BC Children's Hospital

Provincial Health Services Authority

BC Children's Hospital

Pediatric Somatization: Professional Handbook

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INTRODUCTION

At BC Children's Hospital, we have had the privilege to work with many children who have suffered from somatic symptoms. Somatization can be challenging to diagnose and treat, and at the same time, we have found that it is one of the most clinically rewarding areas of practice. Over the years, we have learned a great deal from children and families affected by somatization, and we have compiled our shared knowledge in this professional handbook.

Our goal in writing this handbook is to provide clinicians with the information, resources, and confidence they need to help children experiencing somatization and support families towards a journey of recovery and resilience. This handbook outlines: 1) our understanding of somatization, 2) how we convey this understanding to children and families, and 3) our integrated treatment approach. Our hope is that we can collectively help reduce suffering, support children and families to understand somatization and access the most appropriate care in a timely manner

(Note that throughout this handbook we use the term 'child' to include children and youth. We use the term 'parent' to include parents, caregivers and guardians. We also interchange the terms 'clinician' 'team' 'provider' and 'health care team' to describe professionals who provide assessment, diagnosis and/or treatment).

Specific Resources are marked with this 'key' throughout the handbook

Understanding Somatization

Somatization refers to the physical expression of stress and emotions (often 'negative' emotions). A somatic symptom is a physical (or body) symptom that occurs as a result of stress and/or emotions, rather than a medical condition (e.g., physical illness or injury such as inflammation, infection, neoplasm, endocrine disturbance, etc.).

All emotions have a physical expression. Everyone experiences somatic symptoms during his or her life; somatization is *normal* and *real*. Somatization may occur in the absence of, or in conjunction with a medical condition. When a medical condition is present, we diagnose somatization when the physical symptom occurs in excess of what would be expected based on the known medical condition.

Somatization is often not well understood by children, families, the public, or health care providers. Children may suffer with somatic symptoms for months and even years going from specialist to specialist, all the while withdrawing from developmentally appropriate activities. In our work, we focus on integrating care – medical, psychological, and rehabilitation approaches - to help facilitate recovery and resilience.

Using consistent and clear language to normalize somatization is essential. Our 'foundation language' is used to help families and health care providers understand somatization in a way that is transparent, simple and makes sense.

The Mind-Body Connection and Somatization Explained

- The mind and body are always communicating
- What goes on in our mind (thoughts and feelings) affects our body.
- The **mind-body connection** describes the relationship between our physical and emotional experiences
- Stress and emotions are expressed in physical ways (e.g., tears of sadness or joy, 'butterflies' of fear or excitement in your stomach)
- These physical 'symptoms or responses are automatic responses, they not intentionally produced
- **Somatization** is another way to describe the physical response to emotion or stress that happens because of the mind-body connection
- When this happens, we describe the physical symptoms of the mind-body connection as 'somatic symptoms'
- We all somatise and for some people somatization gets in the way of everyday life and requires treatment

A Somatic Symptom Disorder (SSD) or Conversion Disorder (CD) is diagnosed when symptoms significantly interfere with day-to-day functioning. Common SSD symptoms include pain, dizziness, fatigue, cough, and nausea. Common CD symptoms include fainting, seizures/convulsions, difficulty walking, numbness, and blindness. The Diagnostic and Statistical Manual of Mental Disorder (DSM5) criteria for SSD and CD are shown below.

Somatic Symptom Disorder

A. One or more somatic symptoms that are distressing or result in significant disruption of daily life.
B. Excessive thoughts, feelings, or behaviors related to the somatic symptoms or associated health concerns as manifested by at least one of the following:
   1. Disproportionate and persistent thoughts about the seriousness of one's symptoms
   2. Persistently high level of anxiety about health or symptoms
   3. Excessive time and energy devoted to these symptoms or health concerns
C. Although any one somatic symptom may not be continuously present, the state of being symptomatic is persistent (typically more than six months).

Conversion Disorder

(Functional Neurological Symptom Disorder)

A. One or more symptoms of altered voluntary motor or sensory function.
B. Clinical findings provide evidence of incompatibility between the symptom and recognized neurological or medical conditions.
C. The symptom or deficit is not better explained by another medical or mental disorder.
D. The symptom or deficit causes clinically significant distress or impairment in social, occupational, or other important areas of functioning or warrants medical evaluation.

For the purposes of this handbook, both Somatic Symptom Disorder symptoms and Conversion Disorder symptoms are referred to as ***somatic symptoms***. The experience and expression of these symptoms are referred to as ***somatization***.

We use the term an **element of somatization** when:

- some aspect of somatization is suspected but full criteria for diagnosis of SSD and CD are not, ***or***
- if somatization is occurring along with a medical condition, ***or***
- medical investigations are ongoing, but stress and emotions are seen to play an important role in the physical symptoms.

Using the term an **element of somatization** is helpful in three ways:

