

## “Don’t Touch Me!”

### Working Through Tactile Defensiveness

by Cahty Haarstad, M.S.

We all have those moments. Frustration over a series of seemingly small difficulties piles up until the tears spill over and we meltdown. For me, this moment came the winter my daughter was eight years old. She had just “lost” her fifth pair of mittens in two months. I should have seen it coming earlier in the day: she screamed, cried, and kicked as I repeatedly put the mittens on her hands). Once at school, she managed to “lose” the mittens. That is a serious problem during the winter in North Dakota. I looked at her cold, chapped, red hands in the car on the way home and the tears started to leak. By the time we arrived at our house I was ready for a good cry. Thankfully the rest of my family stepped in and gave me some time to myself.

Later that night, I sat down with a cup of tea to make a list of the things that were bothering me.

I found myself listing all the different sensations, types of touch, or physical contact my daughter refused to allow. I was surprised by how long the list was. It included refusing to wear a hat or mittens, use toothpaste, eat many different foods, allow a toothbrush to enter her mouth, put on skin lotion, get in the tub or shower, wear lip balm, wash her hair, and wear shoes other than one badly worn pair that was too small. Looking back, I realized we had been dealing these refusals since she was three years old. Now these issues were overwhelming my family and causing problems at school. It was time for things to change. This was the start of our education in how to overcome *tactile defensiveness*.

#### What is Tactile Defensiveness?

At some point, every child experiences some feeling they

don’t like. When your child is a baby and toddler, you learn what they like and don’t like by their reactions: spitting out a foreign food, shedding “scratchy” clothes, or the ever-popular “NO!” Most children outgrow these reactions as they grow older.

Children with disabilities may have trouble tolerating or making sense of normal types of touch and movement such as the feeling of hair being brushed or labels in clothing. The sensations are overwhelming, sometimes even painful to them. These reactions are due to tactile defensiveness or touch sensitivity. Children who are tactile defensive consistently respond to typical touches that are not painful in an extremely negative manner and at a level that is out of proportion to the situation.

For some children, tactile defensiveness continues into

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## Letter from the Editor

### Fear Factor® 24/7

I've never been a fan of this show, though my son watches it every now and then. The episode teasers are enough to make me bury my face to avoid seeing the stunts planned for our viewing pleasure. The premise of the show is for contestants to compete for a sum of money by experiencing events or accomplishing tasks most of us find horrifying. Contestants eat bugs, are submerged in a container full of roaches or tarantulas, and are subjected to other situations similar to my worst nightmares. Reasonable people are repulsed by these activities. Most people, I think, would feel ill or want to run in the opposite direction, giving in to a natural (and understandable) "fight or flight" feeling rumbling in their guts. I guess that's why they named it *Fear Factor*.

People who experience tactile defensiveness feel this level of reaction to experiences most people consider common, such as the feeling of wearing a hat, a shirt with a tag, socks with thick seams at the toes, toothpaste in the mouth, or the smell of shampoo. Any one or all of these things can feel the same to a person with tactile defensiveness as one of the creepy games they play on *Fear Factor*. When you think about it, children and adults with tactile defensiveness are living a never-ending version of the show. It takes outstanding courage to get through each event, or try. Imagine how stressful it is to fear something

that happens every day, sometimes more than once, in spite of your feelings. It sounds exhausting, for everyone.

Cathy Haarstad spent years dealing with her daughter's tactile defensiveness. Once she realized the impact it was having on everyone in her family, she decided it was time to take action. Today, she is an expert at helping families dissect what may be bothering their child in different daily activities. In this issue of *Disability Solutions*, Cathy shares strategies for deciding if your child is tactile defensive, what types of touches bother her, and some strategies for working through your child's fears with empathy, compassion, and tenacity.

One of the first strategies Cathy suggests is taking stock of where you are in the process with your child, and what you want it to look like when you are done. This is a great way to help you think clearly. Working with your own child is often full of emotions and frustration. Your ideas of what to do, how to go about it, and whether or not you are seeing progress are twisted by the emotions of the moment. It's normal. The January 4, 2006, installment of *The Editor's Blog* ([www.disabilitysolutions.org/blog.htm](http://www.disabilitysolutions.org/blog.htm)) focuses on goal setting and methods of taking stock to help you see how far you've come—even on the worst day.

Cathy also mentions making the process of whatever you're working on visible for your child. This is especially helpful when emotions are so powerful it is impossible to be calm. If you are stumped for ideas of how to do that, download our back issues on the subject of visual tools for ideas (Volume 5, Issues 5 & 6). All past issues of *Disability Solutions* are available free from our website and can be found on this page: [www.disabilitysolutions.org/news.htm](http://www.disabilitysolutions.org/news.htm).

I hope this issue is helpful to those who are living with someone who has tactile defensiveness. If you have friends whose children fit this category, just remember the courage it takes for everyone to get through each difficult moment. If you think about it in the moment, give them a word of praise when the task is accomplished. Something as simple as, "It's good to see you," will mean the world. It always does to me.

Take good care,



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school age years and beyond. Children with all sorts of disabilities such as Down syndrome, Fragile X Syndrome, ADHD, and other developmental disabilities, may be sensitive to touch. At the same time, many children with disabilities do not develop touch sensitivity that persists beyond infancy or early childhood. As with most things, it varies from child to child.

