



PALLIATIVE CARE

What is palliative care? Palliative care is an invaluable approach provided by a specially trained team of doctors, nurses, and other specialists that focuses on enhancing the quality of life for individuals facing complex medical conditions. By prioritizing comfort, relief from symptoms, and emotional support, palliative care helps patients navigate the complexities of their conditions with dignity and grace. Ultimately, palliative care provides compassion, support, and a pathway to a fulfilling life, regardless of the diagnosis.

How do I know if Palliative care is right for my child?

- 1 Is your voice not being heard by your child's medical team?**
Palliative care emphasizes communication. With palliative care support, healthcare providers take the time to listen to patients and families, understand their concerns and answer their questions. This open dialogue fosters a sense of trust and empowerment, allowing individuals to make informed decisions about their care while exploring their hopes, fears, and goals for the future.
- 2 Are you feeling lost and alone while navigating complex decisions?**
Palliative care providers can help by clarifying choices and providing guidance when making difficult treatment decisions or navigating the healthcare system.
- 3 Do you feel like your child's care is disjointed?**
Palliative care uses a multidisciplinary approach, focusing on working with your medical team to create a comprehensive care plan. The palliative care team coordinates care to ensure effective coordination between different providers and services, ensuring seamless care.
- 4 Are you struggling with managing your child's symptoms?**
If your child experiences pain, discomfort, or other distressing symptoms that are not adequately managed, Palliative care focuses on providing relief from the symptoms and stress of a complex medical condition such as CdLS. The goal is to improve comfort and support both the patient and their loved ones.
- 5 Are you struggling to meet your child's complex needs?**
The emotional and psychological impact of your child's illness can be significant; palliative care offers support not just to your child but to the family, providing resources, counseling, and respite care.

If your child/family is struggling with any of these, Palliative Care may benefit your loved one with CdLS and your family.



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How to Access Palliative Care

Accessing palliative care for a child with a rare disease involves several steps to ensure they receive the appropriate support and resources. By following these steps, you can help ensure that your child with CdLS gains access to the compassionate and comprehensive support offered by palliative care, enhancing their overall quality of life.

1

Be Clear About Your Child's Needs:

Begin by assessing your child's specific symptoms and challenges associated with CdLS. Document your child's physical and emotional wellbeing and any relevant family dynamics.

2

Consult the Primary Care Provider:

Discuss with your primary care physician or specialist your desire to incorporate palliative care into your child's treatment plan, outlining the specific needs you have identified.

3

Request a Referral:

If the primary care provider or specialist agrees that palliative care is appropriate, request a formal referral to a palliative care specialist or team. This may involve contacting your area's hospitals, hospices, or palliative care clinics.

4

Finding a Palliative Care Team:

Many hospitals and healthcare systems have specialized palliative care teams. Inquire about these services through the primary care provider. Alternatively, you can search for local palliative care programs using resources such as the Palliative Care Provider Directory (GetPalliativeCare.org), Get Palliative Care, or the Center to Advance Palliative Care.

5

What to do if Your Referral is Denied:

Contact your doctor to discuss the reasons for denial, contact the CdLS Foundation to explore alternative options in your local area, and appeal the decision. Ask about other supportive care services available in your area and consider seeking a second opinion from another healthcare professional if needed.

Other Items for Your Consideration

Explore Telehealth Options:

If in-person services are limited, ask about telehealth options, especially useful for children with rare conditions who may need consultations with specialists in different locations.

Engage with the Palliative Care Team:

Once connected with a palliative care team, participate in an initial meeting to discuss your child's goals, preferences, and any necessary adjustments to the care plan. This team will work collaboratively with your child and other healthcare providers.

Communicate Openly:

Keep communication lines open with the palliative care team and other medical professionals. Regular updates about your child's condition and needs will ensure everyone is aligned to provide the best support.

Involve Family and Caregivers:

Encourage family members and caregivers to be part of the discussions regarding palliative care. Their involvement can provide additional insights into the child's wishes and enhance support.

Evaluate and Adjust:

Periodically review the effectiveness of the palliative care provided and adjust the plan as necessary. Continuous feedback can help tailor the care to fit your child's evolving needs better.