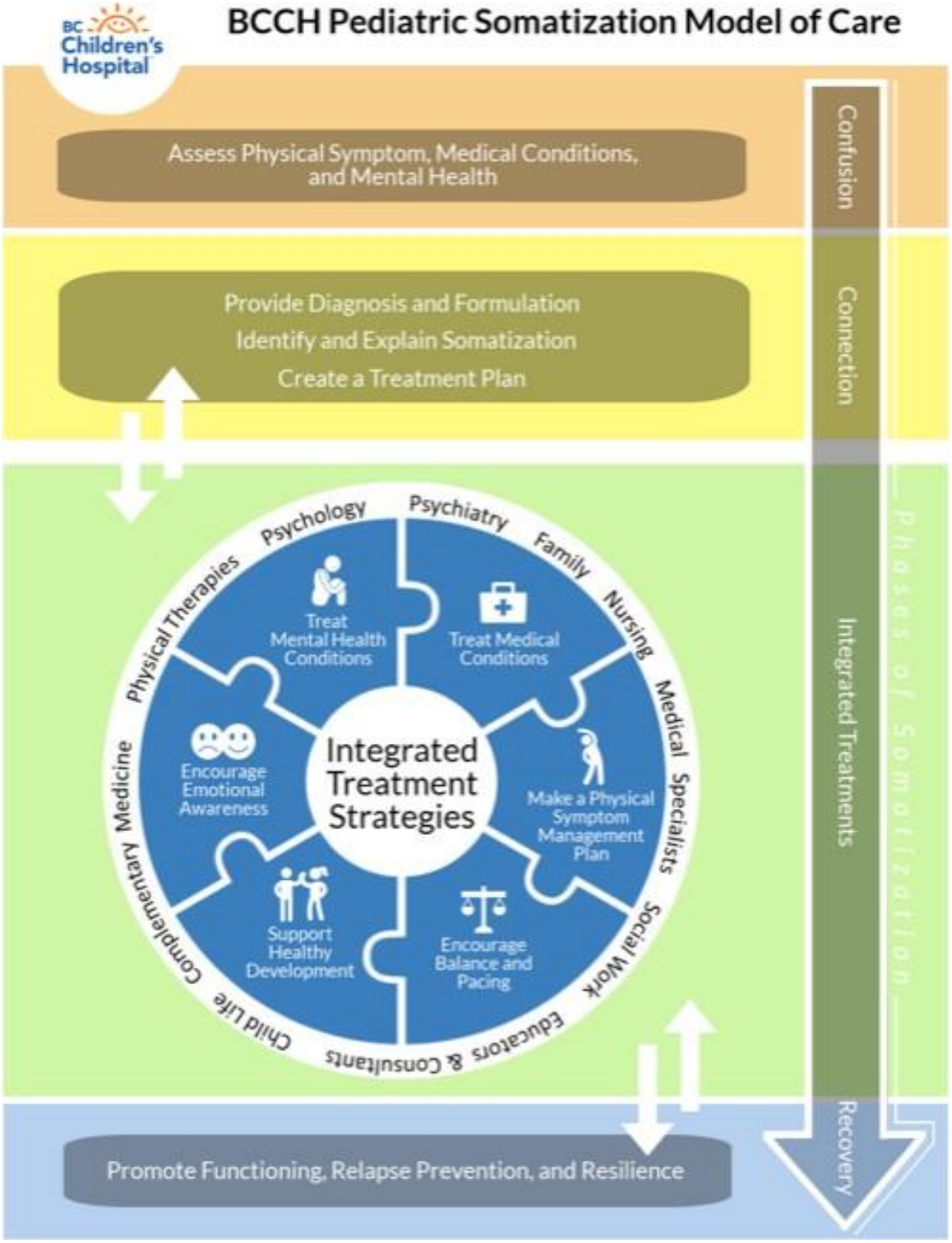
1) to explain that the physical symptom is caused, at least in part, by somatization,
2) to acknowledge the interrelationship between physiological (biological) and stress and/or emotional roots of physical symptoms (the mind-body connection); and,
3) to appreciate that it is not always possible to determine to what degree somatization is contributing to the physical symptom.

In addition to the experiencing somatization, children may also have other mental health disorders. In children, the most common co-morbid mental health diagnoses are anxiety or mood disorders, however other mental health disorder also occur along with somatization. It's useful to note that these mental health disorders may not be apparent initially but emerge as the somatization is treated. Somatization may be the way that anxiety or depression is expressed often without the child's conscious awareness. (See Phase 1 Confusion: Assessment and Intervention)

https://keltymentalhealth.ca/somatization

Pediatric Somatization Model of Care

Our model of care highlights the pathway of care used at BC Children's Hospital. The progression of care moves through phases of **confusion**, **connection**, **integrated treatment** and **recovery**.



Chapter 1

PHASE I - CONFUSION

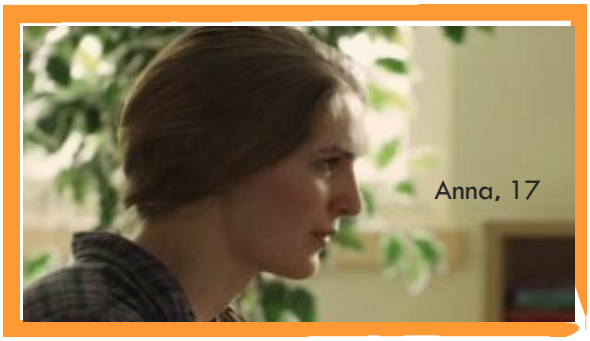
The **confusion phase** in the somatization journey is the period of time when the child presents with physical symptoms and there is uncertainty about the diagnosis with the health care team, child and family. This period can be prolonged for a number of reasons including inefficiencies in the health care system and the readiness of the family to understand and accept the diagnosis. The goal is to move effectively through the **confusion phase** by validating and appreciating the experience of the child and family throughout the assessment process and establishing trust. Creating a collaborative relationship with the family during the confusion phase will enhance planning for appropriate treatments during the **connection phase**.

Physical Symptom Presentation

Somatic symptoms range from ordinary experiences of the physical expression of emotions (e.g., tears of sadness, anger, joy) to more unusual and distressing symptoms such as non-epileptic seizures, gait disturbance and blindness. In between this range of everyday and extraordinary physical experiences are the more common physical symptoms including headaches, stomach pains, fatigue, and dizziness or muscle tension.

The nature and intensity of somatic symptoms is diverse and can be complex, particularly when these symptoms occur alongside a medical condition. Over the course of treatment, new symptoms may develop as original symptoms resolve. There is no one-to-one correspondence between the type of somatic symptom and a particular emotion or stressor. In the confusion stage we emphasize key messages to children and their families: **suffering that is experienced as a result of the somatic symptom is genuine** and **the somatic symptom is not intentionally produced.**

Body Talk: Stories of Somatization (Part 1) Searching for Answers



Our experience is that intentional production of symptoms is uncommon; and, when present, there often is still an involuntary component to the symptom presentation. We always work on the

assumption that that the symptoms are unintentional but stress-responsive (unless there is direct evidence of intentional production of symptoms), as we find this approach is most helpful in achieving treatment gains for children.

The following vignettes are examples of common presentations of somatization.

Somatic Symptom Disorder without a medical condition

Brenda is an elementary school girl who has always been kind and caring. She has many friends and is close with her family. Brenda enjoys being in the school band, however she struggles with math and reading comprehension. During the school year she experienced significant pain in her right arm, radiating from her elbow to her fingers. Brenda was not able to participate in academic or school band activities because of her pain. Her mother is currently on sick leave from work. The results of the medical assessment did not show any underlying causes for her pain.

Somatic Symptom Disorder with a medical condition (an element of somatization)

Raj is an athletic teenager who is involved in competitive soccer and hopes to play for a university team. Raj sustained a concussion during the soccer season and subsequently missed a month of school and playing soccer with his team. His concussion symptoms (headaches, photophobia, concentration difficulties and fatigue) resolved over a month; however, during spring break, Raj's headaches returned. He was not able to successfully return to school or re-join the team in time for the end-of-season play-offs

Conversion Disorder

Sarah is a high-achieving and responsible teenager who keeps her emotions to herself. Sarah has a small and close group of friends. She recently started middle school in an academic enrichment stream. In October, Sarah began having fainting episodes in which she would slump over in her desk or fall to the ground. These episodes occurred up to twenty times a day. No medical cause was found. Sarah continued to attend school, but her fainting caused her to spend much of the day in the nurse's office. Two of her friends often left class to be with her.