No one knows for sure why some children are very sensitive to touch. The most common theory is that defensive behaviors are learned when a child has trouble with *sensory-motor integration*. Sensory-motor integration is the ability to put together, process, and understand information from all of the senses (vision, hearing, touch, taste, smell, movement, and pressure) in a coordinated manner. Putting together the information your child's brain receives from various sensations helps her learn to imitate your movements and participate in play activities. Through these activities your child learns to listen, look at, feel and be aware of her body and the objects and events around her.

### The Significance of Tactile Defensive Behaviors

It is important to understand the difference between a natural tendency to avoid unpleasant sensations and a more serious situation where the sense of touch is a continual source of stress. One way to begin to understand the significance of touch for your

child is to categorize her responses to unwanted touch. Answer the following questions to help you decide. (Check the box if the answer is “yes”)

- Do your child's reactions to touch keep you from establishing a normal or healthy daily routine (basic hygiene routines such as washing face, hair, or hands)?
- Do your child's reactions to touch create frustration and leave parents or siblings exhausted and miserable for a long time?
- Do your child's reactions to touch *get in the way of* activities in different settings such as home, school, family gatherings, and day care?
- Do your child's reactions to touch make it difficult for him or her to make friends or learn social skills?
- Does your child's reaction to touch continue for long periods of time, such as hour or more? Have these reactions continued past early childhood (age five)?

How many of these descriptions fit your child? If you checked two more of these questions, you may want to consider whether your child is touch sensitive.

Use the answers to the above questions and the checklist on page 6 to show the significant impact on your child and family and how it affects your quality of life.

If you are unsure if your child has tactile defensiveness, use the decision chart on page 4 to help you understand what you see in your child. Creating data by putting a number to what your child experiences, helps you make a less emotional decision.

### Identify What Bothers Your Child

Consider all of the steps involved in hygiene and how the ability to tolerate a sensation or touch may be involved. For example, to be clean and healthy, your child must learn to accept the:

- ♦ sensation of soap or a washcloth on her hands or body;
- ♦ scent, and the feel of shampoo and the rubbing motion on her scalp;
- ♦ sight, scent, and feel of hand lotion or sun screen and touches to rub it in;
- ♦ tingling and contact involved in putting on lip balm for cracked lips;
- ♦ weight, feel, temperature, and sensory changes for glasses or hearing aids;
- ♦ weight and feel of mittens, hats or coats in severe weather;
- ♦ temperature changes and skin contact of water from a tub or shower;
- ♦ taste, texture and smell of toothpaste and your help to brush teeth;
- ♦ texture, look, taste, and scent of a variety of healthy foods;

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- ♦ scent, taste, and feel of both liquid and solid medications;
- ♦ pull, tickle, and even pain of a brush moving through her hair and scalp;
- ♦ scratch, weight, restriction, and texture of her clothing;
- ♦ scratch and feel of toilet paper, or tissue or handkerchief on chapped skin;
- ♦ change in temperature in moving from a warm carpet to a cold bathroom floor;
- ♦ hand over hand demonstrations used to teach hygiene skills.

The list is never-ending.

### Types of Touch

One way to understand what your child is feeling is to identify how many different types of touch your child finds intolerable. Use the chart on page 6 as a template to categorize your child's reactions. Add and subtract from the columns to customize the chart to your situation. Here are the general steps:

1. Think about your child's body from head to toe (refer to the list above if you need help).
2. In the second column, list the sensations or types

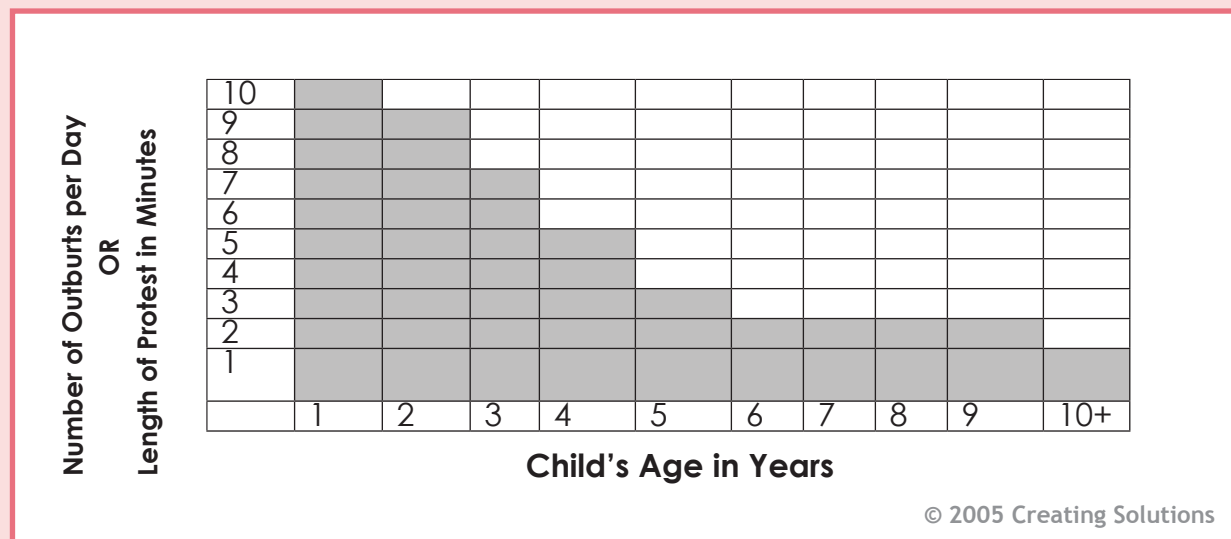
of touch involved in your daily routines. List all the different substances and touches she experiences on that part of her body including touch from a caregiver, clothing, or a health substance such as Chapstick™, lotion, or toothpaste.

