

Supporting Children and Adolescents with Functional Neurological Disorder in the School Setting

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ABSTRACT

Functional Neurological Disorder (FND) can significantly impact school functioning. Symptoms may affect children and adolescents academically, socially, psychologically, and impact school attendance. This article reviews the importance of being able to continue in school despite FND symptoms and recommendations to support this. It will provide a guideline for communication and collaboration with schools and describe the type of information that is helpful to share with school teams. This article will also discuss various accommodations that can be helpful in the school setting. Finally, other resources, such as IEPs and 504 Plans as well as additional sources of information and support are briefly reviewed.

KEYWORDS: School, Functional Neurological Disorder, Accommodations

CASE

BH has made progress with functioning and walking without support as well as engaging in therapy. She continues to have periods of regression where she loses functioning, but they are transient in duration. Her family has shown increased ability to tolerate distress around symptom flares and maintain expectations to empower BH and not accommodate FND by over-attending or offering extra physical support. BH has expressed a readiness to return to school, and her family and treatment team agree that a shift in focus away from treatment and towards regular, daily activities would help reinforce progress.

- What is important to communicate to school to help them understand FND and address concerns about symptoms?
- What could a school transition plan look like?

INTRODUCTION

Youth with functional neurological disorder (FND) are at risk of decreased functioning in the school setting. Given that the school environment is typically the most important non-family context for children, addressing school functioning is critical to multidisciplinary treatment for FND.¹ School can be challenging for many and is often listed as a stressor among youth with FND. Indeed, learning problems²

as well as challenges with attention, memory, and executive functioning³ are higher in the FND population. Additionally, many FND patients also describe challenges of navigating the physical setting of school with their symptoms, experiencing negative interactions with peers or school staff who are unfamiliar with FND, and missing school due to ongoing medical appointments. Some have also had the unfortunate experience of being excluded from experiences or being required to use equipment (e.g., wheelchair) due to school's perception that symptoms were a liability. It comes as no surprise that youth with FND are at risk of school absenteeism,⁴ which can be exacerbated by parent over-protection.⁵ However, ongoing absenteeism has been empirically identified as a perpetuating factor in ongoing functional symptoms.⁶ Thus, supporting consistent school engagement is a primary treatment target for youth with FND.⁷

SCHOOL REINTEGRATION AND ATTENDANCE

Providers are often asked whether returning to school is in the child's best interest, citing the challenges associated with school attendance and perception of the worsening of symptoms at school. Clinical experience and empirical evidence confirm that school attendance and functioning is vital to FND treatment.⁷ To answer families' questions about best educational placements, it is helpful for families to focus on what would be in their child's best interest if FND was not occurring. This allows families to make decisions based on what is best academically, socially, and personally, not based on FND.¹

It is important to clearly communicate to school and the family that FND symptoms should not be a reason for absences. While some may be able to maintain a high level of learning and academic achievement through self-guided study at home, the school environment is rich with important opportunities for social interaction, physical functioning, and distraction. Moreover, if missed school due to FND symptoms was inadvertently contributing to a pattern of avoidance of other distress (e.g., academic stress, negative peer interactions), the expectation of school attendance may highlight other areas of concern that need support.

For youth who have been absent for an extended period due to FND, developing a gradual reintegration plan is essential to supporting their return to school. This type of plan

typically involves a pre-planned schedule with daily expectations of increasing time spent at school over the course of days to weeks. When discharging from an intensive treatment setting such as the Hasbro Children's Partial Hospital Program (HCPHP), a gradual return to school plan is created that allows for increasing time spent at school each day until discharged back to full school attendance. These plans are individualized to the specific needs of the patient. For example, patients with high levels of anxiety about returning will often follow reintegration plans that include an element of "exposure therapy" (i.e., gradually facing the feared situation) and will take place over a longer period of time. The first few steps may involve brief visits to the school parking lot or visiting with a preferred teacher before or after school. Patients with less anxiety may attend one class on their first day back, two classes on their second day, and then quickly transition to a half-day at school before returning full time. A key element of school reintegration plans is that they are followed regardless of FND symptoms. It is not uncommon for symptoms to flare in the context of transitions, including school return.

