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Treatment Interventions III: Working with the Family and Implementing Behavioural Interventions

Abstract Children are born into a family and shaped by the relationships, interactions, beliefs, stories, and experiences within the family system. In this way, the health of the family and the health of the child are closely interconnected, and interventions with children presenting with functional somatic symptoms must always involve the family. All the interventions presented in this chapter—and those presented in Chapter 14 (bottom-up interventions working with the body) and Chapter 15 (top-down interventions working with the mind)—are best effected if they are supported and sustained by the family, are integrated into family processes and ways of being, and enable the family to engage in its own process of change.

The process of working with the family takes place together with and alongside the work with the child (including adolescent) and alongside the implementation of interventions from other system levels. The family

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is part of the family assessment interview—the process of co-constructing a formulation, discussing a treatment plan, and negotiating a treatment contract (see Chapter 3). In this way, from the very beginning, the family is part of the storytelling process that identifies past events that contributed, as well as current matters that are still contributing, to the child's stress and distress, and, in turn, to the activation of her stress system. The natural flow-on from this approach is that, at the outset, the clinician emphasizes the importance of the family in the therapeutic process. Early in this process, the clinician works with the parents to support them in the task of supporting the child as she engages in the treatment program (see interventions outlined in Chapters 14 and 15). Later, as the treatment progresses, the clinician may need to work with the family—or arrange family work via an appropriate referral—to address any residual issues on the parental or family system level that are continuing to stress the child or otherwise slowing her progress. In the sections that follow, we outline some of the family interventions that we use to support children with functional somatic symptoms.

Interventions to Establish a Foundation for Moving Forward

Advocating for the Family in the Health Care System

When initially presenting for assessment to the mental health clinician—or more commonly the multidisciplinary team—many families are confused about the medical process that preceded the referral. Often they do not quite understand the results or implications of the clinical examination and investigations done by the paediatrician:

- How have those results excluded organic illness?
- On what basis has the paediatrician made a positive diagnosis of a functional disorder?
- How is the family to make sense of the different terminologies that different health professionals have used to talk about functional problems?
- Why has a referral been made to a mental health professional?

In the hospital setting, helping to address these shortfalls—and advocating for the family to have them addressed—may be one of the first interventions undertaken by the team or clinician. The advocacy may involve any or all of the following:

- A call to the paediatrician while the family is in the room to clarify the diagnosis and medical findings
- A joint consultation with the paediatrician and family in which the medical process and diagnosis are explained again
- Completion of tests that should have been done and were not
- A referral for a second opinion so that the parents can feel confident about the diagnosis and can move on to engage with the treatment process
- An explanation of the entire process in words that the family can understand.

This intervention helps the family move from a medical model to the systems (biopsychosocial) model of understanding and treating functional somatic symptoms. If this step is not completed, the child and family are unable to shift gears, as it were—from the medical model to the systems model—and unable to engage in the treatment process. Importantly, too, the family are not positioned to help their child get well. Instead, they are likely to go doctor shopping and to take the child down the spiral of chronicity that was described in Chapter 2. In this way, this initial family intervention is a make-it or break-it intervention. If it fails, the entire intervention never gets off the ground.

Identifying the Level of Capacity When Working with the Family

Early in the assessment process—based on the family’s responses and interactions within the family assessment interview—the clinician needs to make an assessment of the family’s capacity or lack of capacity to think about their contribution to the child’s functional somatic symptoms, and their readiness for a family intervention. This judgment will influence whether the clinician includes family interventions upfront and early in

the treatment process or whether the clinician implements family interventions slowly or even indirectly, while trust between the clinician and family—the secure base from which they work (Byng-Hall 1995)—is being further established. In any event, the clinician will begin working on system levels that the family can tolerate, and will progress from there to interventions on the system levels that are more challenging for the family. In this way, the clinician builds a secure base from which to work, bit by bit. Nonetheless, the need to address these different system levels should be raised at the outset so that the child and family are aware, from the very beginning, that all components of the intervention are important.