3. In the third column, separate the types of reactions your child has. The chart on page 6 shows one way to do this.
4. Now go back through your list of routines or activities.

### The Decision Graph

The decision graph counts and plots the number or length of your child's outbursts and illustrates it in chart form. If sensory issues are not a concern, your child will follow the general trend represented by the shaded area of the chart. Because of her disability, the rate her behaviors decrease may be slightly behind peers of the same age.

If the frequency and length of your child's protest behaviors do not gradually decline or if the level and frequency is very high to begin with, you may want to seek help regarding your child's touch-sensitive behavior



Circle all the types of touch your child does not tolerate.

5. Check the box that describes how your child reacts to these touches. It is fine to check more than one.

Sometimes children react differently in different places. It may be helpful to complete a chart for each place your child spends time on a regular basis, such as home, school, grandparents, or child care. This information will help you decide if problem behaviors occur in more than one place or if they are confined to a specific situation.

Most people aren't able to recall information in this type of detail on a moment's notice. Plan to take some time to gather this information over the next week or two. Once you do, you will have tangible information to help you evaluate your situation and start to plan with the people and professionals who support you.

### The Impact Family Life

Tactile defensive behaviors can have a dramatic affect on your family life. Usually it's not a good one. Situations that seem easy for most families are a continual battlefield for children who are touch sensitive. For example, grooming and hygiene are very tactile experiences. Dressing, bathing, washing, and other self-care activities often involve pressure, smells, touches, and sensations that may be on the part of your child's body that may

be most sensitive. Many children quickly learn how to protect themselves, or attempt to, from these unnerving feelings.

Your child's reactions may be so dramatic and intense a simple task becomes a traumatic situation for everyone. It is one thing to ignore the wails of a two-year-old while washing her face. It's another thing to ignore your nine-year-old when she has a melt down in a public restroom when you ask her to wash her hands. Life becomes more restricted for everyone when putting on shoes ignites a flurry of fists pummeling the person holding the shoes.

When a child has tactile defensiveness, it is unlikely her reactions are limited to her family and home. She may react when others approach by pulling away, screaming, arguing, or running from the room. Some children experience such extreme reactions they show physical signs of stress or have a panic attack. Other signs of distress that can be misunderstood include head banging, hand biting, and hitting others.

When a child has touch sensitivity, the typical extra time it takes to do things is even longer. For example, Appearance and cleanliness are critical to social acceptance, job prospects, and good health. However, the struggle to keep your child clean and teach hygiene skills feels like a violation to her physical space leading to very negative interaction. Teaching your

child about grooming, getting dressed, taking medication, and eating takes much of the time in a typical day. When you must factor in several outbursts during the normal routine, it takes away from your time with other children, friends, and your spouse.

### Deciding How to Respond To Tactile-Defensive Behaviors

There are some typical strategies for reducing tactile defensiveness. One is called using a "sensory diet." A sensory diet means taking care to provide a balanced amount of sensory input through a variety of activities. *Joint compression*, is putting pressure on the joints through weighted vests and blankets. Another common strategy is called *brushing*, in which a special brush is rubbed over the skin in a specific way. These methods, developed by occupational therapists, are designed to stimulate centers in the brain and muscles that control a child's view of things they feel.

Usually these activities are provided outside of your child's daily routine and the environment your child has learned are unpleasant. It is difficult to incorporate many of the above strategies into your home, the bathroom, or kitchen, where tasks and struggles take place. While they may work to reduce a child's *overall* sensitivity, they may not be as helpful in teaching your child to tolerate touches in everyday situations that she has

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### Reactions on Different Areas of the Body

| Body Part                     | Circle the sensations your child does not tolerate.   | Mark the level of your child's response (see key below) |   |   |    |    |
|-------------------------------|---|---|---|---|----|----|
|                               |   | P   | R | A | SI | ST |
| <b>Head</b>                   | Washing scalp; rinsing hair; brushing hair; wearing a hat; wearing ear muffs, headband, or hood, hair clips or ties, or _____.                |   |   |   |    |    |
| <b>Face, Nose, &amp; Ears</b> | Lotion, tissue to nose, washcloth, glasses, hearing aid, wind, rain, water, or _____.   |   |   |   |    |    |
| <b>Hands &amp; Arms</b>       | Lotion, mittens, gloves, clipping nails, long sleeves, bandages, watch, jewelry, blood pressure cuff, or _____.                               |   |   |   |    |    |
| <b>Body</b>                   | Shirt, pants, underwear, tags on clothes, lotion, back rub, accidental light bump, shower, tub, pool, coat, sunscreen, stethoscope, or _____. |   |   |   |    |    |
| <b>Legs &amp; Feet</b>        | Long pants, lotion, socks, sock seams, clipping nails, shoes, boots, flip flops, or _____.  |   |   |   |    |    |

#### Key:

**P *Protest or complaint:*** whining, crying, saying "ouch," or making specific complaints, calling names, or spitting.

**R *Refuse:*** saying no, sitting down and refusing to move, pulling away, or running away.

**A *Aggression:*** hitting, pinching, biting, or pulling others' hair.

**SI *Self Injury:*** hitting self, chewing self, gouging, or picking at skin.

**SI *Stress:*** urinating on self, flinching, withdrawing, or classic panic attack symptoms such as shaking, turning white, and throwing up.

