique way of behaving when they are in pain.
- People with Down's syndrome may behave in a similar way when they are in distress and not in physical pain.
- Unexplained pain is very frightening.
- It is important to identify the reasons for any change in behaviour.

# Supporting and helping a person with Down's syndrome who is in pain

Families and carers who know a person with Down's syndrome well can instinctively tell when something is not right. They can pick up on subtle changes in behaviour and posture. People with Down's syndrome may be reliant on family and carers to identify pain and distress and to alert healthcare professionals.

Some people with Down's syndrome will not display subtle changes in behaviour. They may display behaviour that carers find difficult such as screaming, self harming, aggression or resistance to care. If someone is displaying different behaviour as a result of being in pain then they are likely to be scared, confused and unable to communicate what is wrong in any other way.

It is important that carers try to identify the behaviour and posture of the person they care for when they are not in pain. If this changes, they will be able to identify pain and distress quicker. It is also important that these signs are explained to everyone who supports the person they care for.

## To help prevent pain carers can:

- Ask the doctor for an annual check-up for the person they care for. This could identify any current painful conditions or highlight warning signs of any future problems.
- Support the person they care for to visit the dentist regularly.
- Help and support the person to eat a healthy diet.
- Encourage and support the person to take some exercise or do some light physical activities.
- Learn more about the health problems commonly associated with Down's syndrome. This information can be provided by Down's syndrome Scotland.

## To help support a person who is in pain carers can:

- Ask the doctor for a longer appointment. This will give carers and the person more time to explain what is wrong and to ask any questions.
- Follow the instructions on medication exactly. Medication is only effective if taken regularly and at the right dosage level.
- Just being with the person can be very reassuring.
- Try to find activities that will distract the person from their pain but which will not make it worse such as listening to music, light exercise, helping out around the house or garden, watching television.
- Pain can be the result of a number of physical problems or illnesses, but can also be due to mental ill health conditions such as depression. Ensure that all possible causes for the pain are investigated and treated.

Supporting a person with Down's syndrome who is in pain can be difficult, both physically and emotionally. Make sure you find some time to take care of yourself.

## Down's Syndrome

SCOTLAND helping people realise their potential

Down's Syndrome Scotland 158/160 Balgreen Road Edinburgh EH11 3AU

Tel 0131 313 4225 Fax 0131 313 4285 E-mail [info@dsscotland.org.uk](mailto:info@dsscotland.org.uk) Internet [www.dsscotland.org.uk](http://www.dsscotland.org.uk)

Written by Lynda Russell, 2006