SCHOOL COMMUNICATION AND COLLABORATION

The treatment team is well positioned to communicate with schools to provide education about FND and to collaborate to implement accommodations. Although there are often multiple school personnel who will be supportive collaborators, initial communication typically begins with the guidance counselor. The guidance counselor can then integrate other key school members, often the school nurse and a member of the socio-emotional staff, such as a social worker, adjustment counselor, or school psychologist. Initial communication should focus on providing education about FND and answering questions. This education is important to help understand the rationale behind recommendations. For example, the knowledge that a child's functional symptom is a real symptom yet not indicative of medical response will help school understand *why* the child is not in need of medical attention and should be encouraged to stay at school instead of being sent home or to the hospital. For example, a functional paralysis, where the child suddenly can't walk, warrants planful support but not medical intervention. While FND symptoms themselves are not inherently harmful, schools may express concern around potential for injury such as when a child with functional seizures falls to the ground. Although most aspects of FND are unconscious, symptoms can exist on a continuum of awareness, and it's not uncommon to see children exhibit a symptom in a way that is self-protective, such as slowly falling or bracing themselves with their hands. As such, collaboration with school nurses will be especially important for developing a plan that incorporates the needs and limitations of the school setting.

While communication may start with one school team member, often multiple conversations and meetings are needed, as many schools will not have had experience with FND. Schools appreciate as much transparency and information as possible, including any educational materials about FND that can be shared with staff in addition to documented recommendations. After an initial conversation, it will be important to coordinate a larger team meeting in which information and recommendations are shared. This meeting often includes parents so that they can ask and answer questions and provide input to discussions about how school can support their child.

The following pieces of information are often helpful to communicate to school staff: 1) an explanation of Functional Neurological Disorder, 2) the role of increased activation of the nervous system (i.e., stronger emotions, stress, dehydration) in exacerbating symptoms, 3) the lack of inherent harm of FND symptoms to the child, and therefore 4) the lack of need for medical attention, 5) the role of increased focus/attention to symptoms in exacerbating FND, and 6) a description of the child's specific symptoms. Additionally, it may be beneficial to reiterate the "realness" of FND symptoms (i.e., clearly stating that the child is not "faking" or displaying them for attention/avoidance reasons). It is important to prepare school that the child is likely to experience ongoing FND symptoms, and to provide education and recommendations for support when they occur. It is also helpful to explicitly state that the child is safe to stay in class or remain in school and that there is no medical intervention needed. Encouraging patients to think about what they want to say to peers about FND (or have teachers say before they return) can help address concerns of what others will think. Giving guidance for what teachers may say to other students to minimize attention is also important (e.g., "X is having an FND episode and is safe. It would be most helpful if everyone continues to focus on their work"). When children are given brief explanations that they can relate to, they can be more accepting of something that may seem bizarre. An example of this is: "I have FND which is where there are some signals that are not working right between my brain and body, and because of that my leg feels numb and I feel like I can't walk/my body shakes and I sometimes fall to the floor." It is not recommended that children say "It's none of your business" or "I want to keep it private" as this tends to generate more curiosity and, ultimately, rumors. The more succinct and matter-of-fact the explanation, the better. Another important component, however, is including some instruction as to what other kids should or shouldn't do during an FND episode.

SCHOOL ACCOMMODATIONS

Given that daily attendance is a primary treatment target, the provision of accommodations is intended to support a

child's ability to attend school. Allowing reasonable accommodations typically encourages better school attendance by helping the child cope with challenges and stressors in the school setting. However, accommodations should not reward or reinforce poor coping by allowing the child to avoid challenges altogether. As one can imagine, this can be a difficult balance to strike. Providing an explanation for each accommodation can help the school understand the goals and implement the accommodation in a way that fits their setting and meets the needs of the child.

Reasonable accommodations typically fall within the categories of academic, physical, and coping. Academic accommodations are related to workload, classes, and grading. For many patients, FND symptoms (and other underlying or resultant anxiety, behavioral, or mood symptoms) have likely interfered with their ability to complete schoolwork, often through missed schooling due to medical care or symptom flares. Some patients have also been asked to take a leave of absence from the school while pursuing treatment, and thus have received reduced learning opportunities and are behind in schoolwork. It is typical to request minimizing a child's workload to only essential assignments until they can catch up, and/or extending deadlines for missing assignments that may help the child earn a passing grade. Given the higher prevalence of learning and attention problems in youth with FND, it would also be appropriate to recommend a psychoeducational evaluation if there is any clinical indication.²

Physical accommodations relate to modifications to the way the child navigates the school setting or classes. For youth transitioning back to school and focusing their energy on daily attendance, it's helpful to minimize some physical stressors such as rushing through crowded hallways or carrying a heavy backpack. When FND presents as motor symptoms, it is necessary to discuss physical accommodations for ambulating at school. Schools may be quick to want to make physically navigating school as easy as possible, but this would likely be counterproductive to treatment and reinforcing of FND. While it's easier to offer a wheelchair, this wouldn't be recommended if a child has moved past this level of support in treatment. It is preferable that there are accommodations such as extra time or leaving class early to work on getting to the next class rather than an accommodation that inadvertently empowers FND. With motor symptoms, treatment plans may include a progression to "furniture or wall surfing" in which the children are encouraged to support themselves by holding onto what is around them to ambulate as opposed to relying on assistive devices such as walkers. This helps to retrain the brain and make repairs in the mind-body connection.

