



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.
Reaching Out, Providing Help, Giving Hope

When to See An Orthopaedic Surgeon

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Orthopaedic surgery deals with problems of the musculoskeletal system and several can occur in children who have Cornelia de Lange Syndrome. Birth weight in CdLS is often less than five and one-half pounds, and throughout growth children are usually below the third percentile for height, weight, and head circumference. Adults remain smaller than average. At birth a bony spur may be felt projecting downward from the middle of the lower jaw. This almost always disappears by a child's first birthday.

Problems with the arms and hands are the most common orthopaedic findings. Small hands, curved fifth fingers (clinodactyly), and short thumbs require no treatment. Webbing between two or more fingers (syndactyly) can be corrected and may allow better hand use. Limitation of elbow motion is very common and sometimes there is painless dislocation of the upper end of the radius bone at the elbow. Treatment attempts to increase elbow motion are often disappointing. In children who have severe involvement, fingers, metacarpals, and even a forearm bone may be absent. Despite this, most children will use their arms and hands quite well. Attempts at using partial artificial limbs to improve function are usually, but not always, rejected by the children.

Children May Walk at Later Age

Most children with CdLS do not walk independently before three years of age. Conversely, many achieve walking later in childhood, making treatment of lower extremity problems very important. Concern about a child who is not walking merits a good physical examination, but x-rays are not often needed. In nearly every case the cause is delayed neurological development and not a specific orthopaedic problem.

Very small feet are the rule and there may be problems with the foot. Webbing between toes almost never needs treatment. Bunions, much like those seen in adults, sometimes develop, but these rarely need any treatment other than providing shoes with toe areas that are wide enough. Clubfeet usually require surgical correction during the first year, and this is almost always very successful.

Some children are born with substantial portions of their feet missing. An orthopaedic surgeon can determine if a prosthesis will be helpful. Other problems, such as tight heel cords, can be corrected to improve standing and walking. Tightness of the hamstring muscles and inability to fully straighten the knees may occur and should be treated in children who walk.



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Five to ten percent of children with CdLS develop a hip problem with the socket becoming shallower during growth. It may be wise to check an x-ray of the hips every two or three years to make sure this is not happening. If it is, hip surgery will likely be needed and is almost always successful. Another hip problem that occurs in up to ten percent of children with CdLS is Legg-Calve-Perthes disease, a temporary loss of the blood supply to the ball part of the hip. This usually appears as limping and may be the cause of easy tiring. It will usually require treatment.

While scoliosis (sideways curvature of the spine) sometimes develops during childhood, it is not common in CdLS. Small curves are checked periodically, but not actively treated. Moderate curves may be treated with a brace until the child's growth is complete. A brace will usually stop, but not straighten, an increasing curve and does not work in all cases. Children with unpredictable behavior may not tolerate brace treatment. Large curves require surgery to correct them.

Modern spine surgical techniques are very safe and effective, do not require casts or braces afterwards, and rarely require more than five or six days of hospitalization.

When Surgery is an Option

These are the major musculoskeletal problems that can occur in people with CdLS. When surgery is necessary, evaluation for congenital heart problems, gastroesophageal reflux and other intestinal problems should usually be done. Preoperative detection and careful management of the related conditions makes surgery for musculoskeletal problems a safe and realistic option that may provide great benefit.