Assessments and Investigations

Somatization may occur on its own or as a component of a medical injury or illness. It can start in the absence of a medical condition or start with a medical condition and then become a somatic symptom. We take the approach of **walking two paths** when somatization is being considered as a possible diagnosis.

Walking two paths

Walking two paths means that we encourage and support the team and family in pursuing assessment and treatments for both the medical condition and somatization. When there is uncertainty from a family perspective about the diagnosis, walking two paths lets us get started with strategies and interventions to reduce the child's suffering while the assessment is ongoing. This approach reflects the reality that there is often an element of somatization to many medical conditions that we can begin treating right away.

Medical assessment/investigation

A thorough assessment of the physical symptom(s) is vital in the confusion stage. Understandably, many families are focused finding a medical cause for the symptom(s) and reducing their child's suffering. Children and families often perceive that health care providers and others believe that "the symptom is not "real", or "it's all in their head" and this notion is reinforced if their medical concerns are not being addressed. Thorough physical examinations, investigations and imaging are very important in the confusion phase not only for understanding if there are medical conditions but to also build rapport and trust with the child and family.

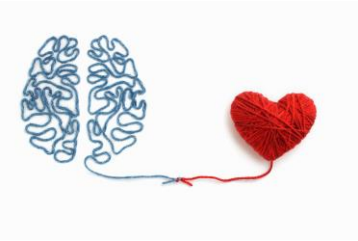
Timing of medical assessment/investigation

There is no clear answer for when assessments and investigations should end. It depends on the circumstances, individual providers, teams and the family. Although we do not want to facilitate unnecessary medicalization of the symptom, iatrogenic harm, or a delay in seeking treatment for the somatic component, we often suggest that our medical colleagues investigate thoroughly. We also suggest thorough assessment of any new symptoms that arise. The walking two paths approach helps in averting a delay in treatment while waiting for assessments and investigations that may take months.

Psychosocial assessment/understanding

A diagnosis of somatic symptom disorder is **not** made on the basis of an individual's psychosocial functioning, stressors, temperamental traits or mental health. It is made on the basis of the physical symptom history, physical examination and investigations. However, once somatization is suspected a thorough psychosocial and mental health assessment is important. This assessment should include developmental and emotional functioning, stressors, trauma as well as psychiatric symptoms.

Eliciting stressors can be challenging. Sometimes families downplay stress. They may be concerned that if they identify stressors the health care team will assume that the physical symptom is "all in the child's head". Other times, children and families have a hard time identifying sources of stress. For example, if the child pushes themselves hard, they are described as 'naturally competitive'. Often when parents report that their child wants to participate in many extra-curricular activities, it can be difficult for the family to appreciate how these 'positive' stresses might impact the child. We often let families know that stress isn't necessarily bad and give examples of 'positive' stress. Also, developmentally relevant stress in younger children, such as loss of a pet, a best friend moving away, a change in classroom, may not be easily identified from an adult perspective.



Understanding a child's temperament and traits is important. Children presenting with somatic symptoms are often sensitive, perceptive and perfectionistic. They often internalize their emotional responses. Some children tend to keep their feelings and emotions 'inside', instead of expressing them in more obvious ways.

Mental health assessment/understanding

In children, the most common co-morbid mental health diagnoses are anxiety or mood disorders, however other mental health disorder also occur along with somatization. It's useful to note that these mental health disorders may not be initially apparent but emerge as the somatization is treated. Somatization may be the way that anxiety or depression is expressed often without the child's conscious awareness.

Subclinical Anxiety and Predisposing Temperamental Traits: Somatization can occur when stressors overwhelm the child's capacity to cope. Some children have temperamental traits that cause them to be highly sensitive to stress. For example, a perfectionistic, sensitive and internalizing child may put pressure on themselves to perform. Often these children are highly sensitive the stress in others, yet they have difficulty recognizing and expressing stress.

Co-morbid Mental Health Disorder: Children can have diagnosable psychiatric disorder such as Generalized Anxiety Disorder or Major Depression in addition to somatization. For example, a child presents with symptoms of depression, as well as non-epileptic seizures.

Underlying and Unrecognized Mental Health Disorder: Children can have somatic symptoms without any identified emotional distress; however, over time as somatization is treated, the anxiety/depressive symptoms may become more apparent. For example, initially a child can

present with a somatic symptom (e.g., abdominal pain) and as they learn to identify their own feelings, the somatic symptom diminishes, and the mood symptoms become more apparent.

Somatic Symptom Presenting as Psychiatric Symptom: Children can present with a symptom that initially appears to be a mental health symptom but is in fact a somatic symptom. For example, a child presents with a "psychotic" symptom (e.g., visual hallucinations) without other typical symptoms of psychosis; the hallucinations may be a symptom of a Conversion Disorder.

Self-harm or Suicidality: Longstanding or severe acute somatic symptoms may cause, contribute to or exacerbate mood disorders. These youth may be at high risk for self-harm or suicidal behaviours.

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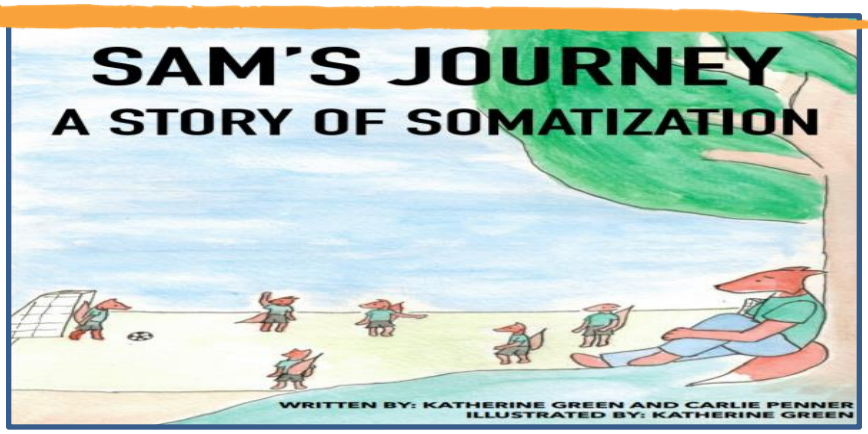
Sam's Journey: A Story of Somatization Kelty Mental Health



Chapter 2

PHASE II- CONNECTION

The making **connections phase** in the somatization journey is the critical link between assessment and integrated treatment. The components of this phase are intended to be collaborative, not only between team and family but within the care team. Adopting a collaborative stance and taking the time to engage in conversations allows for the child and family to feel understood. If the connections phase is rushed, we risk families perceiving that they are being dismissed too quickly and increase the worry that a medical condition is being missed or that others (family members, teachers, doctors, nurses, etc.) think their child is "faking" the symptom. The goal of the connections phase is to move from confusion, where the child, family and medical team struggle to understand the physical symptoms, into a phase of understanding somatization and feel ready to engage in the integrated treatment phase.

