

CdLS

Ages 0-3

<p>What kind of professionals will my child need?</p>	<p>General physician – addresses the overall health of your child Audiologist and Ophthalmologist – addresses any visual and hearing impairments Orthopedist – addresses musculoskeletal issues your child may encounter Cardiologist – addresses heart health, specifically congenital defects Nephrologist – assesses kidney function Gastroenterologist –assesses digestive function Physical Therapist – addresses musculoskeletal and mobility impairments Occupational Therapist – helps your child interact with the environment and learn independence Speech Therapist - helps your child communicate effectively Psychologist - addresses the emotional and social health of your family</p>
<p>What other conditions may affect my child?</p>	<p>GERD – Gastroesophageal reflux disease can be treated with medication, diet changes, or with the surgeries listed above.</p> <p>Vision impairments – Degree of impairment varies from child to child, but most children with CdLS need glasses</p> <p>Hearing impairments – Degree of hearing impairment varies from child to child; hearing impairments often contribute to delays in speech development</p> <p>Developmental delays – Children with CdLS often have low birth weight and a delay in achieving some developmental milestones because of this and other aspects of CdLS</p> <p>Respiratory and feeding difficulties – Due to gastric problems like GERD or congenital diaphragmatic hernia (an abnormal hole in the diaphragm muscle where the stomach can protrude into the chest; this can be fixed surgically)</p> <p>Seizures can occur with no specific pattern, but can be treated with medication.</p> <p>Behavioral problems – Sleeping issues, aggression, hyperactivity can occur in children with CdLS, but can be treated with various therapies.</p> <p>Congenital heart disease – Ventricular and atrial septal defects can be repaired surgically early in the baby’s life.</p> <p>**It is important to know that these conditions are more common in individuals with CdLS, but a diagnosis of CdLS does not mean that your child will develop them.**</p>
<p>What kind of surgeries will my child need?</p>	<p>Surgery is not always necessary, but can be helpful depending on what kind of impairments your child may have. Surgeries can address digestive, musculoskeletal, hearing, or visual problems. This is a list of a few options, but</p>

	<p>consult your doctor for more information</p> <ul style="list-style-type: none"> • Fundoplication and gastrostomy are surgeries that can help address issues of GERD and malnutrition. Intestinal malrotation (abnormal twisting of the intestines) may also be surgically corrected. • Limb correction surgery can be performed if a limb abnormality significantly impairs mobility. This is only done in severe cases. • Orchiopexy is a surgery performed during infancy in cases of cryptorchidism (undescended testis) • Cardiac surgery may be necessary to repair any septum defects in the heart
<p>What therapies are available?</p>	<p>Drug therapy is not used to treat CdLS directly, but may be used for seizures, GERD, and behavioral symptoms.</p> <p>Physical therapy helps keep muscles strong and flexible, which is important for children with joint contractures and hypertonicity. PT can help with walking and using gross motor skill to kick a ball or ride a bike.</p> <p>Occupational therapy helps to teach your child how to care for him/herself and establish independence. This can range from toileting to dressing to writing.</p> <p>Sensory integration therapy helps overcome problems experienced by many young children in absorbing and processing sensory information. Encouraging these abilities ultimately improves balance, and steady movement.</p> <p>Special braces are commonly used with PT and can help compensate for muscle imbalance and improve mobility of an affected limb or joint.</p> <p>Speech therapy helps your child learn to use throat and face muscles properly to communicate, eat, and breathe properly.</p> <p>Water therapy or aqua therapy reduces the pressure on the child’s bones and joints, enabling them to move more freely than they can on land. It helps increase muscle strength, improve coordination, increase endurance, and relieve stress.</p>
<p>What kind of assistive devices are available?</p>	<p>Adaptive devices are commonly used for children with CdLS, especially to help with proper body positioning and mobility. Please use the informational list of adaptive devices, consult your physician, or check out the websites listed below.</p> <p>Wheelchair – used to make getting around easier and can also help in correcting posture and body position</p> <p>Car seats, stroller, and push chairs – help with proper positioning and posture while doing everyday activities</p> <p>Orthotics (particularly for the foot) – to correct some bone deformations</p>

