

Physical Therapy Concerns and Answers

Katherine Farr, D.P.T., Texas Children's Hospital, Houston, TX, CdLS Foundation Clinical Advisory Board Member

After attending the Cornelia de Lange Syndrome (CdLS) conference this past year in California, I noticed a common theme for questions and concerns regarding physical therapy and CdLS. I chose to focus on two main subjects: *1) Is Physical Therapy (PT) hurting my child? 2) How can I help him/her progress towards walking?*

First: PT does not hurt your child. While physical therapists are trained to know the limits of the child, it is important to note that you should also develop a relationship and good rapport with the therapist. Knowing the plan for therapy will allow for better understanding of when the child might be crying to manipulate the situation or when the child is truly in pain. The physical therapist has already performed a thorough evaluation of your child and knows the limits to which he/ she can safely be pushed. It has been my experience that a patient crying during PT sessions is due to the patient being pushed past his/her comfort level rather than actual physical pain. In order for any child to progress, though, he/she must be pushed to levels higher than where he/ she is currently functioning.

Second: Issues and concerns with walking. No one can predict when your child will walk; however, there are some key areas to focus on to progress him or her towards upright standing and walking skills. No matter the child's impairments (e.g. limb abnormalities) the key to developing upright standing and walking skills all points back to core strength. The child must be able to control his or her core in various positions (tummy, back, sitting, tall kneeling and standing) to allow for upright standing posture, balance and mobility to progress towards walking. Individualized treatment programs are best for your child; however some commonly seen treatment techniques and equipment used to increase the core strength include various positions on a dynamic surface (Physioball, BOSU ball, peanuts) with multi- directional movements.

To utilize equipment for incorporating balance with core strengthening, use items such as a platform swing, bolster swing, and the U-gallop machine (mimics movements of riding a horse). Utilizing gravity- assisted equipment such as the Universal Exercise Unit allows the child to be in various positions without the effects of gravity inhibiting them from attaining a position.

Please consult with your child's physical therapist prior to initiating any core strengthening activity to ensure that it is safe and appropriate for your child's current level of functioning. Each child's progress toward the goal for walking varies based on family support, patient motivation and severity of the syndrome.

No matter what advice you receive, always know that your child will only be as successful as you expect him/her to be. Remember, even when it seems that the ultimate goal is not being focused on (e.g. walking), PTs are training and preparing the child for

the ultimate goal, just as an adult training for a marathon. There are months of preparation, even years in some cases, before a person competes in a marathon; the same holds true for a child with CdLS attaining physical milestones.

This is only a brief summary of a few of the PT concerns that have been brought to my attention. Each child is unique and differs from the others, requiring an individualized treatment approach based on his or her abilities.

If you have any further questions, please contact Deirdre at the CdLS Foundation at familysupport@CdLSusa.org.

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