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learned are unpleasant.

#### Strategies to Decrease Touch Sensitivity

Families have discovered a number of solutions that are practical. You can use these to teach your child to tolerate touch and learn self-control. These strategies fall into one of three categories:

##### 1. Avoiding a sensation.

*The source of irritation is eliminated.*

- ♦ Eliminate the need for a substance or item the child dislikes.
- ♦ Change the substance or item so that it is less bothersome.

##### 2. Tolerating a sensation.

*The source of irritation becomes familiar, is tolerated.*

- ♦ Gradually increase exposure to a sensation or substance your child dislikes.
- ♦ Gradually help your child become familiar with new sensations or substances.

##### 3. Controlling responses to a sensation.

*Positive responses to irritation are learned.*

- ♦ Look at an item that is associated with unpleasant touch.
- ♦ Name or label a touch sensation or item associated with the touch.
- ♦ Control or predict when an activity involving touch will

start or stop.

- ♦ Respond to an unpleasant sensation with self-control.
- ♦ Refrain from protesting to gain a desired activity or sensation.
- ♦ Count episodes in which self-control is used.

#### Teach Your Child to Tolerate and Accept Different Touches

You can teach your child to manage sensations they dislike by learning a more effective way to respond to what overwhelms. The first step may be for your child to learn look at or smell the lotion, shampoo, medicine, or lip balm without panicking. Teach your child to do this by helping her see or experience an item associated with a certain kind of touch sensation in a familiar or less threatening context.

For example, if your child is resistant to toothpaste and brushing her teeth, try putting the toothpaste on *your* finger and brush your own teeth with it first while your child watches. Then have her help you brush your teeth. As you do, give her a chance to smell the toothpaste first. Don't bring it too close too fast. Comment on the color. Reassure your child by using a soothing voice and staying calm. Be patient. This will take some time.

It is important to recognize the power of anticipation when teaching your child about

something she fears. Drawing out the process of an unpleasant task only delays the experience she knows is coming and makes things worse. Yet rushing her through the process without giving her the extra time she needs to process what is happening is equally problematic. Giving your child time to become familiar with a sensation and making the routine as straightforward and simple as possible will help strike a balance between these two extremes.

#### Name Substances and Sensations

Suzy did not like to have her face washed. She would do anything to avoid having the washcloth on her face. Suzy would start protesting as soon as she saw the washcloth, in her mother's hand, even if she was using it to wipe off the kitchen counter rather than washing her face. When Suzy saw a washcloth she expected the awful experience of having her face washed. Her mother tried to reassure her by telling her, "hold still; we're almost done" every time she washed her face.

Once Suzy's mother began working on her response to face washing, she realized she was using too many directions for her daughter to process during a stressful event. She decided limit what she said and focused on telling Suzy what to expect instead, using as few words as possible. She also made an effort to control the tone of her voice. She tried to sound calm rather than

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stressed and demanding. As she got the washcloth ready to wash Suzy’s face, she said in an calm, unemotional voice, “This is wet. It is warm. I am going to put it on your face right here.” She points to her own face and then her daughter’s face before touching the wash cloth to her face. All this was done in a moderately fast manner, but not so fast Suzy could not process what was about to happen. Over time Suzy learned to tolerate having her face washed because she knew what to expect and how to describe what she felt.

Children who are tactile defensive are sometimes confused about how substances feel because of the way they process information from their senses. In this case, Suzy had trouble understanding the touch of the washcloth on her face. Your child’s brain may interpret sensations differently, perceiving a sensation you find refreshing as painful. Your child may need more time to adjust to a sensation. A good place to start is teaching her a word for the sensation rather than the name of the task. This helps her discriminate the feeling from the sensation she fears.

Suzy’s mother learned to name the sensation of the washcloth in a reassuring tone by saying, “*This is warm.*” Naming the correct sensation gives your child a sense of control over what she dislikes because she can describe it.

Try to avoid giving directions to your child during a task such as “*hold still*” or “*stop wiggling*,

*I’m not going to hurt you.*” Even though you are attempting to reassure her that the experience will soon be over, to her it feels like she is being given demands on top of the unpleasant experience.

### Change the Aspect That Bothers Your Child

Sometimes, when your child is defensive, you get the chance to be a good detective. Does she dislike toothpaste because of the bright pink color, the strong odor, the zingy taste (which she perceives to be “hot”), the slippery texture, or for all of those reasons? As your child begins to use language or communication skills—such as sign language, symbols, and other conventional nonverbal techniques—you will be able to ask her to tell you what it is she finds so awful about the substance.