Accommodations focused on coping request special permission for the use of relaxation and distress tolerance strategies that would typically not be provided to all children. Children with FND may have comorbid anxiety disorders

as well as experience anxiety about having symptoms at school in addition to general school stressors. Anxiety and stress can exacerbate FND symptoms, thus it is important to engage in coping strategies to help manage this. Within the classroom, coping skills often focus on using small objects or strategies as distraction tools (so long as they are not disruptive to others). Some examples include fiddling with small objects at their desk, squeezing putty or stress ball, or doodling in their notebooks. While the goal is to use distress tolerance strategies to remain in class, there may be times where the child needs extra support, such as checking in with staff or using additional strategies that would need to be used outside of the class (e.g., listening to a relaxation video, shuffling cards, sharing emotions through talking or writing). Having a standing check-in or break with school support staff may be recommended. It can also be helpful to have a certain number of passes (e.g., 3) to use as needed to receive extra support. With a limited number of passes, children are empowered to identify when they really need that extra support.

Keep in mind that the recommendation of accommodations should occur within a fluid process that continually evaluates a child's treatment progress. It is important to work with the family to reduce use of accommodations as the child reacclimates to the school environment. Doing so will allow the child the opportunity to work through challenging situations and gain endurance to more stimulating situations over time.

ADDITIONAL RESOURCES

In many cases, schools can implement the above recommendations and accommodations without formal plans in place. However, it may be helpful to pursue a more official plan that is supported by federal law. In public schools in the U.S., the options are either a Section 504 plan, which "accommodates the environment to make the curriculum more accessible for a child who has a medical condition or specific learning disability," or an Individualized Education Program (IEP), which "modifies the regular curriculum to provide effective education to the child, accounting for medical, learning, or developmental challenges."¹ Both options require that the child has a psychological, learning, or physical impairment that limits a life activity.¹ Children with FND are typically most appropriately supported by a Section 504 Plan. Having a formal 504 Plan can be helpful in terms of communication and accountability. More information about these plans can be found on the website of the U.S. Department of Education (www.ed.gov). Having a formal 504 Plan or IEP may be particularly helpful in scenarios where schools are not appropriately accepting of or responsive to outlined recommendations. In cases such as these, families may also want to pursue talking to an educational advocate who can help guide them through the process and work together

with the school. Resources such as the Rhode Island Parent Information Network (RIPIN) can help connect families to information and support.

For providers, the Pediatric FND Consortium provides education and resources (worksheets, handouts, videos) on their website (fndhope.org). They provide free access to the "FND Support Pack," which is a handout that explains the ways in which schools can support youth with FND. Additionally, the Society of Pediatric Society Special Interest Group for Functional Neurological Symptom Disorder includes a "Fact Sheet for School Teams about FNSD" on their website (<https://fnsdsigsp.wordpress.com>), along with multiple other resources and handouts for the treatment of FND. The Hasbro Children's Partial Hospital Program distributes community handouts to families, schools, and providers (Handout).

CASE UPDATE

BH's school was unfamiliar with FND, and the treatment team provided significant education, including handouts, about FND and ways to empower BH without inadvertently reinforcing symptoms by overly physically accommodating or by allowing for avoidance of stressors. The guidance counselor was the primary point of contact, and she coordinated several team meetings with the school nurse, principal, psychologist, and some of BH's teachers. Virtual meetings that included parents were held in order to discuss clinical recommendations and how school would be able to accommodate them.

A general theme was that BH should receive the minimally necessary amount of physical support, noting that this would shift depending on periods of regression. Other recommendations included minimizing attention to symptoms,

having extra time to work through symptoms, and giving her reminders that she is ok and that her brain is working on repairing the communication with her body. BH planned to carry a laminated card with some physical "steps" to do

Handout

Functional Neurological Disorder (FND)

What is it?

- FND is a condition affecting the functioning of the nervous system and how the brain and body send and receive signals.
- FND presents as neurological symptoms that result in a loss of functioning despite having no underlying physical or structural cause.
- FND is also known as conversion disorder and functional neurologic symptom disorder. FND is a newer and broader diagnostic term introduced in the DSM-5.
- The term "conversion disorder" highlights how, in many cases, underlying emotional distress is thought to be "converted" into physical symptoms. However, **NOT ALL** individuals have identifiable stressors or trauma, which is part of the rationale for using "FND" as a more encompassing diagnostic term.

