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I first met Ryan and his parents in our busy outpatient physical therapy waiting room. He was sitting and waving two American flags, giggling and mumbling as he watched them dance in his hand. He did not look up at me initially when I introduced myself, but once his mom grabbed his hand to redirect his attention, he gave me a sly smile as he glanced at me through the corner of his eyes.

I was asked to see Ryan at the request of Allie Schwartz, MD as part of the MGH Adult Down Syndrome Clinic. He was 22 years old and had a one-year history of right arm pain and loss of function. His mom, Ellen, drove over an hour to bring him to MGH so that I could meet him. She was not sure how physical therapy could diagnose or fix the problem, but she was willing to try anything that could help Ryan.

I brought Ryan and his mother back to a private treatment room. Ryan immediately sat down and started to twirl and flap his flags, mumbling quietly to himself and watching his fingers as he moved them. Ellen reviewed his medical history and explained that Ryan stopped using his right arm and hand abruptly about a year ago. She was unaware of any injury to his arm, neck, or shoulder and noted that he only complained of pain when she asked him to use it. She had already brought him to a neurologist, a hand specialist, and a spine surgeon, and no one could give her a neurological or orthopedic explanation for his pain and disuse of his dominant arm. This was his first time seeing physical therapy for this problem. Ellen also noted Ryan no longer had interest in things he used to love – dancing, playing on his iPad, watching movies, and playing ball with his nieces and nephews. She had wondered if he was depressed, but additional visits and medication adjustments by his psychiatrist did not seem to make a difference.

As I began my PT examination I realized immediately that although Ryan had a limited vocabulary and repeated his words, he was good at following directions and was able to comprehend what I was asking him to do with simplified language and single step instructions. I observed him holding his right arm braced against his body as he pulled his T-shirt over his head with his left hand. I asked him to raise both his arms above his head in an attempt to assess his active shoulder range of motion. He reached as high as he could with his left hand. When I asked him to try with his right arm, he started to, but then grabbed his shoulder and said “I can’t, I can’t. It hurts”. His mom asked him to try again. He sighed and rolled his eyes and said “I can’t” in his deep raspy voice and then lifted his arm twice the distance (to about the level of his shoulder). I then asked him to lie down to assess his passive range of motion. He demonstrated full pain free motion and hypermobility of his glenohumeral joint in both his right and left upper extremities. When I attempted to

test his strength, he would not cooperate for standard, formal muscle performance testing. I knew that I would have to then find an alternative way to test his strength – something fun that would motivate him. His mom had just mentioned that he liked to play ball with his niece and nephew, so I thought I could give that a try. I was very pleased that he was willing to lift and toss various balls, which demonstrated that he was able to load his rotator cuff appropriately, and therefore a tear or tendonitis was unlikely. He then quickly lost interest in participating any further in our session that day.

I discussed my findings with Ryan's mom including his physical presentation, my observations of his behavior, and careful consideration of his medical history and the subjective data that she had shared. I discussed my concern that Ryan may have glenohumeral instability in his right shoulder. I explained that the literature demonstrates that glenohumeral instability can occur in all individuals but is especially present in patients with increased ligamentous laxity, such as individuals with Down syndrome. If Ryan had not been using his arm for over a year, he did not have the muscle stability that he needed to accommodate for his joint laxity, and therefore every time he loaded or lifted his arm he was shearing through his glenohumeral joint and experiencing pain. This would explain why he lost interest in so many activities that he loved: he had been in pain for so long and he could not verbalize what was hurting. I explained to Ellen that in working with other patients like Ryan, I had learned that a single painful experience can lead to disuse of an extremity or fear of an activity, and overtime, that could lead to weakness and a vicious cycle in managing pain in patients with instability.

I asked Ellen if she would be willing to bring Ryan back to see a shoulder specialist in the orthopedics department. I was hoping that Ryan would be considered for a cortisone injection, with the goal of reducing his pain enough to allow us to strengthen and restore confidence in his shoulder. Ellen agreed with this plan.

I contacted Dr. Schwartz to share my clinical findings and thoughts and asked that we send Ryan to see Dr. Jon Warner, an MGH orthopedist and shoulder specialist. I explained how I worked in his clinic and would be present for Ryan's appointment and be able to advocate for his care. She quickly agreed with this plan.

About a month later, Ellen brought Ryan in to see Dr. Warner and as planned, I was present for the appointment. Ellen reviewed the history of Ryan's right arm problem and I provided my clinical findings and reasoning regarding the likely benefit of a cortisone injection. Dr. Warner examined Ryan and stated that he preferred to send him for an MRI to rule out any structural problems prior to considering an injection. Wanting to make sure we had a solid plan before we ended the appointment, I urged Dr. Warner to consider an injection if Ryan's MRI came back normal. I knew that in most cases Dr. Warner prefers to get the MRI results before deciding on a plan, but he was open to my concerns about the level of Ryan's dysfunction and my desire to move the process along. He agreed to my request pending a normal MRI.

Ryan's MRI revealed no structural abnormalities and he received an intra-articular joint injection. He returned to physical therapy a month after his injection and Ellen reported some improvement in his ability to dress and bathe himself, but he continued to favor his right arm with all his activities. She mentioned that he had started to go to the gym with his sister-in-law and enjoyed using the machines available to him.

