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Functional Somatic Symptoms in Children and Adolescents: The Stress-System Approach to Assessment and Treatment

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Online Supplement 16.3

Working with the School

In this supplement to Chapter 16, we discuss the important task of working with the school. A successful return to school is both an intervention and outcome – an important marker of the child’s health and well-being. Working with the school is a fundamental part of the systems intervention. In this chapter we also provide a pro forma letter that we use for communicating with the school.

In the usual course of events, children do not go to school when they are sick; they stay home, recover from the illness, and then return to school. But as we have seen in Chapter 16, when treating functional somatic symptoms, education staff are part of the multidisciplinary team, and going to school is part of the treatment. In this way, in order for the treatment intervention to succeed, all members of the multidisciplinary team need to know exactly what the treatment plan is, and all need to *pull in the same direction*. The manner in which the school manages the child’s illness and the manner in which education staff respond to the child’s symptoms can make or break the treatment intervention. In this context, working with the school is fundamental.

Psychoeducation with Staff at the Child's School

The school needs to know that the child's health concerns are not dangerous, that they are stress related, and that the treatment program will help the child get well. The school also needs to know that going to school, and engaging in the classroom, is a key component of the treatment program and that staying at home will not help the child get well.

Information about safety is particularly important for non-epileptic seizures (NES) – and sometimes other functional neurological symptoms – which, in addition to the possibility, for some children of falling and injuring themselves, can be distressing to witness and can make school staff anxious or uncomfortable. Some schools are very risk averse and would prefer not to have the child at school at all. Nonetheless, calling the ambulance for NES or sending the child home is unhelpful for the child. It gives a message that school staff cannot manage the symptom and that the symptom is unmanageable and dangerous. In actual fact, the child needs to practice her strategies for NES at school with support of the staff. Presentation to the emergency department can be reserved as a last option on the safety plan (see Online Supplement 16.1) when other strategies fail.

Some schools are easy to work with, and others – those where staff have high levels of anxiety and are very risk averse – are not. In the latter scenario the school may promote schooling the child at home to transfer risk away from the school itself. Home schooling is not in the best interests of the child because functional somatic symptoms and school absenteeism can be mutually reinforcing (Sato et al. 2007). It is our clinical experience that the children who do not attend school have worse outcomes because home schooling promotes a variety of factors that function to preserve and amplify functional somatic symptoms (see spiral into chronicity in Chapter 2). When parents or the school brings up the issue of home schooling, the first author's (KK's) team always explicitly state that home schooling is medically contraindicated. In this context, if home schooling has already in place when our team first meets the child and family, a gradual reduction of home schooling, coupled with a gradual increase in school attendance, becomes a key component of the treatment plan.

Education about the symptoms can be done via phone, a school visit, or video conferencing together with written materials sent by email or letter (see pro forma letter, below). Often the school needs a letter signed off by the family doctor, paediatrician, or psychiatrist – a medical professional – stating that the child has been fully assessed and that the child is safe to attend school (see pro forma letter, below). The school will also need a copy of any safety plan that has been designed to manage the functional somatic symptoms (see Online Supplement 16.1).

Fact Sheets

Fact sheets formalize the information that is given to the school, and they can be used alongside other forms of communication (see above). For a more detailed account of fact sheets and some examples of fact sheets, see Cruz and colleagues (2014).

Implementing Safety in the School Context

Clearly documented safety plans need to be used for NES, low mood, suicidal ideation, thoughts of self-harm, or unsteady walking (see Appendix 16.1 for safety plans). For example, a child whose walking is still unsteady – secondary to functional neurological symptom disorder – needs her safety in walking assessed by a physiotherapist, who may also sometimes need to visit the school to ascertain its terrain. And even after the child is safe enough to walk – whether on walking sticks or crutches, or walking slowly on her own – she may still need to leave one class early in order to get to her next roughly on time. She may also need someone else to carry her books or bag.

Because walking is part of the child's daily physiotherapy – she will get well if she continues to walk – walking is promoted. Of course, it would be easier for the school if the child sat in wheelchair. But sitting in a wheelchair is not in the best interests of the child. It leads to increased attention to the symptoms and does not promote movement and behaviours associated with health and well-being. In this context the clinical team needs to be very clear

as to what the child is capable of and what she should be doing to mobilize at school.

Implementing Regulation Strategies at School

The school also needs to be made aware of the regulation strategies that the child is using to manage her symptoms, so that these strategies can be implemented at school. The strategies should be implemented on both a regular basis – for example, for a short period at lunchtime – and as stop/break strategies to manage exacerbations of pain, arousal, or imminent NES (which should be identifiable beforehand by the child’s warning signs). The child may be given a time-out card at school, enabling her to leave the classroom for 10–20 minutes if she needs to implement her strategies. Everything needs to be planned in advance, and the child must know both the plan and her designated support teachers (see below). Alternatively, a bean bag in the classroom can give the child a place to go if she needs to practice her regulation strategies in the moment (without delay).

A Graded Return to School

Some children require a graded return to school. In this context, the number of hours – or sometimes minutes - that the child returns to school has to be titrated so that the child succeeds in returning to school. This graded return can be accomplished in many different ways. In the first author’s inpatient program, the child may begin school reintegration by going to the hospital school in her own hospital bed for just part of the session and by then building up attendance from thereon. In the third author’s (HH) context, some children start a graded return to school with 15 or 20 minutes and increase this time incrementally. In the outpatient setting, if going to school for short periods daily is not possible, the treatment team may recommend that the return-to-school plan include attendance on two separate days (e.g., 30 minutes or 1 hour on Tuesday and Thursday), with an increase to three days a week (and then more) as time goes on. Multiple short days are preferred to one or two long days. Alternatively, the team may give the child

and family the task of working out the graded return themselves, with the understanding that the direction always needs to be toward full-time attendance at school. Our clinical experience is that the success rate for achieving full-time school attendance is enhanced through a graded return.