Common Symptoms:

- Muscle weakness or paralysis
- Numbness
- Speech, vision, hearing, swallowing difficulties
- Abnormal movements such as tics or tremors
- Memory or other cognitive issues
- Functional Seizures, which look like seizures but have no corresponding epileptic brain activity
- Losing consciousness, falling, or periods of unresponsiveness

Examples:

- A girl falls off her horse and is not injured, but her leg seems to be paralyzed.
- A boy cannot see, but there is no physical or structural impairment that accounts for the blindness.
- A girl falls to the floor and is convulsing with her eyes rolling back in her head, but there is no abnormal electrical brain activity when captured by a video EEG.

A Guide for Family, Friends, School, and Community

- What is it?
- What do I need to know?
- How can I help?

Important Considerations

- The symptoms are **REAL** - The individual is **NOT** faking.
- An individual with FND feels as though they don't have control of their body.
- Most aspects of FND are unconscious, but symptoms can exist on a continuum of awareness.
- Symptoms can become more frequent or change in presentation during treatment.
- Sometimes there are triggers for symptoms and other times there are not.
- The goal is to not focus on whether symptoms happen but rather on the emotional expression and distress tolerance work in therapy.
- It takes time for symptoms to improve despite doing the hard emotional work in therapy.
- While FND symptoms may seem bizarre, most people can relate to the experience of emotional distress manifesting in physical ways such as when your heart races when scared or angry, headaches occur when stressed, or you get stomach distress/loose stools when nervous.
- Maintaining regular routines and expectations is an essential part of treatment.
- While there isn't an exact known cause for FND, there often is underlying stress and, in some cases, a stressor(s) that sets off symptoms such as an illness, injury, or series of stressors.

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School can help by...

- Being involved** in the treatment plan, which includes demonstrating acceptance and appropriate management of symptoms
- Helping peers understand** that the student is safe and redirect attention
- Maintaining **ongoing communication** with the home and treatment team including pediatricians and therapists
- Managing distress** at school including safety concerns, bullying, teasing, or academic pressure
- Working with the student to **create a system** that facilitates checking in and getting support when needed

Friends can help by...

- Treating the individual as an **equal** (like any other peer)
- Being respectful** of the individual
- Being informed** by asking teachers or parents for more information

Family can help by...

- Being informed** about FND by talking to an individual's caregivers, participating in family treatment sessions, utilizing appropriate resources
- Learning about **how to respond** when symptoms arise (i.e. "FND mode" – supportive but not overly attending verbally or physically)
- Externalizing the disorder** by talking about FND as a separate entity that everyone is pushing back against
- Not focusing on the episodes** (either frequency or making them stop)
- Supporting expressing** difficult emotions or talking about stressors
- Encouraging** normal, daily activity

What's NOT Helpful...

- Giving too much attention** (e.g., frequently asking how feeling, overly physically/verbally reassuring when symptoms are higher)
- Having negative reactions**, which can decrease self-worth and confidence and worsen symptoms
- Giving the illness more power** by lowering expectations too much around functioning/participating
- Saying **"it's not real"** or **"it's in your head"**

Resources

www.neurosymptoms.org
A guide to understanding the symptoms, causes, treatments, and personal stories of those who struggle with FND.

www.fndhope.org
The FND Hope promotes awareness of this disorder, supports those affected, and advances research towards treatment.

www.fndsigsp.wordpress.com
The Functional Neurological Symptom Disorder Special Interest Group creates a space to share ideas and promote increasing understanding of FND.

How to Respond to a Functional Seizure:

- Ensure that the individual is in a safe space. If needed, move objects away to prevent injury and only move the individual if there is danger. You can reposition if there is something concerning during an episode.
- If fallen and shaking, put something soft under the individual's head.
- Provide brief verbal reassurance that they are having an episode and are safe.
- Observe from a little distance but do not continue to provide verbal or physical reassurance.
- Do not call 911 unless the individual is injured or has signs of respiratory distress. No medical attention is warranted for these episodes, and while they look scary, the individual is not in danger. Functional seizures can be thought of as a neurological panic attack – like a panic attack, an individual appears in physical distress, but no medical intervention is needed or helpful.
- If someone else calls for an ambulance, inform paramedics that the episode is non-epileptic.
- Do not administer medication during an episode.

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to “wake up” her body and gain back control. On days she struggled to attend school due to symptoms, it was strongly recommended that parents still bring her, even if she needed to spend the day in an alternative location attempting to do her work. The team worked to help school understand that while her symptoms look concerning, she is not in need of medical attention and should be expected to remain in the school setting.

BH participated in gradual school exposures, starting with visiting school, taking a tour, meeting her team, and reviewing her schedule. This progressed to her spending an increasing amount of time in school. Once she transitioned to her outpatient team, school continued to coordinate with them around ongoing recommendations.

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