

# **AACPD M Care Pathways Cerebral Palsy and Dystonia**

2024

## **Plain Language Summary**

Dystonia is a movement disorder that can cause slow uncontrolled movements and muscles to get stuck in uncomfortable positions. People with cerebral palsy (CP) often have dystonia. This 'Care Pathway' looks at different medicines and surgeries that can help people with CP manage dystonia. It is for people of all ages with CP and dystonia that is causing "interference", meaning challenges with activities, sleep, pain, sitting, or caregiving. The 'Care Pathway' was put together with the help of doctors, therapists, people with CP and dystonia and their families.

You/your child should only consider medicines or surgery when dystonia is causing interference. This Care Pathway did not look at rehabilitation treatments such as specialized wheelchair seating, but these are often used with medicines and surgery. Managing dystonia requires a team of doctors, therapists, and nurses. It is important for this team to help you/your child to consider different options and choose an approach that matches your goals and what matters most to you. Your healthcare team will complete an assessment to understand the severity of dystonia and how it is impacting you/your child's life. This assessment may include looking at different movements, stretching muscles to measure stiffness, and asking questions about how dystonia impacts daily activities, pain/comfort, and sleep.

When dystonia affects all of the body ("generalized") and causes interference, oral medicines such as baclofen can be used. Since different people can have different benefits and side effects, a medication trial can help you decide if this is a good option for you. We suggest trialing baclofen first, however you/your child and your physician can also consider a trial of trihexyphenidyl or benzodiazepines. If the dystonia is severe, especially if you/your child is in pain from the dystonia or are having difficulty sleeping or being comfortable when you are sitting, other medicines can also be considered such as clonidine and gabapentin. If you see no benefit or no longer wish to take these prescribed medicines, speak with your healthcare team, as they must be stopped slowly to prevent withdrawal symptoms.

When dystonia is more severe, affecting all or most of the body ("generalized"), and does not respond to medicines, you can consider intrathecal baclofen (ITB) or deep brain stimulation (DBS). ITB involves placing a tube with the baclofen medicine into the fluid around the spine. DBS involves placing small wires into a deep part of the brain and stimulating this area. Both DBS and ITB require a specialized health care team. If you/your child experience rapid and severe increases in dystonia (a health emergency called "status dystonicus" or "dystonic crisis"), it is important to seek urgent medical attention. Please see our guide in Section 3 called 'Status Dystonicus: A quick reference guide for recognition and management' for more information on this.

When dystonia is affecting one part of your body ("focal" or "segmental"), for example your arm, and is causing interference, you can consider botulinum neurotoxin type A (BoNT-A) injections into a few targeted muscles.

The severity of dystonia can fluctuate and change over time. This means that your treatment may need to change too. You/your child should see your health care team for on-going care so that you can work together to decide on the best treatments over time for you.