An advantage of this multi-levelled, systems approach is its flexibility and adaptability. It enables the clinician, child, and family to determine interventions that can, even at first, be used to good effect and that, building upon the trust thereby established, enable the treatment to move onto system levels that the child or family may previously have resisted as too difficult or anxiety provoking. What this means in practice is that the treatment is less likely to get ‘stuck’; creative, flexible approaches to the choice of intervention at any particular time are likely to enable treatment to proceed in a positive direction. A less systemic approach—one that locates difficulties at a particular system level, such as the child only or the family only—is much more likely to encounter dead ends, with no obvious options for new, potentially useful interventions along pathways not previously considered.

Using the Body as a Beacon to Track Stressful Events Within the Family and Child’s Social Context

One way to identify the family’s capacity early in the assessment process is to use the body as a beacon to track stressful events within the family and child’s social context—in particular, by initially asking questions about the symptoms and asking questions that help build a context around the symptoms (see case of Paula in Chapter 3). This way of gathering information can help to clarify quite quickly whether the family can manage any direct questions about family function and

family emotional processes, whether the family will spontaneously offer any relational information, and whether gathering information via direct questions is too threatening.

Containing Anxiety in the Family System: The Therapist as a Container of Anxiety

The notion that the clinician functions as a *container of anxiety* comes from the 1940s and 1950s, from the psychotherapy tradition. According to Linda Finlay (2015a, p. 64; 2015b), ‘the concept of *containing* is based on Jung’s (1946) idea that the therapy process can be likened to an alchemical container in which the chemicals are the thoughts and feelings of both patient and analyst which have to be held safely’. The notion of the clinician as a container of anxiety is also implicit in John Bowlby’s conceptualization of the therapeutic relationship as a secure base (Bowlby 1988; Byng-Hall 1995) (see also Chapters 2 and 3).

In working with children and families, *the clinician as container* refers to the holding or containment—the secure base—that the clinician provides in the therapeutic relationship with the child and family. According to attachment theorist Patricia Crittenden, the sense of connection that babies experience in attachment relationships is built up in two different ways: connection via *shared feelings* (affective states) and connection via *doing* (shared action) (Crittenden 2007). In our experience in working with children with functional somatic symptoms, these two ingredients are likewise important in the therapeutic relationship and in the clinician’s role as therapeutic container. While it is important to the family that the clinician connects with the family on *the feeling level*, enabling the family to feel understood, it is equally important that the clinician connect with the family on *the doing level*, enabling the family to engage in the course of therapeutic action that they and the clinician need to take. Along the same lines, Edward Bordin, an American psychologist who saw the therapeutic relationship as the cornerstone of the patient’s change through psychotherapy, described that relationship as involving different elements, including feelings, beliefs and understandings, and actions (Bordin 1979).

Most parents are earnest in supporting the child in her effort to get well, and they are eager to learn what they can do to support the child during the treatment process. But they often feel helpless in the face of the symptoms; they need to rely on the therapist to point the way forward.

Because the behaviours—the doings—that are required of the parents are sometimes counterintuitive, the therapist needs to explain how and why their attention to the child's pain or other symptoms has the unfortunate consequence of triggering and amplifying both the pain and other symptoms. For many parents this is an aha! moment, and they are dismayed that other health professionals failed to provide them with the information that some of what they were doing with the child—in an effort to be supportive and caring—was counterproductive.

Once a common understanding has been achieved, the *doing* ingredient of the therapeutic relationship necessitates that the clinician be explicit—and sometimes prescriptive (as in giving the family homework tasks)—in asking the family to practice new ways of being with the child; these ways need to become part of family interactions in order for the child to get well. The therapist also needs to work and collaborate with the family to help them begin implementing the *doing* part of therapy immediately. Connecting with the family via *feeling together* and via *doing together* contains anxiety. For more detail see later subsections 'Stepping Back and Giving the Child Space' and 'Changing the Focus of Attention'.