When your child is learning to communicate, you will need to watch for clues in her behavior. Usually what you are looking for are very subtle movements that happen before a meltdown. Is she wrinkling her nose at the scent? Or is she OK until the toothpaste actually goes in her mouth? If the toothpaste is a different flavor, does she still react when it goes in her mouth? Does her reaction change when it is a different texture (gel, liquid, or typical paste)? Taking the time to find out exactly what part of a sensation your child dislikes is sometimes an arduous task. Try changing whatever it is about a product, food, article of clothing, or event

that has that sensation.

For example, If your child will not tolerate raw vegetables, maybe she will like them better cooked, shredded, or dipped in sauce. If she dislikes wearing things on her head, maybe a hood or ear muffs will work better.

Involve your child as much as possible in the process of finding toothpaste that has the right taste and texture or a lotion that smells and feels right. Involving your child in smelling and trying different items gives her a sense of control over her reactions. If you are at a loss regarding alternative substances for a task, ask your child’s doctor or pharmacist for suggestions. They often know of products that are affordable, but you have not considered.

It still involves the element of trial and error, but it is worth the time to thoroughly investigate your options. Many families use samples from a dentist or travel-size packages from a hotel, or store to cut down on the cost. If you know what types of smells and textures your child prefers, share that information with others so they can help more effectively.

You may have to make some careful choices. For example, what is most important to your family right now: having your twelve-year-old use grown-up toothpaste she detests and protests using or using a milder toothpaste that comes only in the tube with Big Bird on it that tastes good to her?

### Give Your Child a Sense of Control

Once you realize your child has sensory defensiveness, it is time to reframe how you view her behavior. When she screams, cries, or pulls away, she is communicating that the experience is overwhelming or distasteful. She is not *choosing* to be naughty or bad. Offer your child *reassurance* rather than scolding or demanding that she behave. Teach her to control what is happening by giving her a better way to communicate she is overwhelmed. For instance, learning to say “*Wait, I’m not ready*” is much better than screaming, hitting, or turning the bathroom into a war zone. For this to happen, you must teach your child how to tell you and that you will respect her wishes.

This sounds easy, but it’s very challenging to do. Many families attempt this strategy by first teaching their child to say “no.” They hope their child will use the word or symbol for “no” when they want a sensation or activity to *stop*. However, what the child thinks she’s saying when she says, “no” is the activity will never *begin*. This sometimes results in a child who says “no, no, no” to all the sensations or activities that bother them. Everyone is quickly frustrated when they realize that they are forced not to respect their child’s “no” to give a medication or start a self-care routine and are tempted to give up.

“No” is a powerful word and should always be respected. If you are not planning or able to respect it, you might want to teach your child some other words to say for control such as “*wait*,” “*not yet*,” “*my turn*,” or “*all done*.” That way when you do have to go ahead and put on a bandage or give some medication even though your child



is continually saying, “wait,” you can acknowledge her message without taking her power away. For example, you can say, “I know you don’t want me to do this. I’m sorry, but we have to. We need to keep this cut clean. We’ll cover up the bandage with your pants so you won’t see it.” Then follow through. And while their words did not stop the event, they know why and will also learn to trust you.

Sometimes you might have to put some thoughts into words for your child to teach her how to say she needs you to wait. Hopefully

you will see that you need to do this before they start to cry. For example, “Kathy needs me to wait,” and then immediately wait or stop.

One mother told me she had better luck when she began to cue her child to “get ready,” in a calm, reassuring voice and modeled taking a deep breath. To her surprise, her child stopped yelling and imitated taking the breath and then accepted the washcloth on her face.

*“I realized afterward that I was showing her what to do to get through the moment and giving her words that she could hang on to by focusing on the behavior of getting ready rather than the behavior of saying no, which she had over-learned and communicated by spitting on and hitting me.”*

### Repeat, Repeat, Repeat

Although this can seem a little bit like adding to the torture, doing activities your child dislikes more frequently may help it seem less frightening. One family switched from washing their child’s hair once a week, to doing it daily, to help the experience become more familiar.

This strategy is called, *desensitization*. Be careful, though. Desensitization involves more than just repeating the activity. Here is an example of what desensitization done well looks like.

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Sam’s family sat down and analyzed all the points in taking a shower that bothered their son. He got chilled, hated the feel of the water from the shower head on his skin. He said it felt like needles. He complained that he was drowning when the water ran over his face. He had the words “hot” and “cold” mixed up, especially when he was still sleepy early in the morning. He had no sense of control. The experience of taking a shower seemed to go on forever. No wonder he hated showers.

They also knew that their son really, really liked to go on three-day hiking trips and that meant at least an occasional shower. He also loved sports and that meant, sooner or later, he would need to shower at school. With all this in mind, they came up with a plan.

First they decided he would shower daily to make it part of the routine. They moved the time of the shower to after breakfast so he was less sleepy. They used the word, “warm” to describe the temperature of the water to help with his confusion between “hot” and “cold.” They changed the spray setting on the shower head so it felt softer. They made sure there was a soft, warm towel ready for him as he stepped out of the shower so he would not become chilled.

*“What a difference,”* his dad said afterwards. *“He still doesn’t like showers, but we can use the showers in the campgrounds without people thinking I am*

*murdering or abusing my ten-year-old son.”* Desensitization can turn a power struggle into a win-win solution for everyone when it is done thoughtfully.