An important consideration throughout this process of a graded return to school is to maintain and increase the child's sense of predictability, control, and mastery. Extra teaching support, a reduced number of lessons, reduced (or no) homework, and social facilitation/adjustments are examples of school interventions that may be necessary for treatment success.

In summary, attendance at school is both a treatment intervention and an outcome. Attendance at school contributes to the child's health, and as her health continues to improve, her time at school – and her reintegration into life as usual – is increased accordingly. Burn and crash cycles, in which the child does too much and then crashes, need to be avoided. It is better to start attending school on a graded basis – for example, on alternating days and for shorter periods – and then to build up from there.

Identifying a Designated Support Person

Children function best in the context of emotional bonds 'with parents (or parent substitutes), who are looked to for protection, comfort, and assistance' (Bowlby 1988, p. 3). In this context, it is crucially important that the school choose a dedicated person (or two) who are designated as having responsibility for supporting the child. A positive and safe relationship between the child and this person provides a secure base for the child in the school setting. We usually recommend that the child and this person have regular meetings to evaluate the child's progress over the previous week(s) and to prepare for the challenges of the coming week(s), always with a view to the multidisciplinary treatment plan.

Addressing Bullying and Other Stressors at School

Sometimes, the school is the source of the child's stress. Bullying – which now includes bullying via social media – is a recurring theme in the family

Text Box 1
Pro Forma Letter to School
[for description, see page 8]

Dear [name of recipient at the child's school]
Re: [Child name, DOB, hospital record number]

[Patient] has been an inpatient at the Children's Hospital at Westmead from the [date] to [date] for treatment of functional neurological symptom disorder (FND).

[Patient] experiences non-epileptic seizures, which are the body's way of responding to anxiety and stress. These are not epileptic seizures and are not dangerous. [Patient] has been fully investigated and **his/her** symptoms are not due to a medical or organic cause (i.e., seizures are not epileptic).

The treatment for non-epileptic seizures is to manage stress in the body while returning the child to normal functioning. During this admission, [Patient] attended daily hospital school and physiotherapy and psychotherapy sessions. [Patient] has learnt to identify early warning signs for **his/her** episodes and been taught strategies to bring **his/her** body's arousal down, including [example: **slow breathing, muscle relaxation, and imagery techniques**].

He/she should return to school on [date] in order to maintain gains made in hospital. To assist with [Patient]'s return to school, the following management plan is recommended for **his/her** non-epileptic seizures.

MANAGEMENT PLAN FOR NON-EPILEPTIC SEIZURES

- [Patient]'s episodes are not epileptic seizures and are not dangerous. There is no need to phone for an ambulance or to apply first aid (unless her episode has caused other injuries).

- When **[Patient]** notices **his/her** early warning signs, **he/she** is to get to a safe place (on the ground) and use **his/her** strategies.
- If **[Patient]** has a non-epileptic seizure, there is no need to intervene except to ensure that **he/she** is safe (e.g., she will not hit her head) and wait for the episode to pass. One staff member only is sufficient to supervise; other staff and students are to calmly resume their normal activities. When **[Patient]** comes out of **his/her** episode, **he/she** may need reminding of where **he/she** is. **[Patient]** is to return to **his/her** normal activities when **he/she** has settled, and is to remain at school.
- If required, **[Patient]** may take a 10-minute break in the sick bay or somewhere quiet. During this time, **he/she** is to use **his/her** strategies as listed above. After 10 minutes, **[Patient]** is to return to **his/her** normal activities.
- **[Patient]** should participate in normal school activities unless otherwise indicated.

Please do not hesitate to contact us for any queries.

Yours sincerely,

[Sign off by psychiatrist/neurologist and clinical psychologist or other team member]

stories we encounter and also in research findings (Kozłowska et al. 2011). If bullying is an issue, then it needs to be addressed as soon as feasible (Eisenberger and Lieberman 2004).

Addressing Learning and Other Academic Issues at School

For children with unrecognized learning difficulties or lower IQ, academic expectations may be a source of stress – and activate the child’s stress system – in and of themselves. In this context, attending school will, on a daily basis, be stressful for the child. Such issues must be addressed as part of the

treatment plan – on the school system level – if the multidisciplinary team is going to be successful in helping the child (in part by enabling the child to switch off her stress system). As part of the treatment intervention, it may be necessary to assess the child’s intellectual capacity via cognitive testing. It may also be necessary to ensure that appropriate supports and reduced expectations are established both in the school setting and in relation to the parents (see, e.g., the discussion of school issues in Chudleigh and colleagues [2013]).

Pro Forma Letter for Non-epileptic Seizures

Text Box 1 presents the pro forma letter that the first author and her team use for children with non-epileptic seizures. The letter is usually signed by a physician (typically a psychiatrist or neurologist) – to give a medical signoff to the diagnosis and assessment of safety – and the team’s clinical psychologist. The letter can be adapted as needed to other functional somatic symptoms or can be expanded if the non-epileptic seizures occur alongside other symptoms.

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