Facilitating Healing from Adverse Experiences in the Health Care System

As discussed in Chapter 3, some children and families have experienced unhelpful—and sometimes frankly abusive—interactions in their efforts to obtain help for the child via the health care system. Sometimes the child and family feel dismissed or emotionally battered because of inappropriate, mean, or ignorant comments made by health workers (see Chapter 3). An important intervention during the assessment process is to probe for such negative experiences, listen to what happened,

acknowledge the child and family's pain, confusion, and anger, and highlight the dearth of knowledge about functional symptoms in the medical and paramedical world. Usually, this sort of frank acknowledgment about what has happened enables the family to leave it behind and to connect with the treating team in a positive way. Sometimes, the emotional damage has been so significant that it may be necessary to implement trauma-specific interventions with the child or even a family member, potentially around specific memories or events (see 'Trauma-Processing Interventions' in Chapter 14).

Starting the Intervention with a Working Formulation

Some children and families are forthcoming with information, and others are not. Separate from these initial attitudes toward disclosure, some children and families provide the clinician with rich information; others omit information because they do not realize that it is important or because they are unaware that events in the child's life have affected the child adversely; still others, at least at first, do not trust the process and choose not to share what they know. Sometimes additional sensitive information is offered by the child or family once trust has been established. In this context, and with the information that is available at the time, the clinician and family need to co-construct a working formulation and, if agreed, to start treatment. With time, as more information becomes available, the working formulation evolves, and treatment interventions can be updated in turn.

Peppa was a 12-year-old girl with sudden-onset functional paralysis of both legs and episodic whole-body shaking. Peppa was a high achiever. Prior to her illness she had been an elite dancer and had ranked academically at the top of her class two years in a row. Peppa reported that she had grown up in a loving and kind family. She maintained that her growing up was 'the best' and that she had never once been angry with her parents. Akin to Peppa, her parents were unable to identify any stress or difficulties that may have contributed to their daughter's illness. But the

team's experience of the emotional interactions within the family was inconsistent with the family story. During the first half of Peppa's admission, her father, frustrated by some aspect of her clinical care, accosted the female resident—the most junior member of the team—with a volley of questions. A week later, and coinciding with the new rotation of residents, the father repeated this behaviour, picking out the new female resident who had insufficient knowledge to respond to his questions and points of dissatisfaction. The resident felt sufficiently rattled that she subsequently made sure to protect herself by going to the ward with a colleague. The same pattern of interaction was observed with other professionals on several other occasions. It was through these interactions that the team understood that Peppa needed to be a good girl and needed to use a Type A attachment strategy—one that prioritized compliance, performance, inhibition of negative affect, and expression of false-positive affect—to facilitate a close relationship with her father and to ensure that she obtained his love and approval and was not the object of his anger. (For attachment strategies see Crittenden [1999], Farnfield et al. [2010], and Online Supplement 4.1.)

Structural Interventions Involving the Family

Stepping Back and Giving the Child Space

Most parents are distressed about their child's symptoms and would do anything possible to fix those problems. In this context, it can be difficult for parents to step back and support the child as she engages in treatment. But she is, after all, the only person who can track her body from the inside and the only person who can implement body-based strategies to help down-regulate her stress system. Parents whose child has been ill for a prolonged period find this stepping back especially difficult because the process of adapting to the illness has resulted in changes in both the parent-child relationship and family dynamics (see the spiral into chronicity in Chapter 2).

Parents also need to step back from other aspects of the program—for example, physiotherapy sessions—to give the child space to work without parental attention to her symptoms.

Some parents find it helpful to know that the child's symptoms are most likely to first settle when the child is participating in enjoyable activities that take place in contexts where the parent and the treating team's therapists are not present—for example, when she is enjoying learning activities at school, interactions with the adolescent group, or physical activities with the physiotherapist. Others find it helpful to know that their attention to symptoms will amplify them. Yet others are encouraged to learn that their stepping back and giving the child space is a treatment intervention in itself. In this context, providing parents a clear explanation for why the clinician is asking them to step back (i.e., that the child is learning to take responsibility for her own body) can help the parents to do so without feeling blamed for the child's symptoms. Providing regular emotional support to the parents can also be helpful—for example, by calling them on a daily basis and giving them updates as to how the child is going in their absence, especially in the early stage, when the parents are still adjusting to the need to step back.