### Don’t Give Up Too Soon

Find out how many opportunities your child needs to learn to tolerate sensations without protest. Most people need at least thirty days to form a habit. A child, who is tactually defensive, may need forty-five or even sixty days to accept only one part of a routine that is difficult. Show your child her progress with a simple chart. Post-it notes or 3 x 5 cards are easy to stick on the mirror or inside a drawer or cupboard in the bathroom. A calendar can also be used to show progress. If a calendar is too abstract for your child to understand, use objects to measure success.

### Make the Desired Behavior Visible

One family decided to reinforce their child for tolerating a smidgeon of toothpaste on the brush to counter bad breath that came with his many sinus infections. They started by putting a tiny amount of toothpaste on the brush and brushing for ten seconds. Every time the routine was finished, whether he cried or not, his mother sat down and read him a short story. When she was done, she left the book on the counter. As the books piled up, the boy began to see a connection and his attempts to push away the toothpaste went down. The

faster he finished the routine, the sooner he got to the books. A big protest over a little toothpaste just wasn’t worth it to him. Soon he and his mom were counting the books and there was one less battle every night. After a long time, his mom slowly increased the amount of toothpaste that he used and the length of time she brushed. Eventually he began to hold the brush and try it himself.

Afterwards she commented, “I expected Ryan to brush his teeth because I said so. I really didn’t take his protests seriously, I just wanted to get it over with but it was always a battle. So I had to back off, start small and take it a little at a time. At first I was afraid that I was just giving in to him, but in the end I realized I had given him the time he needed to be successful and made the whole thing less of a pain for both of us. I would still be battling with Ryan if I hadn’t changed my approach. Instead we put in the time it took to overcome this problem and now we are free to do a lot of other things.”

### Teach Your Child How To Predict When a Sensation Will End

Research shows that children with disabilities will engage in an activity not because they like it, but because it is familiar. Sometimes we are not able to get inside our children’s heads and change the chemical reactions that cause him or her to perceive touch as irritating. Of course we consult

with physicians and check out any medical treatments or therapies that may help. Most parents want to know what they can do at home and how to change things as their child grows.

What we can do is to teach our children to predict what will happen, how it will begin, what happens next, and how it will end. As your child learns the routine, it will become familiar and eventually she will build a memory that competes with the sensitivity.

Your child may never learn to *like* a sensation but she may learn to get through it or put up with it. You can do this kind of teaching by setting up a routine. Even if your child has a significant intellectual disability and does not fully understand words or the reason for events, she can learn to recognize objects, symbols, photos, or behaviors that will indicate when a routine will start and end. This gives her a greater understanding and sense of control of the situation.

A family decided that their sixteen-year-old son simply had to wear gloves when the temperature dropped below zero. They put them on. He ripped them off. They put them on. He ripped them off. Eventually he gave up but the next day it started all over again. One day his older brother, put the gloves on his younger brother and immediately handed him the keys to the car. To his amazement, his brother kept the gloves on, clutched the keys, and marched

out to the van. His behavior told his family that keys not only meant time to go but also time to keep the gloves on. Now his family is working on keeping the gloves on after the car starts until it warms up.

### **Be Consistent— Make it a Routine**

One family took a look at the bedtime routine and found that grandma and two older siblings were each going about the routine in different ways. They noticed that Bud screamed about putting Carmex on his lips before bed a lot less when his oldest brother helped out. Bud had dry skin that is often a concern for people with Down syndrome. Without treatment his lips were always bleeding by morning. At first they thought they were on to something until they realized that his screaming was less because his older brother was simply skipping this step. Bud had learned that sometimes his screaming resulted in no Carmex. At least that's the connection he made.

Bud's family looked a little harder to find the reason why this step was being skipped. "Guys don't use this stuff," Bud's brother told his grandmother and sister. The family compromised by buying some Chapstick instead. Once the routine was consistent, Bud learned that screaming resulted in sympathy but he still had to use something on his lips to stop them from cracking. Once his lip healed his brother was able to show him

in the mirror that he was a "cool looking dude." Taking care of his lips became part of the routine and eventually Bud's protests stopped altogether.

### **Add an Element of Fun**

There are many ways of making activities fun. It is important to find solutions that work for the whole family so you can follow through and be consistent. One family blew bubbles while their child's hair was being brushed. Another family found this brought on fits of uncontrollable giggling which were difficult to stop. One family read a story to their child as he got dressed in the morning but then had to quit when they realized this interfered with teaching privacy.

One creative mom took a picture of her daughter, put it on cardboard, covered it with contact paper and cut it into a puzzle. For each "difficult" activity that she tolerated, the child was awarded a piece of the puzzle. When the puzzle was complete she could trade it for breakfast at a fast food restaurant. The morning routine began to center around putting the puzzle together rather than running away from mom. Another family had no time for putting puzzles together. They used small "goldfish" crackers as rewards when their child took the seizure medication he disliked, but needed.

Discover what aspect of a routine your child likes best, and use that to create an element of fun. Many

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## “Don’t Touch Me!”

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children with disabilities tend to repeat movements and while this can be annoying, self defeating or even harmful, this tendency can also be used to counter dislike of certain sensations.