Provide Diagnosis and Formulation

When should the formulation of somatization be introduced? If you think the child may be experiencing somatization or that there is an element of somatization as part of their medical condition, we encourage you to introduce the concept of somatization early. Discussing the concept that stress, emotions and physical symptoms are linked, provides a foundation for early intervention and support even prior to the completion of all the medical investigations (i.e., in the confusion phase).

Introducing the Mind-Body Connection

We are going to order some tests and investigations to determine if there is a medical condition causing this symptom.

At the same time, we know that stress and emotions make physical symptoms worse and can, sometimes, even play a role in the onset and maintenance of physical symptoms.

We also know that having physical symptoms like this, having medical tests, and waiting for the results is often stressful for children and their parents.

Because the mind-body connection between stress, emotions and physical symptoms are so powerful, we want to find out about the different kinds of stress or emotions that [child] is experiencing.

Who determines the diagnosis?

The medical care provider (family doctor, pediatrician, medical specialist, or nurse practitioner) determines the diagnosis/formulation since they have assessed the physical symptom and evaluated the medical workup. This can be confusing because somatization is considered a psychological process and Somatic Symptom Disorders are classified as mental health disorders. However, the diagnosis is not made on the basis of the patient having psychosocial stressors, certain temperamental or personality traits, or other psychiatric disorders. These factors alone do not mean that a child is experiencing somatization. The diagnosis of somatization is based on the medical examination and workup.

What should the diagnosis be? What language should be used?

'Somatization' is a diagnosis for a psychological process, and Somatic Symptom Disorder and Conversion Disorders are specific diagnoses. In most circumstances we have found it helpful to provide direct and explicit language rather than using fewer specific terms (e.g., functional, psychogenic, medically unexplained, amplified, non-organic, etc.). A lack of consistent language leads to confusion for the child and family, as well as the health care team. We use the following language for formulation and diagnosis

Somatization – This is a formulation term that we use more often than Somatic Symptom Disorder (SSD) or Conversion Disorder (CD). The term encompasses both specific diagnoses and we make sure families understand that the Integrated Treatment Approach applies to either SSD or CD.

Somatic Symptom Disorder (SSD) or Conversion Disorder (CD) – When families or teams are interested in having a specific diagnosis, we encourage the use of the appropriate diagnostic term, and typically will go onto use the term somatization when talking about treatment.

Element of somatization - Our medical care providers often use the term an 'element of somatization' rather than 'somatization' or Somatic Symptom Disorder or Conversion Disorder, particularly early in the process when there are pending medical assessments and/or test results. Using the term 'an element of somatization' is also appropriate at the end of the medical assessment process when somatization exists in the context of a medical condition (not an uncommon occurrence). It acknowledges the complexity of the 'medical' and 'somatic' (mind-body) connection in certain clinical situations (e.g., Irritable Bowel Syndrome (IBS), migraines, Postural Orthostatic Tachycardia Syndrome (POTS), concussions, etc.).

Only in *rare* cases, do we choose to completely omit any reference to somatization, 'element of somatization', Somatic Symptom disorder, or Conversion Disorder. In those cases, the team discusses stress, emotions and coping in the context of physical symptoms and typical or not remarkable medical findings.

Validating the Child and Family's Experience

Prior to communicating the formulation and/or diagnosis, it is important to spend time trying to genuinely understand the experiences of children and families. In many cases, their medical journeys have been confusing, frustrating, or upsetting. In doing so, clinicians can also model support and

acceptance of negative emotions. Allowing sufficient time for this process, provides a trusting foundation on which somatization and the mind-body connection can be explained and understood.

We want to acknowledge the suffering that the symptoms have caused and the impact they have had on [child] and your family.

Having these kinds of experiences can be very difficult. People can feel helpless and uncertain about the future.

Sometimes, experiencing these symptoms, going to doctors and hospitals, and worrying that something bigger has been missed can lead to confusion, frustration, or fear.

It makes sense that you are so concerned about what could be causing these symptoms.
You have been working hard to do all you can to help [child].

Who communicates the formulation/diagnosis to the patient and family? And how?
The medical care provider should communicate the diagnosis to the patient and family, ideally the team and family meeting (please see below for details).

In delivering the formulation/diagnosis, the medical care provider should first review:

A summary of the symptom presentation
The results of the physical exam
The results of the medical investigations

These should be reviewed in detail with time to allow patients and family members to ask questions. Also, it is important to check in with the family to see if they are expecting other tests to be performed. If so, take time to explain why these are not needed at this time. Reviewing the formulation/diagnosis is a process and families may benefit from more than one meeting.

Usually, the diagnosis of somatization is not one of exclusion and it is important to convey this to the family and other health care providers. The formulation is made based on the symptom description, the physical exam, and the interpretation of the investigations **and** the knowledge about medical conditions and their presentations.

Communicating the Diagnosis

Starting the conversation

- *You first experienced [physical symptom] last year and over the past few months it has become more frequent and intense. You have also started to have a few other symptoms, including [details].*
- *You saw your family doctor, and two pediatric specialists – a cardiologist and a neurologist and most recently you were admitted to the hospital.*
- *The doctors have all examined you and ordered lots of tests and investigations including [details]. It was very important to do these tests.*
- *In medicine, we listen carefully to the description of the symptom, we do physical exams (like listening to your heart) and we ask for special tests (like blood work and x-rays).*
- *Our diagnosis is based on these results and our knowledge of the symptoms that are associated with the medical condition.*

If the child has a somatic symptom with no medical condition:

- *Let's review the tests and investigations you have had:*
  - *Description of symptoms*
  - *Summary of physical examination*
  - *List of tests and results*
    - *"Your MRI did not show any abnormalities."*
  - *Summary of major conclusions*
    - *"Your heart is functioning the way we would expect."*
- *Based on your symptoms and our assessment we do have a diagnosis.*
- *You have a serious and complex condition that is not a result of a medical illness or injury.*
- *You have what we call somatization/Somatic Symptom Disorder/Conversion Disorder.*
- *We are going to explain what a somatic symptom and somatization are – these aren't words that many people know about.*

If the child has a somatic symptom with a medical condition:

- *In addition to your [medical condition], you have what we call somatization.*
- *Many medical conditions have a component of somatization.*
- *This is not a word that many people know about, so we are going to explain what this means.*

Explain the Mind-Body Connection to Understand Somatization

The mind-body connection and somatization

Reinforcing understanding of the mind-body connection helps a child and their family understand somatization. The goal is for the children and parents to make the links between the child's specific stressors, emotions, and physical symptoms.

