

DYSTONIA

Bottom Line 'Evidence-Informed' Recommendations for the Management of Dystonia in Individuals with Cerebral Palsy

Authors (AACPD M Dystonia Care Pathway Team): D Fehlings (team lead), L Brown, A Harvey, K Himmelmann, JP Lin, A MacIntosh, J Mink, E Monbaliu, J Rice, J Silver, L Switzer, I Walter.

Plain Language Summary

Dystonia is commonly seen in cerebral palsy (CP). Dystonia causes increased stiffness in the muscles associated with a body part getting stuck in uncomfortable postures. This in turn can cause pain, disrupt sleep and make care-giving activities such as dressing difficult. Dystonia can be focal involving only a few body parts or generalized involving many muscles in the body.

The first step to managing dystonia is determining how severe the dystonia is and how it is impacting on the individual. A rehabilitation therapist is often involved in the assessment and can recommend important strategies such as seating and determining if splinting will be helpful. If the dystonia is generalized and causing pain or interfering with function the next step is often the introduction of oral medications to decrease the dystonia. A common oral medication used is baclofen. Other medications can also be considered for specific indications. For example, a medication called gabapentin can be used for painful dystonia. If a few muscles are consistently stiff and painful then a medicine called botulinum toxin can be injected into the stiff muscles and this can help them temporarily relax. If many muscles are very stiff, then more aggressive treatments can be considered such as a treatment called deep brain stimulation or intrathecal baclofen. Deep brain stimulation involves placing an electrode stimulator into the deep part of the brain called the globus pallidus and stimulating this area of the brain to reduce the dystonia. Intrathecal baclofen involves placing a catheter into the fluid around the spinal cord to deliver the baclofen medication to reduce dystonia. Both treatments involved care by a specialized health care team.

One of the important features of dystonia is that it changes a lot in its severity and location. This means that the amount of treatment required can vary and should be re-evaluated on a regular basis by the health care team. The successful treatment of dystonia can bring about improved comfort for the individual with CP and enhance ease of care-giving.