	<p>and make walking easier, prevent hip migration, and prevent joint contractures</p> <p>Tricycles – not only for recreational use, but also used for physical therapy purposes</p> <p>Walkers and gait trainers – help support your child while walking (and learning to walk)</p> <p>Toileting chairs, Sleeping aids, Table and chairs, Bathing aids –used to make everyday activities more manageable</p> <p>Special handles and grips - for eating utensils, pens, pencils, making it easier for your child to hold things.</p> <p>Communication aids – such as a book or poster to spell out messages, and specialized computers that can talk for your child if he/she is difficult to understand.</p> <p>Computer technology – can help with multiple daily activities, like scanning documents, typing, pointing, etc. This can be very helpful if your child is non-verbal.</p> <p>Helpful websites: http://pattersonmedical.com/ http://www.ottobockus.com/ http://www.especialneeds.com/home.php</p>
What sort of expectation should I have for my child’s intellectual development?	Each child with CdLS usually experiences moderately delays in all areas of development, but severe speech delay is typical. Children who have severe speech impairment are likely to have intrauterine growth retardation, hearing impairment, upper-limb malformations, and some motor delays. The amount of intellectual capability varied from child to child and depends on the degree of the syndrome. Consult with your doctors to help understand what can be expected of your child.
What sort of expectation should I have for my child’s physical development?	Physical development depends on the severity of CdLS. Any major malformations are normally surgically correctable. It is important to monitor your child’s physical health as he/she grows in order to ensure the best outcomes. Again, it is impossible to tell what any child will be capable of, but consult with your doctor for more information.

CdLS

Ages 4-12

From the ages of 4-12 you will still need to continue using the same information as above about what doctors to consult and therapies that are available, so please refer back to the chart for ages 0-3. This chart includes additional things you may need to do after your child turns 4.

What should I continue to do?	<ul style="list-style-type: none"> - Keep regular appointment with your general physician, audiologist, ophthalmologist, cardiologist, nephrologist, and other therapists. Regular check-ups help to monitor potential complications that may come as your child grows. - It is especially important to consult your orthopedist in cases of hip deformities that may require surgery. - Enjoy your child!
What will my child	Going to school is important for emotional and social development of your child.

do for school?	<p>Your child has a right to attend public school and receive the same free education as every other child. Before sending them to school, you should know if your child has a learning disability or physical disability that may impair their learning. If he/she does, then they qualify for special education assistance. Depending on the school district, your child may be “mainstreamed” and placed in general education classes with everyone their age, but with a modified work to accommodate their learning disability. This is known as “inclusion” in the public schools. Your child may also be placed in a special education classroom with other students who qualify for special education accommodations.</p> <p>Additional information about Individualized Education Programs (IEP): US Department of Education</p>
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CdLS

Ages: 13-18

What new challenges will my child experience as he/she gets older?	<p>Puberty can be a difficult time, but it may be especially challenging for teens with CdLS. Continue with regular appointments with your doctors to monitor your child’s health and consider how therapies, surgeries, and adaptive devices described above may help your child.</p>
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CdLS

Ages: 19 and beyond

What new challenges will my child experience as he/she gets older?	<p>Although CdLS is not a progressive disease, it is important to continue with regular appointments with your doctors to ensure that no complications arise and any life-threatening issues (like heart defects) are addressed. People with CdLS live well into adulthood.</p>
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References

1. CdLS Treatment Protocols. CdLS Foundation, Inc 2011. Available at: <http://www.cdlsusa.org/what-is-cdls/treatment-protocols.htm>. Accessed on: March 27, 2011.
2. Medscape Reference: CdLS. Medscape 2011. Available at: <http://emedicine.medscape.com/article/942792-overview>. Accessed on: April 1, 2011.
3. CdLS overview. CdLS World, 2011. Available at: <http://www.cdlsworld.org/xwiki/bin/view/CdLSWorld/What+is+CdLS>. Accessed on: April 1, 2011.
4. Benson, Melanie. Cornelia de Lange syndrome: a case study. *Neonatal Netw* 2002 21; 3: 7-13.
5. Liu, JL., Baynam, G. Cornelia de Lange Syndrome. *Diseases of DNA Repair* 2010. 685: 111-123.
6. My Child’s Special Needs. US Department of Education. Available at: <http://www2.ed.gov/parents/needs/speced/iepguide/index.html>. Accessed on: April 2, 2011.