Changing the Focus of Attention

Many parents are distressed when they discover that their attempts to look after the child—for example, by frequently asking the child about her pain—have actually made the situation worse, contributing to the intensity and frequency of the child's symptoms. In this context, parents usually work hard to change their focus of attention. One way for them to change the focus of attention is by talking to the child about the progress that she is making with her mind-body strategies. This shifts the focus of attention from the symptoms themselves to what the child is doing about them. It also changes the focus of attention to the child's capacity to regulate her body, thereby increasing her sense of self-efficacy and control. Another way to change the focus of attention is for the parents to make sure that, when they spend time with the child, they engage in activities that are enjoyable for everyone—that is, that they connect by *doing together*.

Unfortunately, some symptoms—for example, non-epileptic seizures (NES)—necessitate action. During a seizure, the parents are asked to make sure that the child is safe and comfortable. If music is one of the

strategies that help the child to regulate, parents might, for example, pop an earphone into the child's ear and play some music or the relaxation script that the child uses to help her down-regulate. Otherwise, parents need to sit quietly by the child, waiting or reading. Once the event is over, parents may coach the child to engage in her mind-body strategies to down-regulate her stress system. Once the child is settled, they will encourage the child to continue with what she was doing before the onset of the NES.

Whatever the symptom, changing the focus of attention is difficult for parents; when their efforts at managing this aspect of the treatment program are going well, it is helpful to provide them with feedback and encouragement to that effect.

The mother of Paula—the 15-year-old, bed-bound adolescent girl we met in Chapter 3—was very distressed when she found out that constantly asking Paula about her pain functioned to amplify the pain. She wondered why no one had told her that before. In this context, she and Paula's father accepted the therapist's suggestion that the hospital admission provided an opportunity to step back (see also above), to allow Paula to manage the therapeutic components of the admission on her own (free of her parents' attention), and to practice not asking Paula about her pain—for example, by asking Paula (during their evening visit) about what she had done or achieved that day.

Timetabling Activities: Getting on with Normal Activities as Much as Possible

Outside of the treatment program, parents are encouraged to persevere with, and timetable in (see also later subsection 'Daily Timetable'), any normal activities that the child is able to engage in. The key message given by the family to the child is that life goes on and that resumption of normal activities is treatment. In the initial phase of treatment, these activities may be graded to ensure that the child isn't overdoing it (see Figs. 16.1 and 16.2). Many families struggle to find the balance between doing too little (leading to slower progress and potentially frustration with the pace of improvement) and doing too much (causing

