

Decisions for Duchenne

How to make the right choices...



by: Misty VanderWeele



4 Over-Looked Ways to Make Life Altering Decisions for Your Duchenne Child.

First I must tell you I am not a doctor, I am not a physiologist, I am not running a non profit Duchenne Organization, I am just a mom who has been there done that and still doing it. My intention is to assist other Duchenne parents navigate the emotions associated with the Sacred Journey of Duchenne. I understand that Duchenne forces us to make the hardest of decisions of our lives.

To use steroids or not too, back surgery, heel cord lengthening, to tracheotomy or None Invasive Ventilation, to do medical trials and treatments or not too, not to mention all the daily stuff, like keeping up with the latest research, Physical Therapy, Occupational Therapy, and Individual Education Plan's. All the while hoping your child won't die before a cure is found.



Yes, Duchenne sucks!

And if you are like me, you too have spent endless time awake at night curled up with your tissue box afraid and agonizing over what to do for your Duchenne child, closing your eyes so tight wishing this was not happening, not to mention dealing with the powerless feeling of seeing Duchenne ravage your child's body.

However I have not only survived but **THRIVED!**

Recently I was asked how can you say Duchenne and thrive in the same sentence? It is because thriving is a state of “being” not a destination. It is about living the very best you can right now with whatever hand you have been dealt to the best of your abilities.



With saying all this I must preface,

I believe every family has the right to do what they must for the best of their own child's life. No one answer is the "right" way. However I am a bit of a rebel and tend to not do everything the doctors say to do or even the top Duchenne organizations, why you ask? Because there is 4 things I do first BEFORE I make any life altering decisions after I have gathered all the facts. It's what all the great's do, like Stephen Covey's *7 habits of highly effective people* or Napoleon Hill's,

Think and Grow Rich plus a few golden nuggets I have discovered on my own. So if you have ever agonized over what to do or worry and fear has kept you awake at night or you often feel damned if you do, damned if you don't? You have come to the right place at the right time.

So lets jump right in!



Tip #1 Pro's & Con's



Seems simple enough and you might already be doing this at least in your head. You must do the ole pro's and con's list. But I take it a couple steps further.

I actually get out a piece of paper draw a pro's and con's side and start writing, when I have exhausted all my options and written until I am cross eyed. I draw a big open circle and title it "GUT FEELINGS".

I believe deep within each and everyone of us is a vast "knowing" and since it can't be explained we often don't listen to that gut feeling (instinct).



