

Understanding Functional Neurologic Disorder

What is Functional Neurologic Disorder?

Sometimes children or teens can experience neurologic symptoms in their bodies, even when their bodies are healthy and they have no neurologic disease or damage. These symptoms can last for a short or long time, and can range from mild to severe. Sometimes the symptoms can be muscle shaking that look like seizures. Sometimes the symptoms are tingling, numbness, or an inability to walk or see. Sometimes the symptoms can disrupt all of the areas of a child's life, and they can miss school, sleep more or less, get out of their normal routines, and avoid doing the things they used to enjoy. When this happens, it's called a Functional Neurologic Disorder.

When a child has a Functional Neurologic Disorder it is often very stressful for the whole family. It can be particularly frustrating for parents because they want to help their child to feel better and protect them from the symptoms. Parents sometimes feel that because there is not a clear and identifiable medical cause then doctors think the symptoms are all in their child's head. This is not true— Functional Neurologic Disorders happen when neurons misfire in the body and the brain gets stuck in the messages it is receiving and giving. Essentially the brain and body can get in a cycle of not communicating smoothly with each other and will send inaccurate messages. This process can happen for a variety of reasons.

Although many people have never heard of Functional Neurologic Disorder, it is more common than you might think, and experienced by many children and teens.

Functional Neurologic Disorder is a treatable condition. While there is no single medicine that cures functional neurologic disorder, it is important to know that it CAN be treated. Most children learn how to get their symptoms under control and get back to their normal lives, although it can take work and time.

What Causes or Affects Functional Neurologic Disorder?

The brain receives and sends messages to the rest of the body in very complex ways. Many different factors can contribute to the conversion symptoms. These can affect how your child's body experiences the misfiring of neurons, including any of the following:

- A triggering event such as an injury or illness
- Sensitivity to sensations in the body
- Conditioning of the autonomic nervous system
- Behavioral habits like activity level, diet, and exercise
- Functional factors like school, activities of daily living, and scheduling
- Social or environmental factors like family life, how others respond to the child's symptoms, and social support
- Psychological and emotional factors like stress and reinforcement

What is the treatment for Functional Neurologic Disorder?

- 1) Changes in the environment
 - Getting back into normal routines and expectations

- Having a daily schedule and routine
- Adjusting parents' responses to child's symptoms
- Daily practice of skills learned in therapies

2) Behavioral Health follow up for:

- Learning relaxation and symptom management skills to help your child self-calm
- Helping your child to understand that her body is safe and she can participate in all of the activities she enjoys, even if she is still having some symptoms
- Getting support and guidance for all of the changes the family is making in the home environment

3) Physical Therapy, Occupational Therapy, Integrative Medicine if needed

4) Consistent scheduled check-ins with primary care physician

How Can Parents Help?

Many parents feel worried or upset when their child has worrisome symptoms. This makes sense. One of your primary jobs as a parent is to protect your child from hurt or harm. You likely have been spending your time trying hard to do this while looking for the cause of his or her symptoms. When a child has a Functional Neurologic Disorder, however, a parent's job changes a bit.

Now, instead of being your child's "protector", you need to be your child's "coach". This means that you need to find ways to encourage and support your child's

return to normal activities and his or her recovery from pain. So, how do you do this?



The following checklist includes some great ways to “coach” your child back to health:

- ✓ **Set an emotional example.** You may feel worried or frustrated as your child is working to recover from their symptoms. This is normal. However, it is important to remain calm and try to manage these feelings, especially in front of your child. Your child will draw strength from your calm reaction and will be better able to deal with his or her symptoms. If you feel yourself getting tense or upset, try breathing slowly and deeply. You also may want to talk over your concerns about your child's health with a trusted friend or health professional.
- ✓ **Encourage normal daily activity.** Going to school, doing chores, and participating in activities are all important for recovery. Participating in normal daily activities, even when having symptoms, gives your child a sense of control over the pain. As your child feels more in control, anxiety (and the associated stress response) will decrease.
- ✓ **Create a plan to gradually increase daily expectations.** Functional Neurologic Disorder can disrupt your child's activities—school, friendships, hobbies, etc. Your child will need your help and support to get back to his or her daily routines. Here are a few key steps:

- **Step 1: Set a consistent daily expectation for participating in one area** (e.g., half day attendance at school, 30 minutes attendance at a club meeting or play date). Start with a small enough amount of time to ensure your child's success and build from there.
- **Step 2: Your child should attend the activity for the agreed upon amount of time each day.** This should happen regardless of symptoms or other health concerns. Your child should leave the activity at the scheduled ending time even if he or she is feeling well. Doing this will encourage feelings of success and help prevent symptoms from getting worse on the following day(s).
- **Step 3: Your child's progress should be re-evaluated weekly.** If your child has been able to complete the plan for the previous week without increased symptoms, then expectations should be increased slightly for the next week. You might increase time spent in the same activity or add a small amount of time on a different activity. Again, this added time may be as little as 30 minutes. Remember, slow and steady is the key!
- ✓ **Resist the urge to ask your child if she or he is having symptoms.** Symptoms are worse when children pay attention to them and better if they are distracted from it. Asking about symptoms encourages your child to scan his or her body, look for symptoms, and (usually) find them. If your child happens to be distracted from the symptoms at any given moment, we want that to continue. It is perfectly okay for your child to come to you to tell you about his or her symptoms. However, if this becomes frequent, you might think about scheduling a specific time each day for a 5-minute "symptom report". This can reduce your child's focus on symptoms at other times of the day.
- ✓ **Improvement is first measured by increased functioning.** Your child is recovering when you see even a small gain in your child's ability to do the things he or she once did (e.g., go to school, participate on a sports team). For most of our patients, the symptoms go away *after* they are back to doing their normal activities.
- ✓ **Encourage positive coping with symptoms.** Gently remind and encourage your child to use skills like deep breathing, distraction, relaxation, positive thinking, etc. during conversion episodes. These skills also can help prevent episodes if used before event that seem to trigger pain (e.g., eating, going to school, having a test). At first, your child may need more encouragement and help from you to use these skills (e.g., playing a distracting game or practicing relaxation skills with you). Over time, using these skills will become easier and your child's self-confidence will increase.
- ✓ **Use rewards effectively.** When your child is sick, it is natural to give lots of extra attention, affection, and privileges. You want to make your child feel better! But when a Functional Neurologic Disorder is

present, extra attention, affection, and privileges are best used a little differently. Instead of using these things to make your child feel better when he or she is not doing well, you can use these things to reward your child's efforts to manage symptoms and/or to meet daily expectations. Praising effort is very important. This encourages your child to keep trying and not give up. When your child is having trouble helping him or herself, or is complaining about symptoms, gently encourage more positive behaviors and walk away. But, remember to check in every few minutes to "catch" your child making an effort and offer praise! Offering special rewards or activities for reaching important recovery milestones (e.g., first time sleeping over at a friend's house, first week of school with no absences) also can help increase effort.

- ✓ **Stay positive.** Use positive language and encourage your child to do the same. For example, you can say: "You are such a brave girl. I know that you will be okay." This helps your child to focus on how well he or she can cope with symptoms, instead of how bad the pain feels. Remind your child how well he or she has coped with difficulties in the past. Talk about the symptoms being temporary and eventually getting better or going away. Using neutral words when talking about your child's experience (e.g., "episode" versus "attack") also can help make symptoms more manageable.
- ✓ **Encourage regular exercise and sleep.** Low impact exercise like swimming or biking is good for everyone, but especially for a child with a Functional Neurologic

Disorder. Exercise helps to improve the immune system and activates the pain relief response in the brain. Like everything, start small and work up! Good quality sleep also is related to your child's ability to manage his or her pain. Your child should go to bed at the same time each night, get up at the same time each morning (even if she or he is not attending school regularly), and only use his or her bed for sleeping (not for doing homework or watching TV).



A Final Reminder: A long-term problem requires a long-term solution. Quick solutions do not work for symptoms that have become more chronic. Children who do the best over time make slow and steady progress in functioning first. If your child has been having symptoms for a very long time, it may take a similar amount of time for the symptoms to go away completely.