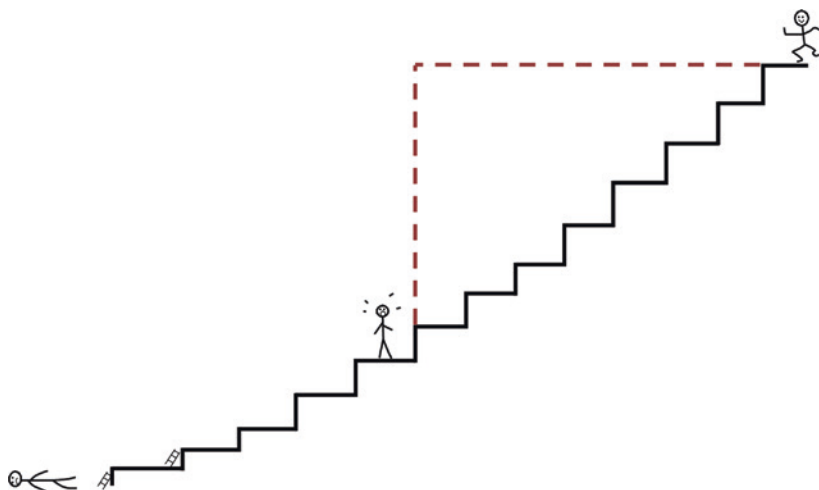


Fig. 16.1 Staircase metaphor for the treatment process. This illustration of the stairs is a metaphor for how in the initial phase of treatment the activities that make up treatment—self-care, physiotherapy, going to school—may be graded to ensure the child is not overdoing it and to avoid a crash. In other words, the treatment process for functional somatic symptoms is like a staircase made up of many small steps. Treatment starts with very, very small steps and continues with small steps. Over time the steps add up to mark significant progress (see dotted line). If at any point the steps are too hard, they can be further broken down into smaller steps (represented by the ladder). The drawing shows that when the child is very ill (depicted by the figure at the bottom of the stairs), the goals for the activity will be modest (the small low stairs at the bottom of the staircase), and that sometimes it will even be necessary to use a ladder to get up the small stairs (depicted by the ladder). When the child gets better and has more energy and capacity, the stairs will be correspondingly bigger. For example, going to school may start with a few hours a day in a wheelchair, build up to more hours and transferring out of the wheelchair, and then build up to even more hours and leaving the wheelchair in the school office. For some children, if the principle of gradual increase (one small step at a time) is not explained clearly, then the child sees just one big staircase (depicted in the broken line)—and thinks ‘I cannot do this’—which can provoke anxiety and trigger significant increases in arousal (© Trond H. Diseth 1991. Reprinted with permission)

the child to crash, a potentially serious setback). The timetable—which is upgraded as the child’s capacity improves—aims to find the right balance. Finally, with coercive children, the timetable is a key element of the behavioural intervention (Sells 1988; Kozłowska 2016).

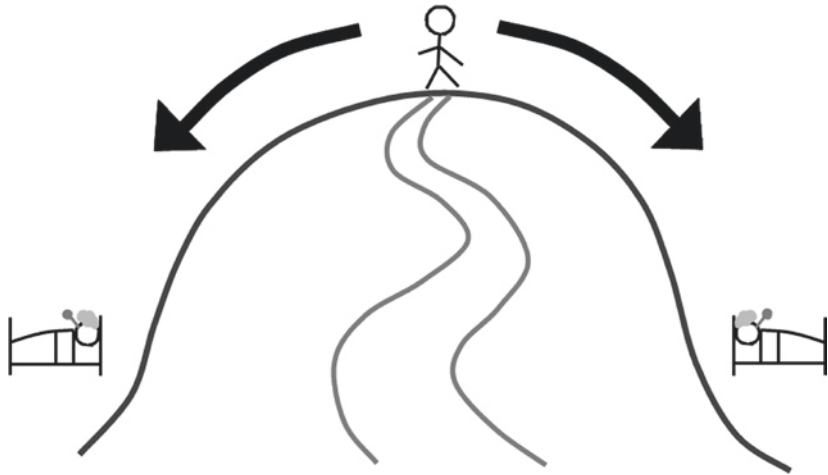


Fig. 16.2 Path on the mountain metaphor for the treatment process. This line drawing shows that the treatment process for functional somatic symptoms involves a balancing act that can be likened to the child walking on a narrow path on the ridge of a mountain. If the interventions that make up the treatment program are not challenging enough, the child will slide down one side of the mountain and will remain sick. If the interventions that make up the program are too challenging, the child will slide down the other side of the mountain and will retreat back into bed, into the sick state. When the treatment program is just right, the child progresses slowly—along the narrow path—to a state of health and well-being (© Kasia Kozłowska 2019)

Intra-familial Issues and Interventions

Learning Skills to Identify and Talk About Stress and Distress

The therapeutic process of helping the child and family to make links between stressful life events and escalations of the child's symptoms is crucially important. A family that acquires this skill will be better able to support the child in the face of future stress. Because most families have conceptualized the child's symptoms as distinct phenomena and have not made the connection between the symptoms and the events in

the child's life, these skills are ones that the family needs to learn. In this context, the clinician works to support the child to communicate to her parents when she notices that her stress system is activating, to support the parents to communicate to the child when they notice her stress system is activating, and to support the family as a whole to notice what events or situations the child finds stressful. For some parents, an emotional-coaching intervention may be helpful (Gottman and DeClaire 1997; Owenz 2017).

