

Clinician's Corner

I Never Treat Gross Motor Function Classification System (GMFCS) V; I Treat Children

By Pragnesh Nathavat, BPT, NDT Trained

This child, MH, is already six years old, and he can't sit independently yet. He is at GMFCS V, so I don't think he is ever going to stand or walk now. Pragnesh, please understand you can never change a GMFCS level. So, it's a waste of your time, and still you advise them regular therapy? I have explained the same to his mom. Why in the world you want to treat GMFCS V?" These words rattled my ears during a phone call from an orthopedist who saw my client for the first time. His MRI showed agenesis of the corpus callosum; his body showed quadriplegia with dystonia, and his face showed a mere smile and love.

Well, why in the world I treat GMFCS V? This question from that surgeon brought a lot of thoughts flowing into my mind. Finally, when I asked myself the same question, my answer was, "No, actually I haven't treated GMFCS V. And I would never in my life. Rather, I treat children who may be functioning at GMFCS level V."

His mother is smart, and she, too, understood exactly what GMFCS V meant. Then why did she bear the expense and take her time bringing him for therapy for three long years? Yes, his GMFCS level stayed the same for three years. And the therapy world, including myself, may accept that children do not change levels. That was not my rationale for treating MH. I treated the child and the functions he could achieve, not his classification.

For this child, my first thought was that he is a child with beating heart and lively breaths who has a right to enjoy his life. After bearing that in my mind as the priority, I could then use classification systems and prognoses to evaluate his motor functioning. That is what I have learnt and I have been learning in my Neuro-Developmental Treatment (NDT) courses. First, respect and consider your client as an individual. We treat that individual who deserves to live a

life meeting his potential, who needs to enjoy this beautiful world. We do not treat a classification system; we treat a child.

Working with MH and His Family

When MH started therapy with me three years ago, the biggest challenge in his life and his parents' lives was their night's peace. MH has generalized dystonia, and his arousal used to remain consistently high. He used to cry out the whole night, or he would seem irritated and scream frequently in the midst of silence through the night. I looked at his difficulty having a peaceful night sleep as his participation restriction. I worked to decrease his arousal with strategies that I learned in different Sensory Integration (SI) and NDT courses – whole body compression, proprioception, gentle rhythmic bouncing on a ball, and rocking, relaxing swinging. I also treated him using the principle elongate, align, and activate. He eventually learned that there are many layers between his restless hyper-aroused stage and complete shut-off or sleep stage. And those layers give him the chance to enjoy his lovely surroundings and cherish communication with people. I helped to make him aware that his body can calm down and that can give him an amazing feeling of rest.

That worked, and within a few weeks he started sleeping a full night, and so did his parents! What a change it was in a family's life. I could help them buy peace using our NDT principles and techniques. Hey wait, I couldn't change his GMFCS level. But that is not what I was trying to do. I was not treating GMFCS V; I was just helping a family to make their life better.

Another challenge for MH was his constipation. His pectorals and rectus abdominis are in continuous states of strong contraction most of the time, making any trunk movement difficult and not giving his core muscles any chance to activate. In addition, he used to lie down in bed most of the day. These situations must be affecting his peristaltic movements and must be troubling his digestion and passing of stool. His mounting discomfort may further make him tighten his trunk and extremities strongly, creating a vicious cycle. I found this was also one of the reasons for his low food/nutrition intake. So, I started working with him in sitting for full sessions on an active base of support. I tried hard to teach him to calm down his trunk movement muscles and kick the core muscles in. His parents made an appropriate chair for him to sit in at home, and then he could spend prolonged times in this posture. He started passing stool more frequently. With this change, not only did his trunk movement muscles stop contracting constantly, but his tightened fists started to let go. His diet and nutrition improved,

and this upgraded version of MH could explore life more than ever before. Today, whenever he has a mini-vacation from therapy for more than 10-12 days, he again starts having severe constipation and becomes tight. With the restart of therapy, he returns to his previous comfort in 2-3 sessions.

As we continue in therapy, we are working for orientation of his head so that he can sustain good eye contact with others. We work on his core muscles and his visual and vestibular orientation using the same principles of ABC (alignment, base of support, and centre of mass) to keep his trunk and head well-oriented in space, and that gives him ample opportunities to enjoy relationships with his parents, siblings, and others. He enjoys listening to music and visual toys and sometimes also holding his favorite toys in his hands. Ultimately, it's all about his comfort and satisfaction and that of his family's.

The Purpose of Therapy

MH's GMFCS level was V, and it is still V. I could not change it, because I never tried to change it. I work instead to help him and his family expand their participation in life in meaningful ways. I am happy that I never treated his GMFCS level. I am happy that I could help him and his family sleep, smile, and live with comfort and peace.

After consultation with the orthopedist when his mom was again at my clinic the next day, I could not resist telling her, "It is fine that someone again reminded us that MH is at GMFCS level V and that we can never change that. We know that we have come a long way, and we are happy with the changes we could make. Had we been not able to make such wonderful changes, there would have been no point in stretching out his therapy for three years." And in return I got a pleasant surprising answer from his mom, "No, Pragnesh, you are wrong. Even if we could not make any change in his life, still I would have gone for all these years working for his betterment. He is my son, not just a mechanical piece made of bones, muscles, and organs. If we failed to make any change in him, all the hard work that I, my family, and you have done for him would be the only thing that might have made me feel that my son is a living human being. Whatever work we have done to make his life better was just for our sense of respecting the individuality of my son. Whatever improvement we have achieved in his life is just byproduct." And this spirit made my eyes so wet. I feel so proud that I treat MH, and not GMFCS V.

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