By using the language in the Mind-Body Connection and Somatization Explained text box (see below), we can explain the mind-body connection and somatization in a clear and transparent way that normalizes somatization and emphasizes that the symptom is real and not intentionally produced. We have found that using this direct explanation is more effective than using metaphors (e.g., computers and connecting wires, car alarms, etc.).

Explaining the mind-body connection and somatization

- *The mind and body are always communicating*
- *What goes on in our mind (thoughts and feelings) affects our body.*
- *The **mind-body connection** describes the relationship between our physical and emotional experiences*
- *Stress and emotions are expressed in physical ways (e.g., tears of sadness or joy, 'butterflies' of fear or excitement in your stomach)*
- *These physical 'symptoms or responses are automatic responses, they not intentionally produced*
- ***Somatization** is another way to describe the physical response to emotion or stress that happens because of the mind-body connection*

> *For example, when I am experiencing stress, I get migraines. I get them for other reasons too, when I don't get enough sleep, or I get dehydrated but when I am stressed, I often get a migraine. [Ask parent] what happens in your body when you get stressed?*

- *When this happens, we describe the physical symptoms of the mind-body connection as 'somatic symptoms'*
- *We all somatise and for some people somatization gets in the way of everyday life and requires treatment*

As mentioned above, there are rare cases when we chose not to use the term 'somatization'. In these cases, we still review the points above, leave out the points referring to somatization and focus instead on the mind-body connection and the "physical expression of stress and emotions"

Explaining the mind-body connection after diagnosis

- *When we first asked about stresses in [child's] life, she told us that she didn't have any stress. It was also hard for you, as parents, to think about any specific stressful experiences around the time the physical symptoms started.*
- *As we learned more about [child] we understand that there may be a few stressors that could be having an emotional impact on [child].*
- *Children may keep their experience of stress to themselves or have a hard time recognizing their stress and emotions.*
- *Sometimes when we are not able to fully process or express stress, or we have strong emotions or mixed emotions, our body processes our emotions and stress for us.*
- *When we bottle up our feelings, for example to avoid dealing with a difficult situation or to avoid worrying or hurting someone, our bodies start talking for us.*
- *The way each individual person physically experiences stress is unique.*
- *Often the physical way we experience stress relates to either a physiological vulnerability or a learned physical vulnerability.*
- *What I mean by vulnerability is like the example I gave you previously about my migraines – I get them for physical reasons and when I get stressed it also gets expressed through migraines – this is my vulnerability.*

See the next page for clinical vignettes and associated explanations

When stress/emotion adds to physical symptoms

The body is familiar with sending signals to alert us of medical symptoms, and it can also become the body's pathway of expressing stress and/or emotions.

Somatization can happen with many different medical conditions. For example, a teen with epilepsy has seizures due to an electrical misfiring in the brain that sends signals to the body. The pathway used for epileptic seizures is 'familiar' to the body and can become the same pathway that stress and emotions are expressed, producing non-epileptic stress induced seizures.

Expressing emotions and stress by familiar pathways can also happen with migraines, broken bones that have healed, and many other medical conditions or injuries.

When stress/emotion causes physical symptoms

Everyone has stress! But what causes stress is different for each person. We are not always aware of our own stress or knowing what causes stress for children/youth.

Everyone's body has a different way of showing and responding to stress/emotion. In a stressful situation, one person might faint from feeling overwhelmed while another person might faint.

Sometimes stress and emotional experiences are so private, they get 'bottled up' inside without the person being able to recognize their own stress, and their body does the 'talking' for them through somatic symptoms

Clinical Vignettes and examples of explanations to families

Somatic Symptom Disorder <u>without</u> a medical condition

Brenda is an elementary school girl who has always been kind and caring. She has many friends and is close with her family. Brenda enjoys being in the school band, however she struggles with math and reading comprehension. During the school year she experienced significant pain in her right arm, radiating from her elbow to her fingers. Brenda was not able to participate in academic or school band activities because of her pain. Her mother is currently on sick leave from work. The results of the medical assessment did not show any underlying causes for her pain.

What we know of Brenda is that she is a very sensitive and perceptive young girl and that she tends to keep a lot of stress bottled up, as it is hard for her to express herself emotionally. She doesn't want to worry anyone and wants everything to be 'OK'. In our discussions with Brenda, we understand that she is actually really worried about you since you have been on sick leave from your job. Although she loves her band class, she has been teased recently by some of the other children. The pain Brenda has been experiencing is real and disruptive to her day-to-day life. We believe that this pain is an expression of her stress and emotions about these situations. Her body is expressing her struggles because it is difficult for her express herself in other ways that are more usual for children her age (e.g., behaviours, mood, etc.)

Somatic Symptom Disorder <u>with</u> a medical condition (an element of somatization)

Raj is an athletic teenager who is involved in competitive soccer and hopes to play for a university team. Raj sustained a concussion during the soccer season and subsequently missed a month of school and playing soccer with his team. His concussion symptoms (headaches, photophobia, concentration difficulties and fatigue) resolved over a month; however, during spring break, Raj's headaches returned. He was not able to successfully return to school or re-join the team in time for the end-of-season play-offs

We are confident that right now there is no reason to believe that Raj's symptoms represent any further injury or illness, and that the reason why Raj continues to have these symptoms is because there is a component of somatization with his recovery. After speaking more with Raj, his stress seems to be focused on what it will be like for him to return to school and soccer. Raj is concerned that at this level of competition in soccer, he will get injured again; and, that if he were to return to the sport now, he would be expected to play in the finals. We can work together to help support Raj's paced return to his activities and clarify with him some of the expectations he has placed on himself or perceives what other expect of him.

Conversion Disorder

Sarah is a high-achieving and responsible teenager who keeps her emotions to herself. Sarah has a small and close group of friends. She recently started middle school in an academic enrichment stream. In October, Sarah began having fainting episodes in which she would slump over in her desk or fall to the ground. These episodes occurred up to twenty times a day. No medical cause was found. Sarah continued to attend school, but her fainting caused her to spend much of the day in the nurse's office. Two of her friends often left class to be with her.

We understand from Sarah that there have been some social stresses in her peer group [name the potential source of stress] and we understand that her grandmother, who she was very close to, is terminally ill. Sarah's fainting episodes are an important example of how the mind and body work together to manage stress and emotions. On the one hand fainting is a way for her body to protect her from emotionally experiencing strong feelings and stress, yet at the same time Sarah's mind has protected her body from ever being hurt despite all the fainting episodes she has experienced. By helping Sarah work through her emotions and manage her stress, we are allowing her mind and body to do the work that they are best suited for and communicate in a more typical way.

Responding to Concerns about the Diagnosis

Children and families usually understand and accept the formulation and diagnosis shared with them and are willing to move forward and engage in treatment planning. However, there are times when the children and families may disagree or express concern. Families who have children presenting with sudden and/or severe symptomology typically experience a significant amount of anxiety and fear that something is being missed. Similarly, families whose children who have suffered chronic symptoms have been to multiple medical providers, undergone multiple investigations over time, and may also continue to seek a 'medical' diagnosis. The following are some concerns that families may raise and examples of our responses.

