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**Abstract**

The author of this short story is a parent who began her advocacy efforts on behalf of her son from the time he was born. The necessity of defending his needs made her more assertive and she explains how parents also need to learn when to speak up and when to leave things alone. **Keyword: Advocacy**

# **HOW DID I GET THIS TOUGH?**

## **FIGHTING FOR YOUR CHILD'S RIGHTS**

"Kate, you're overreacting," my husband tells me gently as I run on about the community sports program. "You have to choose your battles. If you try to fight all the injustice in every system, you'll exhaust yourself."

I stop mid sentence and consider what he has said. I groan inwardly as I realise he is right. This situation does not call for "full battle gear" and an aggressive posture.

I sit back to think about this habit of combativeness/assertiveness that has become part of who I am. How did I get to be like this? Why do I question everyone's motives? Why do I feel compelled to point out the inefficiencies in every system, to right every wrong? Why don't I just let things go?

I have come to the conclusion that it is not always the issue itself that drives me or determines my response, but rather it is a mindset I have developed that clicks me into combativeness for any issue. I am always alert and ready for the next person who will say something "cannot be done", because I want to be the first person to ask why it cannot!

This mindset causes me to overreact in more situations than I would like to admit! It colours circumstances more vividly - making them seem more intense than they actually are. But in other situations, the attitude of "I will take you on" is essential in getting answers I want or services I need for my son with cerebral palsy.

I do not like being typecast as pushy, bitchy, argumentative or as the mom-every-one-wants-to-hide-from, but I have been called all of those things. And it hurts sometimes. It makes me feel uncomfortable, embarrassed, annoyed or invalidated at times. I smile as I tell my husband, "I was not always this tough you know!" (We have been married for five years, and he willingly and skilfully step-parents my two sons). I remember when I was a shy, inarticulate observer, offering my opinion only when asked. I was the kind of person who thought of the perfect thing to say after the meeting or conversation was over. Assertiveness was not one of my "natural talents". But that was before I had a child with a disability. It was before I had someone who needed me to be articulate and assertive, wary and combative.

I developed assertiveness (some call it pushiness) because this kind of mothering required it. I became wary because I did not trust anyone but me to effectively advocate for my child. The necessity of defending his needs, protecting his rights and procuring services for him triggered all my survival instincts, and I was forced out of my shell. But when did I change?

## **THE BEGINNING**

I think it began shortly after my son was born prematurely. During those agonisingly long days in the intensive care nursery, watchfulness became my job. I felt like I had to stay alert or my "miniature" son might die. After all, there was a room full of critically ill infants. How could I expect the staff to really care about my baby?

I learned to watch the dials on the machinery, to watch my son's respirations, to watch intakes and outputs and to watch doctors and nurses watch my son. Somewhere in the intensity of it all, my assertiveness was born and wariness became my new "modus operandi".

I started to ask questions: "What is this procedure for?" "What is the effect of that medication?" "Are you sure he's supposed to look like this?" "Who are you and what are you doing to my baby?!" I tried to address my questions to a different person each time so they would not consider me a pest. As the professionals scrutinised my baby, I scrutinised them.

## **FULL ALERT**

If you have a "normal" child, this watchfulness or wariness continues through the first days or weeks at home. Then it slowly relaxes to a less intense level once you realise Baby is breathing, sleeping and squirming appropriately. It is different when you take a special needs or at-risk baby home. The watchfulness does not ever stop. Day-to-day, week-to-week, a state of full alert exists. Even if your baby does not suffer from a life-threatening condition, your emotions operate in a crisis mode - always on for a new emergency or a new shift in the situation. Your mind leaps forwards, backwards and sideways trying to sort out the deluge of information - the doctors' reports, nurses' instructions, conflicting or ambiguous diagnoses, appointment, feeding and laundry schedules.

You are trying to anticipate the next demand on your emotional energy in the midst of a hailstorm of opinions. Everybody has something to tell you. The opinions come from professionals, from well-intentioned relatives and from people who do not know "beans" about your situation!

You want to scream at everyone to shut up so you can organise your thoughts, so you can stop the world from spinning, so you can catch up with your life (as it used to be). You struggle with that ever persistent fantasy: Maybe there is something that I can do to make my baby all right if I can just think for a moment! If only I could turn back the clock! You desperately want to fix your child and to fix the predicament that is constantly spinning your life at a dizzying speed. All your mothering instincts tell you that you are responsible for this child and, yet, you still feel helpless to change his condition.