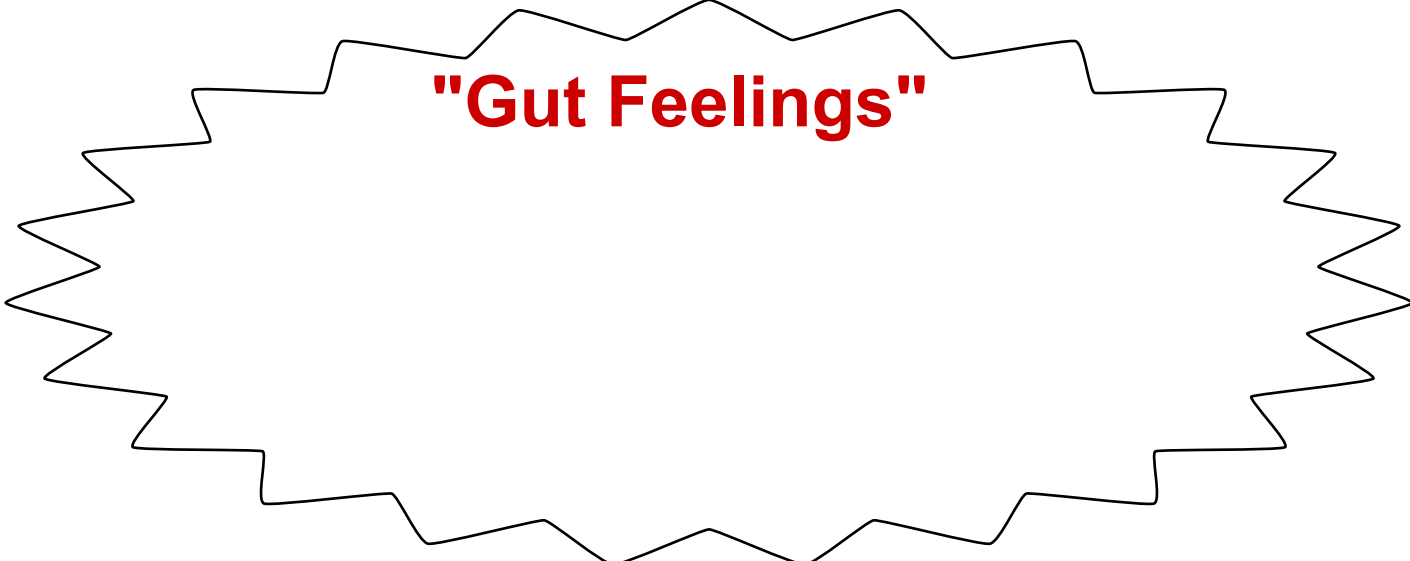
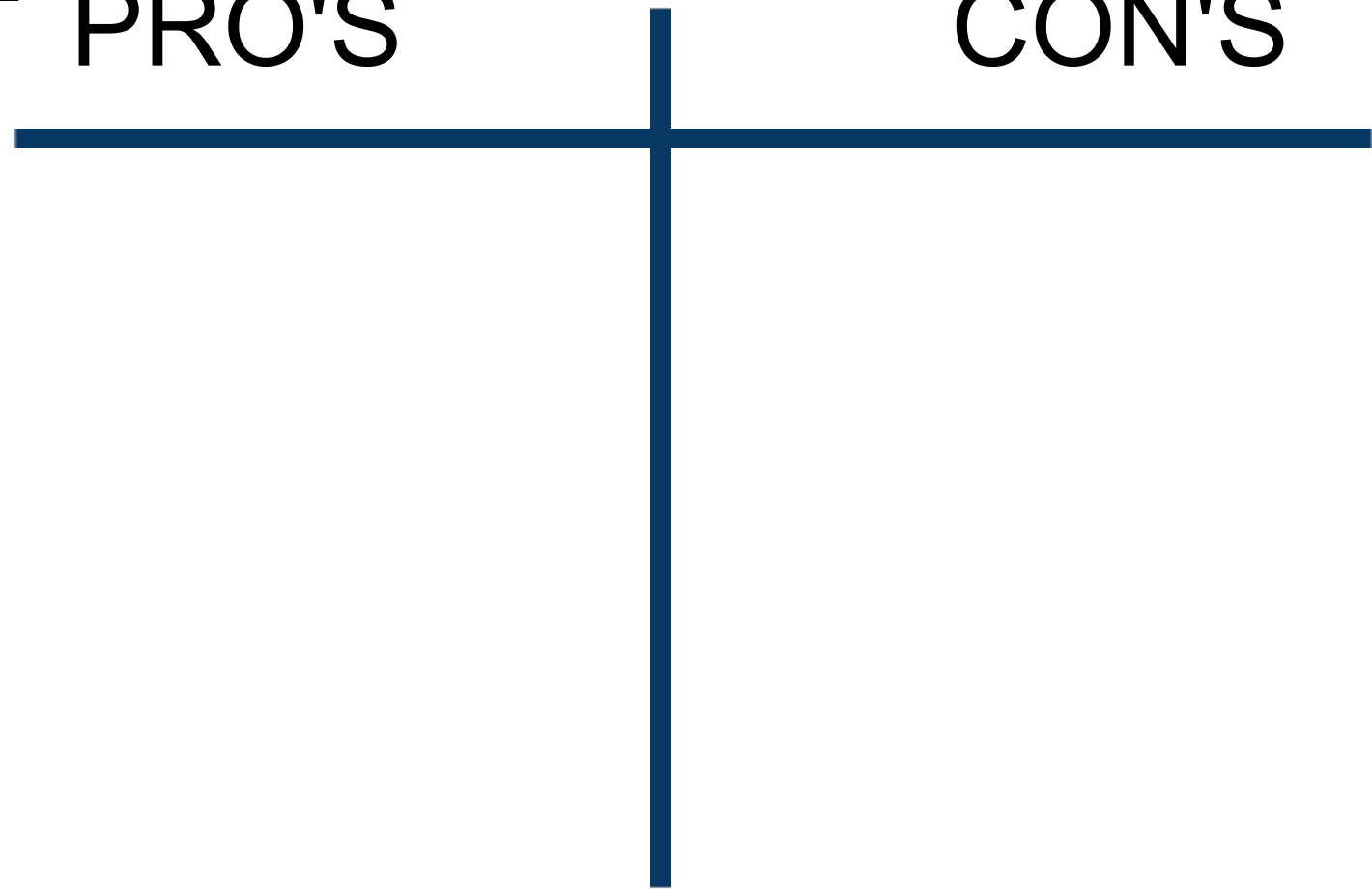
we silence it and don't take it serious. We think, "who am I? I am not the expert". We think the answer is outside ourselves that someone else has it covered. Not true, YOU, the parent are the only one who has the final say, You are the one who has to sleep at night, you and your child are the one's who has to live with the consequence of whatever decision you make. Not anyone else.



EXAMPLE

PRO'S

CON'S



Tip #2 Get Back To Nature



My favorite, if you have read *“In Your Face” Duchenne Muscular Dystrophy All Pain All GLORY!* you know I love the great outdoors. In my opinion there is no better way to clear the head than to get out in nature. Even if you live in the city it is possible, there is parks and often time nature is just a 30 minute car ride. When you get there remember to **BREATH** in your surroundings.



Tip #3, Just ask



This one is a biggie and the number one over looked aspect to not only decision making but life in general. I also write about this in the book. I literally ask for a sign on what to do. I know it seems a bit corny, but tapping into the spiritual side of life, the energy, is the fastest way to make a sound decision. One that you can live with and that is what is important! **HINT:Keep a look out for when the "ah ha" ! moment happens and your sign appears and you have your answer.**



Tip #4 Sleep On It



This is the last thing I do after completing the first 3 tips. My mind and body needs rest from the heavy stress of all the worry and thinking.

Being extremely tired makes is near impossible to have enough focus for any kind of decision

making , let alone keeping your emotion in check. When you are tired and frustrated everything is much more overwhelming. I often say. "I need to go to bed and start all over." Sleep can be the very best medicine so you can jump back on the horse the following day at the top of your game. Your child needs you and you need you so the next time you feel all out of whack in a jumble of nerves and not knowing what to do try sleep. (HINT: Take a relaxing bubble a bath before tucking in.)



*Two roads diverged in a wood, and I...
I took the one less traveled by, and that
has made all the difference.*

~Robert Frost

Fact: Robert Frost lived through losing 3 of his children.

<http://www.answers.com/topic/robert-frost>

MistyVanderWeele.com



Notes:

MistyVanderWeele.com