Betsy, the 13-year-old girl with NES whom we met in Chapter 14, always told her parents that she was fine. On weekend leave from the Mind-Body Program, Betsy had had a good weekend with few NES. However, on coming back to hospital, Betsy had a series of NES. Betsy admitted that she hated being in hospital, so the link between Betsy's NES and her distress pertaining to the return to hospital was made. A week later, on the afternoon of discharge for the school holidays—the Mind-Body Program does not run during holidays—Betsy also had a series of NES. The therapist asked the family what had happened to trigger the NES. Betsy's mother said that earlier in the afternoon, Betsy had phoned her and sounded frantic. In the phone call Betsy had told her mother that after she had packed up her things for the trip home, the nurses had put her temporarily into the treatment room—a room that was full of medical gadgets. In that room Betsy had imagined needles going into her arm. Her anxiety and arousal had escalated, and she had triggered her NES. The therapist noted that the treatment room episode—like that of coming back to hospital—were excellent examples of how, when Betsy became very aroused or anxious, her NES were triggered. She suggested that Betsy and the family were getting better at noticing the circumstances in which Betsy's body activated.

Addressing Health Issues in the Family System

Quite often the child's distress pertains to the well-being of her parents. In this context, ensuring that parental health issues are being addressed can be an important component of the intervention. This can involve addressing areas of both physical and mental health.

Addressing Other Family Issues

The storytelling process often elicits other family issues that may need to be addressed. Common issues that contribute to activation of the child's stress system include family or parental conflict, breakdown of important relationships, and differences in parenting. For example, if the formulation is that the child's stress system is activated because of sustained parental conflict, then this needs to be raised with the parents in a way that they can tolerate and hear, because with unremitting conflict the child will not get well or will keep relapsing with new health problems (see case of Rudi in Chapter 9). However, because these issues are not specific to working with children with functional somatic symptoms, we do not discuss them in detail here. For helpful resources for working with such issues in family therapy, see Rhodes and Wallis (2011) and the many other wonderful family therapy resources available in the literature (e.g., Dallos and Draper 2010).

Working with Behavioural Interventions

Behavioural interventions are a basic component in treating functional somatic symptoms. Whether the child is managed in the community or in the hospital setting, the treating team and family need to implement a structure—a behavioural program—around the child that facilitates normal daily activities and that helps the child move toward health and well-being. The members of the family are, indeed, key players in all behavioural interventions; they support, sustain, and maintain those interventions whenever the child goes home. Common behavioural interventions that we use day in and day out are included below.

Daily Timetable

The daily timetable visually sets out the patient's activities from waking up to going to bed. It includes bedtime and waking time, eating times, activity times, the time and frequency of the regulation strategies that the child is practicing daily to down-regulate her stress system, and

also time to rest. The third author (HH) and the multidisciplinary team she works with view the timetable as a *dosette box* for a treatment whose ‘ingredients’ are the specified activities—carefully chosen and ‘tailored’ to the individual child—and their total effects.

For both the patient and the multidisciplinary team, the timetable is an important tool that, for either a day or a week at a time, organizes the treatment program. For the *child*, the timetable provides predictability and promotes the sense of control and mastery. These factors may help to lower the child’s arousal and worries/anxiety—which is an intervention in itself and also important for maintaining the child’s motivation. For *cooperative* children, the timetable provides scaffolding for the day and establishes a predictable rhythm for it. For *uncooperative* children, the timetable provides the treating team and family with a way to check whether a child is actually taking responsibility by engaging in the interventions that will make her better.

For the multidisciplinary team and also the family, the timetable is an important management tool ensuring that everybody involved knows exactly what the treatment plan is and that they all *push in the same direction*. And since the child’s schedule is set in advance for the day regardless of her symptoms, having the timetable in hand preempts the need to start each day by querying the patient about her symptoms (‘How are you feeling?’ ‘How is your pain or energy level?’ ‘Will you be able to do this and that?’)—a sure way to exacerbate them.