My goals for that treatment session were simple: start to strengthen Ryan's right upper extremity, improve his confidence in the use of his right arm and hand, and teach Ellen strategies to encourage the use of his arm at home. I suspected that the traditional ways of strengthening with bands and weights would not work for Ryan, but since he was enjoying going to the gym, I thought I would give it a try. But no luck. Ryan refused to try any activity with a band or weight and repeated "I'm too old" or "No, I can't." So it was time to think outside the box. How, I wondered, could I motivate Ryan to use and exercise that right arm?

I thought if I could engage Ryan in a meaningful functional task, I might be able to get the results I wanted. So, I put two weights on a high shelf and asked Ryan to reach them down so that his mother could use them. He obliged and reached up with both arms to get a weight in each hand and he brought them over to his mom. This gave me a chance to assess his range of motion and see how much weight he could tolerate lifting. We tried this 3 more times with different weights before he lost interest in the activity. We then tossed a ball back and forth, and I reminded him of how much fun it was to do this with his niece and nephew. We encouraged him to use both hands to catch and toss a ball, which he did inconsistently, until he made it clear he did not want to play with the balls any more. We then sat down and pulled out some games: Memory and Perfection. We played a few rounds of each, trying to encourage the use of both his right and left upper extremities.

When it was clear that Ryan had had enough physical therapy for the day, Ellen and I discussed ways to continue to encourage Ryan to use his right arm at home. We knew he liked the equipment at the gym and discussed different types of cardio and weight machines that required the use of both arms. We also discussed the benefit of "High Tens" to use both hands in a moment of excitement, rather than a "High Five" in which he can favor his right. Given that he likes to be helpful at home, we discussed having him clear the table or put dishes away where he would have to use two hands to stabilize plates and dishes. And finally we discussed playing games at home, such as Memory and Perfection, to encourage the use of his right hand to manipulate smaller objects. Ellen was appreciative of all these suggestions.

Ryan returned to the physical therapy clinic a month later. Unfortunately, Ellen reported only minimal improvement since his last visit. She had encouraged him to try clearing the table and dressing with his right hand, but he continued to avoid using his right hand consistently. I knew I would have to rethink my plan of care for Ryan, since my previous suggestions had not worked as I had expected. So I looked to the evidence on motor learning, which supports using tasks that are motivational

and functional when learning a new skill, or in Ryan's case, relearning a skill. Shumway-Cook and Walcott have written multiple papers and textbooks in the physical therapy literature on motor control and motor learning. Their theories stress the importance of developing a set of internal processes associated with an experience in order to have a permanent change in the ability for an individual to perform a specific skill or behavior. I applied this information to Ryan's situation. I knew we would need him to continue to practice some of the functional tasks that we had discussed before so that he could learn to be successful with them. But we also wanted to find additional ways to continue to motivate him to use his dominant arm again. And, maybe we just needed more time.

We discussed his gym program progression, including the use of free weights, since Ellen reported that Ryan was now willing to use them. I encouraged her to help him less with ADLs because having him do things independently would encourage him to use both hands, such as getting out of bed or putting on a jacket or sneakers himself.

We reviewed the idea of having him go back to playing ball with this niece and nephew, which they had not tried yet. We discussed using snack or "treat" foods to have him use both hands, such as opening a bag of chips or a small candy, to have a positive association to using both his hands when eating.

The following month, Ryan returned to physical therapy and his mom was very happy to report that he was no longer reporting pain and that he involuntarily used his right arm regularly again. He was dressing himself, clearing the table, and eating with both his hands. Ellen happily reported that the things that Ryan had previously lost complete interest in were all things he loved to do again –using his iPad, playing with his niece and nephew, dancing, and listening to music. Since our therapy goals had been achieved and we had a home program in place, we decided to make that day his last session. We progressed his strengthening program and I discharged him from my care.

I received an update from Ryan's mother a few months later. Ryan was using his right arm normally again, and she was grateful for all the patience, guidance, and care she and Ryan had received in physical therapy. She admitted that originally she was not sure that physical therapy would be helpful in ultimately getting Ryan to where he needed to be, but she was so pleased that she was wrong, and that Ryan is back to his old, playful, and entertaining self again.

#### SAMPLE QUESTIONS:

##### **Clinician/Patient Relationship:**

1. In your narrative you had to develop rapport with both Ryan and his Mom. You describe that although his Mom wanted him to get better, she was skeptical of how PT could help. You then discuss a month later when you saw him again he only had minimal improvement. How did this impact your

rapport with Mom and how did she continue to trust to continue with physical therapy?

**Clinical Decision Making:**

1. You discuss how Ryan was hypermobile in his shoulder joint; was it a clinical risk to recommend a cortisone injection? Can you take us through your clinical decision making?

**Collaboration/Teamwork:**

1. In sounds like you coordinated not only with Dr. Schwartz in the MGH Adult Down Syndrome Clinic, but also with Dr. Warner whom you also work with in another clinic. Can you speak to how this worked in terms of collaboration and how communication usually flows between multiple providers? How is it handled if there is a disagreement?

**Movement:**

1. You mention that Ryan did not cooperate with strength testing. Can you describe what you observed and how you knew he was able to load his rotator cuff appropriately?