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# **Primary Lymphedema in Children and Adolescents: Understanding a Rare but Significant Condition**

## **Introduction**

Lymphedema is not just an adult condition—it can affect children and adolescents, too. While less common, primary lymphedema in younger populations presents unique challenges in diagnosis, treatment, and long-term management.

## **What is Primary Lymphedema?**

Primary lymphedema is a chronic condition caused by a malformation or dysfunction of the lymphatic system. Unlike secondary lymphedema, which is caused by damage or obstruction from surgery, cancer treatment, or infection, **primary lymphedema is congenital or hereditary**. It results from developmental abnormalities in the lymphatic vessels that impair normal lymph drainage, leading to fluid accumulation and swelling—most commonly in the limbs.

## When Does It Appear?

Primary lymphedema can manifest at different stages of childhood:

- **Congenital Lymphedema** (present at birth or within the first year of life)
- **Lymphedema Praecox** (develops during puberty or before age 35, often in girls)
- **Lymphedema Tarda** (onset after age 35, though rare in pediatric cases)

The most common form of lymphedema in children and adolescents is **lymphedema praecox**, which typically emerges during puberty's hormonal and growth changes.

## Causes and Risk Factors

Primary lymphedema is often idiopathic (no identifiable cause), but in some cases, it's linked to genetic conditions such as:

- **Milroy Disease** – congenital lymphedema, often affecting the lower limbs
- **Meige Disease** – typically begins in adolescence
- **Turner Syndrome, Noonan Syndrome**, and other rare hereditary disorders

Family history plays a significant role in many of these conditions, although spontaneous mutations can also cause them.

## Signs and Symptoms

Early recognition is crucial. Symptoms of primary lymphedema in children and teens may include:

- Persistent swelling in one or both legs, feet, or (less commonly) arms
- A feeling of heaviness or tightness in the affected limb
- Hardening or thickening of the skin over time (fibrosis)
- Recurrent skin infections (cellulitis)
- Discomfort, embarrassment, or self-consciousness—especially during adolescence

Swelling may be subtle at first and worsen gradually. It sometimes becomes more noticeable after prolonged activity or heat exposure.

## Diagnosis

Diagnosing lymphedema in children can be complex. A thorough clinical evaluation is key, often supported by imaging tests such as:

- **Lymphoscintigraphy** (to assess lymphatic function)
- **MRI or ultrasound** (to rule out other causes of swelling)
- **Genetic testing** (if a hereditary condition is suspected)

Pediatricians may refer to a lymphedema specialist or vascular anomalies clinic for comprehensive assessment.

## Treatment and Management

While there is no cure for primary lymphedema, **early and consistent management can significantly improve outcomes** and quality of life. Treatment usually includes:

- **Complete Decongestive Therapy (CDT):** A gold-standard approach that combines manual lymphatic drainage (MLD), compression garments, skincare, and exercise.
- **Custom compression garments:** Designed for growing bodies and available in child-friendly styles
- **Physical therapy:** To maintain mobility and reduce swelling
- **Psychosocial support:** Significant for adolescents dealing with body image issues

Surgical options such as lymphovenous anastomosis or lymph node transfer are rarely used in pediatric patients and only in specialized cases.

## Living with Pediatric Lymphedema

With the proper care, children and teens with lymphedema can lead active, healthy lives. Education and support are essential—not just for the child but for the entire family. Working with experienced lymphedema therapists and supportive school staff can make a meaningful difference in daily life and self-esteem.

## Final Thoughts

Primary lymphedema in children and adolescents is a lifelong condition that can be effectively managed. Early diagnosis, compassionate care, and comprehensive treatment are the cornerstones of helping young patients thrive. Increased awareness among healthcare providers and caregivers reduces diagnosis delays and improves long-term outcomes.



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