One family used counting as part of the routine for hand lotion. The mom counted the number of drops she put on the back of her child’s hands which were less sensitive than the palm, she discovered. She counted the number of strokes—always ten—to rub in the lotion. Her child, who liked repetitive movements, stopped fussing to listen to the counting and knew it would end when she reached ten. One day she stopped at eight and he told her to “keep going.” She knew that the routine was helping her son focus on something other than the sensation.

Another family tried the counting suggestion, but found that the words irritated their child even more. In fact, the more reassurance they offered, the louder and longer their child protested. They decided to stop talking all together when putting lotion on their son’s hands, which were very dry and cracked. Over time he realized that when lotion was applied, he could count on some silence. Soon he was refusing to let go of his parents hands after the lotion was rubbed in. Eventually they were able to teach him to use lotion to calm down.

Not using words helped them become calmer too. “At first this seemed strange. I thought I

needed to tell my son step by step everything I was about to do. I thought that would help him know what was coming. But it just made things worse. I learned that my son knew what was coming when he saw the lotion bottle. He didn’t need all those words. I learned to listen to my son’s behavior.”

### **Respect Your Child’s Sensitivity & Trust Your Instincts**

Recognize that your child’s preferences are a very powerful force in their life and treat them with respect. There are many ways to respect your child’s sensitivity. Research suggests that children with tactile sensitivity or defensiveness prefer firm rather than light touches. Reducing and respecting sensitivity may involve even more strategies, though. For



example, approach your child from the front or side so she can clearly see you and is not startled. You may be grasping your child’s hands to take her through the motions of an activity, such as putting on socks. But her hands may be the most sensitive or she may need them to use in communicating she needs you to wait. Instead it may be more helpful to first obtain her permission and then gently guide movements from the elbow to assist her.

Becoming more knowledgeable about your child’s discomfort allows you to make reasonable efforts to desensitize her while still setting and teaching limits. If the occupational therapist has recommended general desensitization techniques such as brushing, it is reasonable to schedule these as a warm up to the more practical sensations in the daily routine. If some sensations are overwhelming, it is reasonable to try to reduce them. For example, if a full shower is too intense, try using a hand shower in the tub or getting an inexpensive showerhead that creates a softer or harder flow. If your child hates liquid medications, it is reasonable to ask the physician for pills that can be taken in applesauce or other favorite foods. It is *not* reasonable to force the medication down her throat with a medicine spoon. It is reasonable to let your child hold the spoon and control the experience as soon as she or she is able.

### Rehearse How to Tolerate the Sensation

Rehearsing how to tolerate something means pretending to go through the activity yourself and showing your child how you want her to respond to the part of the routine that bothers her. One way to do make this more concrete is to create a visual social story about the situation. Include the name of the activity, the steps involved, how it will feel, and how you want your child to tell you to wait and other things she can do during the activity. Be sure to include the payoff for your child's efforts—from her point of view. These stories can be as elaborate or simple as make sense to your child and you have time to create. Some children prefer photographs depicting the routine. Others prefer symbols, stick figure drawings, or words alone. Include cues you will say, such as “get ready, get set, go” within the activity. Another way to rehearse is to have another family member model what to do by taking their medication first. Another method is to do it first yourself, such as putting on a hat and mittens or tasting a food first while your child watches. Sometimes it helps to suggest first closing her eyes and then opening them later. Try letting your child listen to music with headphones or look at a video while dressing. There are as many strategies as there are situations to use them. Keep testing until you find one that seems to work.

Teach your child key words to describe what you want him to do. Don't rely on general phrases such as “be brave” or “let's get it over with.” Use specific words or phrases, such as “rub the lotion in without complaining.”

### One New Sensation at a Time

We love our children, although it's hard to remember that in the middle of meltdown. We are in this for the long haul. As parents, we tend to panic as our child gets older and we realize we are still doing a lot of the work. Make a list of the top three things you want your child to tolerate and plan to give each one three months of effort. At the end of nine months, you'll have a better sense of accomplishment and feel a lot better about yourself and your job as parent. You need to avoid being overwhelmed and so does your child. Taking things slowly and deliberately is the best way to do that for both of you.

### Implementing a Plan For Your Child

Your family may decide to use some of the strategies in any or all of the ideas described above. Your decision will be influenced by the age of your child, the frequency and intensity of her responses, and the social expectations you have for her. In general, avoiding a sensation works best for very young children and becomes more difficult when a child is older and their world expands to places outside your immediate control.

Teaching a child to tolerate or control her responses to a touch sensation is appropriate at any age. To begin, it generally works best to first reduce the frequency or intensity of a response. As you gain progress in this area, you will devise strategies to eliminate a negative response by teaching new behaviors that replace protests, screams, aggression or self-injurious behavior.

### Telling Others about Your Child's Tactile-Defensive Behavior

It is important to share information about extreme tactile defensive behaviors with others such as educators, care providers, physicians, family, and select friends. It is not always easy to do. Support group meetings are often devoted to discussing concerns such as illness, treatment, therapy, learning, or school-related issues. Your family may not want to bring up how much difficulty you have with your child's care routine. You may be uncomfortable discussing your success or failure in teaching personal cares skills at a planning meeting or during a visit to the doctor.

This is especially true as your child grows older and other children seem to have mastered many more skills than yours. Fearing the thought of being overdramatic, you may downplay your experiences or calmly mention them in passing. As a result, health professionals and educators may

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not realize how many battles are happening at home or their intensity. They may see your stress, but be unsure of when and how to assist you and your family. Without support, your family will struggle on alone to teach a touch-sensitive child to clean or care for him or her self.