The family disagrees with diagnosis and does not accept that there is stress in child's life:

- *We agree that we cannot be 100% certain that there is not an underlying medical cause for these physical symptoms.*
- *We are certain that [child] does not have any serious medical condition that is causing these symptoms.*
- *We appreciate your time and motivation in finding a way to understand/explain what is causing the symptoms.*
- *We can go over the possibilities and ideas you have researched and discuss how your thoughts/ideas relate to the medical investigations and results that we have completed to date.*
- *While we continue to discuss your questions and concerns about a diagnosis, let's agree to work on the stress your child is experiencing right now as a result of having these symptoms*.
- *We can start by discussing options for symptom management and also supporting [child] with some stress management techniques*.

The family wants a second opinion

- *Thank you for letting us know that you are seeking a second opinion from another provider.*
- *It would be very helpful, and in [child's] best interests, if we could connect with that provider to share our results with them and hear their formulation of [child's] symptoms.*
- *With this shared communication we can all be on the same page to understand her needs. Let's also have a discussion about what therapies you are seeking so that we have the best combination of treatment approaches*.

The family believe that the health care providers think the child is "faking" the symptom

- *We want to reassure you that although we have found no medical cause for the [child's] symptoms.*
- *We are equally certain that they are experiencing the symptoms.*
- *We know these symptoms are real; and we can see that your child suffering and they have been significantly affected.*
- *Somatization is such a complex condition and there may be a number of factors that have contributed to onset of these symptoms.*
- *I think we can agree that we share the common goal to reduce your child's suffering by starting treatment for these symptoms and helping your child get back to some of their usual activities.*

Helping children and families explain the diagnosis to others

A child has been rushed to the Emergency Department because of a sudden onset of visual disturbance following a few weeks of dizziness and difficulty walking. The child is admitted to the hospital and is being cared for by the neurology team. An MRI, EEG and eye exams have all come back as 'normal' and the treatment team has been speaking with the child and parents about stressors. The parents have been updating extended family members and friends about the child's condition and the care they are receiving at the hospital. The neurologist and team members explain that the child does not have a serious neurological condition – instead they have diagnosed the child with a Conversion Disorder and that the physical symptoms are a result of psychological stress. The treatment is physiotherapy and psychotherapy.

The example above is common in hospital setting. In situations where the family understands the diagnosis there may still be reluctance to start treatment for somatization. Families may be under pressure from friends and extended family members get more tests or not leave the hospital before they have a better answer. Hesitance to move forward with treatment can also occur when a family or child is uncomfortable thinking of how they can explain that there were no medical findings to explain the child's severe symptoms. For these reasons, we have found it most helpful to be proactive with children and families by having the 'What do we tell other people?' discussion.

We remind children and families how complex somatization is and we acknowledge how difficult it can be to explain to others. For the **child**, we ask them to think of questions others might ask them and then we help them use their own words to explain their condition and treatment. We follow the same process with **parents**. Parents typically appreciate this conversation; and it also provides an opportunity for them to clarify their understanding of the diagnosis and the treatment plan.

Examples of Child/Youth Explanation

- I went to the hospital because I had trouble seeing and walking and my parents were really worried.
- The doctors did a lot of tests and found out that I don't have a really serious (bad) medical condition or injury.
- I am doing some physiotherapy to help with walking and I'm learning about why my body is having these symptoms and strategies to get better.

- I went to the hospital because the symptoms from my concussion that happened months ago seemed to be getting worse instead of better.
- The doctors ran some more tests. It seems that I am recovering from the concussion; and these symptoms are not related to my injury.
- They explained that because stress and emotions can be expressed physically these symptoms are likely related to the things that are going on in my life.
- They taught me some pain management strategies that are helpful. I am also learning how my stress affects my body and some better ways to deal with stress and other things that are bothering me

Examples of Parent/Caregiver Explanation

- We were really worried when our child was having trouble walking and talking.
- The physicians at the hospital had a lot of questions and ran a number of tests.
- The good news is that they did not find any serious medical condition or injury.
- They explained that our child was experiencing somatic symptoms – sometimes called Conversion Disorder.
- So, although our child is having these symptoms, they are not because of a brain tumour or encephalitis.
- Instead, it seems like our child is experiencing stress and sadness; and, since it is hard for them to talk about it, their body is doing the talking for them.
- Our child is receiving physiotherapy to help them improve their walking and balance and talk therapy to help them find better ways to deal with their stress.
- We are all still monitoring our child closely.

'I understand what is going on with my child, but I don't know how to explain it to my friends and family'

- We were concerned that our child's concussion was not healing and that the symptoms seemed to be getting worse instead of better.
- When we took the child to emergency, they ran some more tests and went over the course of child's symptoms.
- They also asked about any stresses in our child's life.
- They explained that it is likely that our child has recovered from the concussion, but that the headaches are somatic symptoms.
- So, our child is experiencing real and painful headaches but not because of the concussion, instead they seem to be related to stress and emotion.
- We started to talk to our child some more and realized that they are really stressed about school and sports.
- They taught our child pain management strategies and also encouraged us to talk to the school and child's coach.
- Our child is also doing therapy to help him cope with stress in a different way and to be able to talk about emotions instead of bottling them up.

Create an Integrated Treatment Plan

After the careful process explaining the somatization formulation, the next element of the **connections** phase is generating the **integrated treatment plan**. The plan is highly individualized and will change over time. A detailed description of the elements of the Integrated Treatment plan are found in the next section. In this section, we talk about how to introduce treatment components and collaboratively decide to start treatment.

Acceptance, Readiness and Agreement to 'walk two paths'

Some children and families feel ready and often eager to start the treatment process and others may have reservations because they are still struggling with the somatization formulation (see above 'Responding to Concerns about the Formulation/Diagnosis'). For these families, we introduce a 'walking two paths' approach before we explain the integrated treatment model. This approach aims for treatment to be able to begin for children whose families who have concerns about accepting a somatization formulation and/or who have ongoing medical concerns about their child's physical symptoms. The primary goal of the 'walking two paths' approach is to reduce the child's suffering and/or increase functioning for the child; and reduce the possibility of a family disengaging with the health care team and possibly trying to seek further medical investigations independently.