## **MY FIRST BATTLE**

I fought my first "battle" over the grief and guilt that comes from feeling helpless. Some parents work it out talking to each other, others by talking to a counsellor or to another exceptional parent. I talked to anyone who would

listen! But it was so hard for me to admit to those feelings. I felt like I should only be focused on my baby, and to spend time on my inner struggle was being selfish.

Talking about my feelings of grief and guilt was an essential part of coming to grips with a kind of mothering I had not expected and for which I had not been trained. I had to grieve for the shattered dream of not bringing home that "perfect" baby. I needed to clear the way for a fresh perspective on who this baby was.

Getting tough once I faced the fact that special needs parenting was going to be my reality and that it was not going to magically go away, I realised that I would have to stay tough - tough enough to question professionals who want to limit or ignore my son's abilities; tough enough to convince educators where my son belongs in their system; tough enough to withstand other people's suggestions that "If I had him for a day (a week, an hour) I would have him walking, talking, potty trained, eating, etc.," and tough enough to deal with agency people who do not have time to answer phone calls and listen to your requests, or who listen but cannot meet your request in any speed other than I'll-get-to-it-when-I-can or who have no real understanding of what it is like to be waiting for a piece of equipment or an appointment that requires their authorisation.

### **ASSERTIVENESS IS VALID**

It is unfortunate that it is usually the mother who deals with agencies on behalf of an exceptional child, because in our culture a woman who acts assertively is often invalidated, considered a troublemaker or, worse, a bitch. When a man wants to be assertive, register a complaint or hold someone accountable for his job, he is applauded and gets action. When a woman tries the same things, she is sabotaged with negative labels and criticism. But that is another almost inescapable fact of exceptional parenting!

My energies, physical and emotional, are often drained by the inner battle of feeling compelled to ask for something for my son and feeling guilty and uncomfortable about doing it! I am sure the agency folks who perceive me as so demanding and pushy would be astonished to find me at home crying in frustration - agonising over the next demand I will have to make of someone (who ironically is supposed to be providing services to my son) and dreading the next come-tell-us-all-about-yourself re-evaluation.

### **PATIENCE ON PERMANENT VACATION**

Somewhere along the way in these past twelve years, much of my patience went on permanent vacation. I have no patience with "systems" which seem to have built-in delays, but I do try to have patience with the people who work in the systems (often pointing out to them how their system should change!) I have found that a little pleasant pushiness can bring good results. I am not belligerent, but I am persistent.

When a piece of equipment is prescribed for my son at the clinic, it always takes a long time for any action to be generated. I call a few days after the

clinic to "remind" the office staff that I am out here ... waiting. I know that my prescription/request is sitting on a desk in a pile of other paperwork and that unless I call attention to it, I will be waiting until it slowly works its way in front of somebody.

My calls do not always get immediate results, but I like to think they speed things up and help the agency staff connect a person with the paper. My calls make them familiar with my name, and future calls are more likely to be acknowledged. Besides, it makes me feel good to be doing something, as my mothering instincts urge me to stay in control of the situation. I try to strike a balance between knowing when to borrow equipment instead of requesting it, knowing when to buy necessary items instead of going through agency paperwork and knowing when to flat out beg for what I need!

### **TOUGHNESS, FRUSTRATION, EXHAUSTION**

It is not easy being tough and it is not easy shifting out of tough, so my husband and children often see and feel the effects of my frustration, short temper, exhaustion. I have days of not feeling quite caught up with my life; moments when I wonder if I have missed something I should have seen or something I should have done.

I am always on the edge, fencing with anxiety, holding back grief, coping with guilt. And my "sensors" are still always "ON", constantly and unconsciously monitoring my son's whereabouts, alert for the sounds of distress - the wheelchair has tipped over; its fuse has blown; he has to go to the bathroom. So there is a continual slow leak on my energy reserves. But that does not distract me from a full and happy lifestyle, because being an exceptional parent has become my lifestyle. Most of the time I manage to keep my sense of humour. Most of the time I am able to take a deep breath and take the next step. And I have learned that I do not need to apologise for being demanding on behalf of my child.

### **I AM TOUGH**

I have applied my assertiveness skills to all aspects of my life - sometimes with good results and sometimes not! I am learning that there are situations that are best left untouched, despite injustices and inconsistencies; there are systems I cannot fix; there are people who do not need my input. Sometimes it takes a conscious effort to keep my mouth shut! But if a situation arises involving my family or a friend or one of my committees and someone needs to speak up, often I am the one to do it. I am well-equipped now - from practice and experience - and I am tough.

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