In some situations, you may sense that others, including professionals, are critical of your parenting. They may see your skills as the reason for your child’s poor hygiene. You may believe that professionals have decided that you do not know don’t understand why it is important to teach about hygiene. This kind of criticism does nothing to assist your child or the rest of your family.

In an attempt to reassure you that “all children have these kinds of behaviors,” a doctor, educator, or provider may unwittingly discount the problem. If your family begins to feel intimidated or uncertain you may quickly stop asking for the support you need. After all, who wants to admit that their eight-year-old won’t take a bath or a ten-year-old won’t allow their face to be touched or a fourteen-year-old still won’t use toothpaste? Families feel the need to save face in meetings as much as professionals do. Even when teachers offer to “work on this problem” at school, you may decline because, no matter how well intentioned, it implies to you that you have not done your job.

The best approach to use in

response to your own concerns or any perceived criticism is to take the lead and bring the topic up with health professionals, educators, and other support people. Ask to talk with your child’s teacher or the school nurse privately before a meeting. Visit with the clinic nurse prior to seeing your child’s physician. This may be a good time to bring up your concerns. Remember, though you feel anxious about the problem, launching into a long story filled with details is usually not helpful. Instead, try a brief overview that puts your concerns into perspective. “My child is very defensive about physical contact. Her reactions are extreme. Offering reassurance or taking things slowly aren’t working for us. We need some practical suggestions for specific problems. Can you refer us to someone who can help us plan for behavior change at home or help us find out what might be causing these problems?” Making a brief list of the sensations and reactions your child has or using the decision graphs provided earlier may be helpful. It gives the other person objective data, rather than emotion. The physician or teacher may ask you to provide examples or more details. From there they can make informed suggestions and together you can decide on a reasonable plan of action.

Parents need practical answers that readily address problems. Ignoring your child’s defensiveness or waiting for him or her to

outgrow it, are two strategies that probably will not work. If your child is touch-sensitive, she displays a level of reluctance that lasts longer and is more intense than most children with or without disabilities. Waiting for your child to get over it or come around will not get your five-year-old dressed for school, or your fifteen-year-old into the shower. While your child’s responses may mature as she grows, this can take several years and there are no guarantees. It is unreasonable to ask your family to simply wait it out. It may be an appropriate response for a child without touch sensitivity, but it isn’t always helpful to tell your family to be patient during a twenty-minute meltdown. Nor is it fair to say her refusal to be touched is something all children experience, because it is not. Your child’s reaction is more intense than usual and these reassurances do not offer a way to end twenty-minute screaming episodes. Tactile defensiveness that persists beyond early childhood and interferes with attempts to build healthy habits or teach daily living skills is a concern that must be addressed. A plan to reduce sensitivity will give you a sense of control and help make things better for everyone. Use the plan to build the support you need.

### **Conclusion:**

Families find many ways to help touch-sensitive children. Whether working with a professional, or trying new approaches on your



own, it is important to think through what you want to achieve and find a win-win strategy for reaching your goal with your child. When your child is ready, involve her in taking responsibility

for getting tasks with unpleasant sensations done. Help her think of creative strategies of her own. Find another family, through a parent support group and ask them what has worked for them.

Today my daughter is a happy, healthy fifteen-year-old who now tolerates most of the sensations that caused us so much grief.

We get through daily routines without flinching, refusals, or behavioral outbursts. Our journey to this point was not easy. It required a lot of research and

hard work. However my search for better answers led to developing techniques that effectively taught our daughter to tolerate a wide variety of sensations. I hope they are helpful to you, too.

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## Recommended Resources

### ***The Out-of-Sync Child Recognizing and Coping with Sensory Processing Disorder***

by Carol Stock Kranowitz, M.A.  
Published by Perigee Trade, 2005.  
ISBN: 0399531653. \$15.95

This ground-breaking book should be required reading for everyone. The author does a fine job of explaining the abstract idea of sensory integration dysfunction and how it affects a child's ability to learn. It includes suggestions for selecting activities for a sensory diet as well as ideas about how to implement them.

### ***The Out-of-Sync Child Has Fun: Activities for Kids with Sensory Integration Dysfunction***

by Carol Stock Kranowitz, M.A. Published by Perigee Trade, 2003. ISBN: 0-399-52843-1. \$14.95.

This book is full of child-centered activities that are SAFE—Sensory-motor, Appropriate, Fun, and Easy—for children in need of a sensory diet. The author includes more than one hundred activities with detailed instructions for target age, materials needed, preparation, and how to do the activity.

### ***Making Sense of Sensory Integration***

by Jane Koomar, Stacey Szklut, Sharon Cermak, David Silver (audio cassette).  
Published by Elle Curve Records; Unabridged edition, 1998. ISBN: 1893601269. \$22.00.

Short on time? You can learn about sensory integration on your way to work. This audio cassette is one of the most balanced, well thought out and practical presentations for parents on the topic of sensory integration dysfunction currently available. The tape provides a good overview of sensory integration and comes with a booklet with checklists that help you organize your thoughts and questions.

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# Disability Solutions

*A Resource for Families and Others Interested in Down Syndrome and Developmental Disabilities*

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