Goal Setting

Setting small tangible goals in skills of daily living, physiotherapy, psychological work, reintegration to school, and so on is imperative to ensure that the child continues to progress.

Managing Avoidance Behaviours

Avoidance behaviours are common in children with functional somatic symptoms. Usually children will avoid certain activities because they are associated with pain or fatigue, or because the child might be afraid of

having an NES, and so on. Many children also avoid certain activities because of anxiety: negative anticipatory thoughts, catastrophizing, and so on. The overall treatment program is designed as a behavioural intervention that includes all the activities that the child needs to re-engage in and re-master—such as getting up in the morning, exercising, going to school, and engaging with peers.

The Traffic Light Safety Plan

We include safety planning as a behavioural intervention because the child may need to use it as a reference point on a daily basis and, when necessary, to act as the plan requires. The *traffic light safety plan* is used as a way of identifying, and of implementing an immediate response to, low mood, suicidal ideation, and thoughts of self-harm (see Online Supplements 16.1 and 16.2). Also, in children with NES, who face the risk of falling and injuring the head, identifying the antecedents of NES events enables them to protect their physical safety by immediately assuming a sitting position (the first action documented on the safety plan). The first author (KK) and her team use a *traffic light system* developed by mental health clinician Danae Laskowski. Using that system, the child develops the safety plan with her individual therapist and summarizes it in a visual representation, with events or states coded as green (safe and stable), orange (beginning to activate; use mind-body techniques to settle), or red (high risk) (see Online Supplement 16.2). The safety plan is shared with the family, school, and other persons who implement the plan. The parents can carry a copy of the safety plan with them in case they need to take the child to the emergency department. The safety plan is updated as the child learns additional strategies to manage perturbations in body state, arousal, thought processes, and mood.

Using a Bike/Rugby Helmet to Protect the Head from Falls

Children with fainting episodes or NES are potentially at risk of injuring themselves from falls until they have gained control over these

episodes (usually by recognizing the antecedents [warning signs], lowering themselves safely to the ground, and then engaging in mind-body techniques to lessen their arousal). When such a risk is present, we have, at times, used bike or rugby helmets to protect these children's heads.

Betsy, the 13-year-old girl and ballet dancer with NES whom we met earlier in the chapter, had NES that were very difficult to manage. Betsy found it difficult to notice warning signs, and after the NES she had no memory of them. At first, she thought everyone was trying to keep her in hospital for no reason at all. She broke down wailing when she saw one of her events on her mother's phone. When an NES occurred, Betsy would fall. In the first author's room, she fell face down, narrowly missing the metal rail of the chair. In the hospital she sustained multiple injuries—sometimes by falling off the toilet—despite being nursed one to one. During one event she fell into her food, and her face and hair were covered with vomited watermelon. On a gate pass home, she cut open her head and bled profusely onto the bathroom floor. During the latter part of her admission—and on integration to school—Betsy wore a rugby helmet.

Working with Other System Levels: Don't Forget the School

There are also other system levels that are important when working with children with functional somatic symptoms. The most important of these are the school system, the health care system, and, when children live in small communities, leaders within those communities. While each of these areas of work could be the subject of another chapter (as could other topics), we need to keep this particular book within manageable limits. With regard to the school system level, we have provided the reader with some ideas in Online Supplement 16.3.

In this chapter we have discussed interventions pertaining to the family system level. Family interventions are a fundamental component of the treatment intervention because they enable parents and families to

support the child with functional somatic symptoms in her efforts to get well. We have described commonly used behavioural interventions that are typically collaboratively implemented by the child, family, and clinician. Family interventions aim to increase regulation within the child's stress system, to create safety in the child's family and social contexts (because safe contexts do not require activation of the stress system), to strengthen nurturing relationships (because mammals regulate better in the context of close relationships), and, by doing all these things, to increase the child's capacity for managing stress and distress, thereby building resilience so as to buffer the child from future stress.

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