



CdLS Foundation

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

Orthopaedic Issues in CdLS

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Musculoskeletal troubles are common in individuals with CdLS, with some problems occurring at birth and others arising with age. Major issues involving the limbs at birth include absent hands and/or forearms, missing digits (toes/fingers) and club feet. The most common orthopaedic findings in CdLS are as follows:

- small hands and feet;
- incomplete extension of the elbows, often due to
- dislocation of the forearm bone at the elbow;
- incurved and short fifth fingers;
- short thumbs placed low on the hand; and
- skin webbing between the second and third toes.
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Most children with CdLS will use their arms, hands, and shortened forearms very well, particularly since fine motor skills are a strength in CdLS.

Elbow issues – It's important for therapists working with individuals with CdLS to understand that the elbows may not be able to fully extend because of a boney defect. Stretching will not improve this ability.

Missing hands/fingers – Surgery is rarely helpful for absent hands or missing fingers, and prostheses for the forearms or hands do not usually improve function compared to the child's own ability.

Club feet –Surgery should be performed for club feet in infancy (if casting has not been successful).

Lower extremities – Surgery may be needed for release of tight heel cords and occasionally for hip dysplasia in older children.

Scoliosis – Curvature of the spine may be present, but rarely needs surgical correction.

Bunions – These boney bumps on the joint of the foot, at the base of the big toe, are very common with aging in CdLS. Management measures often include nothing more than wider, looser shoes.

Walking – The majority of children with CdLS walk independently somewhat later than their peers. However, despite the small size of their feet, almost all individuals with CdLS are ambulatory by adulthood, as long as their feet are in good weight-bearing position. A child



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who is not walking merits a good physical examination, but x-rays are usually not needed, and the cause is more likely developmental than orthopaedic. Specific walkers may be recommended, depending on the abilities of the upper extremities.