WALKING TWO PATHS

*The term **walking two paths** refers to the simultaneous processes of*

I. *Continuing medical assessments, investigations and treatment as appropriate over time (in fact, ongoing relevant medical monitoring and check-ins are highly recommended) and*
II. *Beginning psychological and rehabilitation treatments and strategies.*

Agreeing to move forward with treatment - 'walking two paths'

- *At this point in time, what we would like to suggest is that we agree to 'walk two paths' for [child] - the medical path and the somatization path.*
- *On one path, we will continue to monitor [child's] physical symptom, watch for any changes to the symptom, and figure out if there are any more assessments that need to be done.*
- *At the same time, we will walk together on another path: We can work towards reducing the impact [child's] symptoms are having in their life.*
- *We will support [child] with symptom management and help [child] to get back to her normal life as much as possible during this time.*
- *This other 'path' also includes exploring experiences of stress and emotion.*
- *Going forward, by helping [child] understand how stress and strong or mixed emotions can affect their body, [child] will also have the opportunity to learn ways to manage their symptoms.*

Describing the Basic Treatment Approach

The BCCH Pediatric Somatization Model of Care outlines the elements we have found most helpful in treating children with somatization. Elements of treatment are integrated and draw on different specialties within health care and on a variety of aspects of the child's life and family. Part III of this handbook describes the integrated treatment model in detail.

When the diagnosis and explanation is shared with the family, we usually provide an overview of the treatment model and outline the basic elements of treatment.

It can be very helpful to provide the family a copy of the treatment model to reference during the discussion. We often allow for a more detailed conversation about the child's individual treatment plan with a follow-up conversation. During this conversation, we will provide the family Integrated Treatment Model Family Worksheet (see Chapter 5: Resources) and complete the worksheet collaboratively. A copy of the completed worksheet should be provided to all of the child's key health care providers and revised as needed regularly.

Describing the basics principles of treatment

- *We have every expectation that [child] will get better.*
- *We know about how to treat somatization.*
- *There are a number of different elements that we use in treatment for somatization, including*
  - *learning how to manage and cope with the symptom(s),*
  - *learning about stress, emotions and the mind-body connection*
- *We will work together to plan and access the elements of treatment that [child] needs.*
- *A major goal of treatment will be to help [child] get back to their regular activities in a manageable way.*

Physical Symptoms, Functioning and the Integrated Treatment Approach

The Integrated Treatment Model focuses on helping children have functional lives (i.e., lives with meaningful, rewarding activities), rather than full symptom reduction as a key element of recovery. When families first are introduced to the Integrated Treatment Model, it is not uncommon for them to have a belief that it is important for the child's physical symptoms to be gone before they try and return to activities. Having a direct conversation about this at the outset of treatment planning helps treatment move forward and sets the stage for recognition of stepwise progress and recovery.

The family do not want their child to return to activities (e.g., school) until they are symptom-free

- *If we wait for [child] to be 100% symptom free before returning to their activities, like school, it will be even harder on him/her in the long run than returning on a part-time basis now.*
- *Even though it isn't easy, we find that when children get back in their 'normal' routine, with some of the accommodations we have suggested for [child], this actually helps their overall recovery.*
- *Isolating from friends and worrying about getting behind in schoolwork can make symptoms worse.*

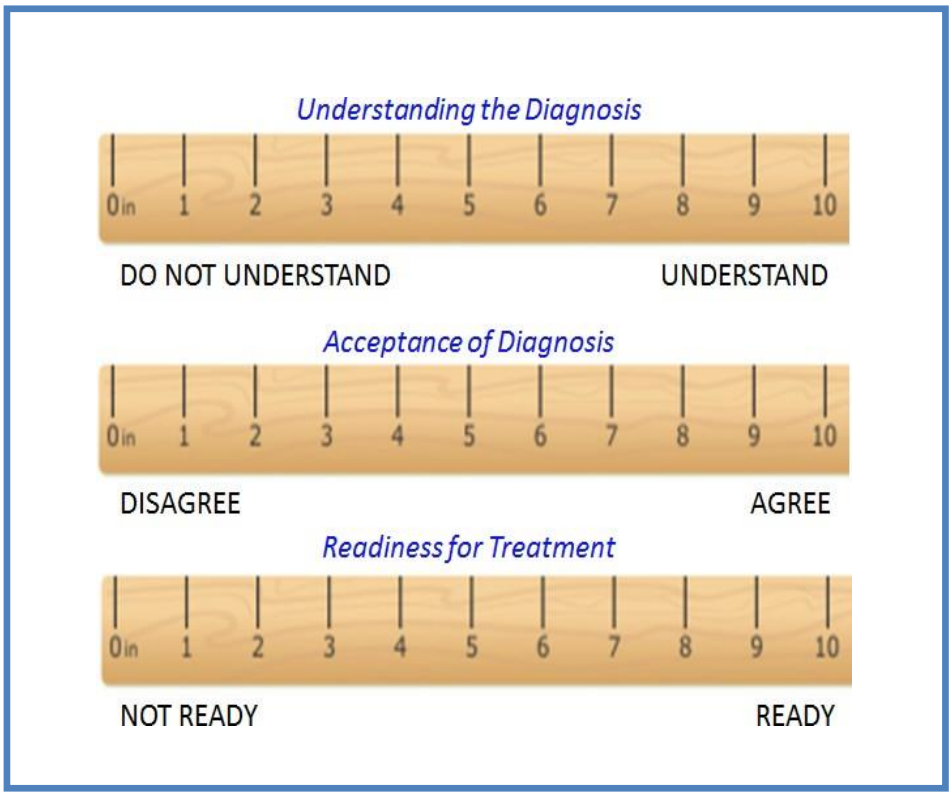
Ongoing Involvement of the Medical Team

As was mentioned in the section above outlining the 'walking two paths' approach, it is critical that the family understands that communication with medical care providers does not end after the somatization formulation is provided and integrated treatment begins. Families are more likely to accept and participate in psychological/psychiatric treatment if a medical provider is involved with ongoing care.

It is important to have at least one physician to continue to be involved in the child's ongoing care. Ongoing care may range from infrequent monitoring, with re-assessment when new symptoms emerge, to weekly check-ins. The plan for ongoing medical care should be outlined when the integrated treatment plan is made.

READINESS RULER

Providers might want to take the time to do a 'readiness' check in with families. For example, families might be ready to start treatment planning AND still have questions or concerns about the diagnosis. This process can increase the collaboration and communication between the team and family. Consider asking the child and parents to independently indicate their readiness in terms of understanding the diagnosis, agreement with diagnosis and readiness for treatment.



