Chronic Pain Management

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Editor's note: Dr. Smith, medical director at the Down Syndrome Clinic of Wisconsin at Childrens’ Hospital presented a review of pain management literature at the 2011 Down Syndrome Medical Interest Group (DSMIG) meeting and provided his findings to Down Syndrome News. Always consult your physician first.

Acute and chronic pain is common in adults with Down syndrome (DS). Acute pain that is delayed in diagnosis may become chronic.

Signs of pain may not be recognized easily.

There are several reasons to think about pain in adults with DS.

• Many adults with DS have some arthritis, particularly in the neck, but also knees and hips.
• Many people with DS do not communicate well, especially under stress. Even if they typically communicate fairly well, they may not understand what is happening to them and thus are unable to communicate it. Rather than complaining of pain, they may change their behavior.
• All people change their behavior when they don’t feel well, but most of us can talk about it. Behaviors in people with DS are frequently misattributed to their having DS, or to dementia. For example, “stubbornness” may reflect a medical problem —not a cognitive delay!
• The geriatric and dementia literature supports looking at behavior to diagnose chronic pain and then using a treatment trial to see if pain caused the behavior change.

A protocol is recommended for physicians in evaluating and treating pain in people with DS.

1. Ask the patient. Put the answer into the context of all the data.
2. Ask the caregivers or parents. What is the change? Caregivers should be concrete in describing the behavior, not just saying what they think caused it. A change of behavior or function is a reason for seeking medical advice, but is often not recognized as due to pain.
3. Perform an examination, including observing how the person with DS acts. For example, consider pain if person is rubbing his neck, limping, refusing to walk, or not allowing people to touch certain areas. Examine the joints, neck, and back for evidence of pain or arthritis (e.g., limited ability to turn neck).
4. Evaluate further as needed. If the cause of the pain is treatable (e.g., gallbladder disease, colitis, ulcers, dental pain, gynecologic problems, headaches), treat the cause.
5. Otherwise, begin a medication trial by starting with acetaminophen (650 mg three or four times a day) on a routine basis, not just as
needed. Nonsteroidal anti-inflammatory drugs (e.g., ibuprofen, naproxen) can have significant side effects in people with DS, so should be avoided. After two weeks, stop and evaluate for benefit — benefit may not be obvious until the medication is stopped. If there is no significant improvement, try a low dose narcotic pain medication, oxycodone (one half of a 5 mg tablet three times a day), routinely for two weeks. Hold if drowsy. At the same time, prevent constipation with both a stool softener and stimulant (one to three Senokot-S® tablets twice a day — adjust to a steady dose so you don’t “confuse” the colon). Reduce dose if diarrhea. Underlying constipation may also require a dose of MiraLax®.

6. If medication trial is beneficial, continue medication and consider additional treatments such as physical therapy.