The Team and Family Meeting

We have found that one of the best ways to provide a somatization diagnosis and enhance collaboration is through a **team and family meeting**. Team members include key professionals involved in the child's care (e.g., hospital specialists, pediatricians, psychologists, school counselors, etc.). For children admitted to hospital, ideally the team meeting occurs prior to discharge. For children receiving care in the community a virtual meeting can be organized. The team and family meeting helps the family understand that the child's symptoms are being taken seriously. It also reduces miscommunication and mixed messages. Discussions points for the team and family meeting should include:

- ☐ Ensure dedicated time for the meeting
- ☐ Provide a summary of physical symptom(s)
- ☐ Review the clinical findings from the physical exam and investigations
- ☐ Validate the child and family's experience (the symptom, concerns about the symptom and the impact the symptom have had on the child and family)
- ☐ Provide the somatization formulation/diagnosis (stated by a primary physician/nurse clinician involved with the child's care) along with the clinical rationale for the formulation in relation to the clinical findings, physical exam and investigations
- ☐ Explain and normalize the mind body connection and somatization
- ☐ Ensure that the family understands that the symptoms are not under the child's control, not 'all in their head' or that the child is 'faking' their symptoms.
- ☐ Recognize and address family's level of acceptance of the diagnosis and readiness to move forward in to integrated treatment
- ☐ Introducing the 'walking two paths' concept in relation to acceptance, readiness and treatment planning
- ☐ Ask how the child and family how they will explain somatization to others
- ☐ Introduce and convey confidence in the BCCH Integrative Treatment Model for Pediatric Somatization
- ☐ Discuss and review the key initial elements of the Integrated Treatment plan for the child
- ☐ Plan for ongoing communication between health care team members and the family
- ☐ Ensure the meeting time is managed so the child and family can ask questions, raise concerns or request clarification.
- ☐ Consider allowing the parents some time with the team prior to the child joining the meeting

Chapter 3

INTEGRATED TREATMENTS

Flexibility is the hallmark of the six elements that make up the **Integrated Treatments phase**. At any given time, one or more of the elements may be the focus of treatment and the elements do not have to be completed in a specific order. The focus depends on the child and family's individual needs and readiness for treatment, the available resources, the health care team's expertise, among other variables. The key to successful treatment is flexibility, active collaboration and consistent communication with the child, family and all the care providers.

Treat Medical Condition(s)

Treating an identified medical condition is essential. It can be difficult to distinguish between the medical and somatic symptoms (e.g., migraines, post concussive syndrome, and abdominal pain in a child with Crohn's). This is why we take the "walking two paths" approach and encourage appropriate medical treatments of the physical symptom and any identified medical condition. If there is no identified medical condition, we strongly suggest a primary physician, or a specialist continue to schedule follow up appointments to monitor and check physical symptomatology. Ongoing care may range from infrequent monitoring, with re-assessment when new symptoms emerge, to weekly check-ins. If new symptoms arise, they should be assessed appropriately.

Actions

- ✓ Treat any identified medical condition
- ✓ Ensure ongoing medical care provider involvement for routine follow-up visits
- ✓ Arrange for further medical assessments if indicated for new symptoms or changes in symptoms

Outcome

Appropriate treatment of an identified medical condition to reassure the child and family that they can confidently pursue treatment for somatization without being concerned that medical issues have been missed.

Treat Mental Health Condition(s)

Somatization and other mental health disorders are often interrelated. There is no evidence based pharmacological treatment that has been shown to be effective for somatization. However, there is clear evidence that treating a co-morbid psychiatric disorder is effective. Mental health conditions should be treated appropriately with psychoeducation, psychotherapy and/or psychopharmacology.

Mental health conditions, such as anxiety or depression may be identified in the initial assessment and treated, but typically the co-morbid mental health conditions become more apparent over time. For example, we refer a number of our children to a Social Anxiety Group Treatment after they have completed the Mind Body Connection Group so that they are not overwhelmed with too many

treatments at any one time. We often choose the Mind-Body Connection Group first because the somatic symptom is more prominent, but as children gain an understanding of somatization the somatic symptoms become less prominent and other mental health issues may be more easily identified and appropriate treatment sought.

When suicidality or self-harm is identified it becomes the focus of treatment.

Actions

- ✓ Educate the child and family about the relationship between mental health conditions and somatization.
- ✓ Treat mental health conditions using psychoeducation, psychotherapy and/or pharmacotherapy.
- ✓ Intervene with a safety plan if appropriate for suicidality or self-harm behaviours.

Outcome

To support healthy recovery by attending to and treating other mental health conditions and ensure that safety measures are in place

Develop a Physical Symptom Management Plan

Patients and families benefit from development of a plan to manage distressing physical symptoms, especially in the initial stages of treatment. Medication, behavioural coping strategies, physical therapies, and complementary therapies may be considered to alleviate or reduce the intensity of symptoms and help patients cope in the moment. Behavioural strategies including relaxation, distraction, and mindfulness can help patients develop a sense of control, mastery, and hope. When clinicians make these plans with families, they also communicate their understanding of the validity of the patients' physical suffering. This can be particularly useful for families who are ambivalent about the somatization diagnosis but can share the goal of wanting to reduce symptoms.

Actions

- ✓ Teach patients to become proficient and independent with monitoring the symptoms, so they can "catch" them early.
- ✓ For a small subset of patients, use medication to target pain and insomnia.
- ✓ Prescribe the use of home remedies, including icepacks, stretching, exercise to treat symptoms.
- ✓ Empower patients to independently use behavioural coping strategies such as diaphragmatic breathing, progressive muscle relaxation, visualization techniques, distraction activities, mindfulness, and cognitive strategies.
- ✓ Develop a safety plan for what patients can do for when symptoms worsen. Include a description of how others should respond at these times.
- ✓ Involve physical and occupational therapy for rehabilitation of disturbances of gait, coordination, and sensory impairment to prevent long-term outcomes of physical inactivity. Referrals should include a communication of somatization to ensure there is no duplication or request for additional medical workups.

- ✓ Refer to massage therapy to help alleviate symptoms.
- ✓ Ensure complementary therapies are well integrated with all other components of the symptom management plan.

Outcome

To empower patients and families to think broadly about self-management strategies at their disposal to aid symptom relief, reduce impairment from the symptoms, and promote a sense of control and mastery.

See Chapter 5: Supplemental Resources for Families

Encourage Balance and Pacing

Somatic symptoms may take over a child's life and have a significant impact on family members. We often encounter children who have stopped attending school, reduced their participation in extracurricular activities and social interactions with peers. Somatic symptoms are often the reason for withdrawal from these activities either because the activities are experienced as stressful and/or the somatic symptoms prevent the child from attending or participating in activities. We also know that somatic symptoms are stress sensitive.

Engagement in active treatment requires a balanced and paced approach in contrast to an all-or-nothing approach to support to recovery. The balance and paced approach for managing stress, thinking about symptoms, returning to day-to-day activities and physical rehabilitation not only promotes recovery, but enhances resilience, coping and development beyond the reduction of symptoms.

Pacing is considered a graded return to function and activities. Pacing of physical symptom recovery can be accomplished through increasing activity, graded exercise and following a physiotherapy routine. Return to school and extra-curricular activities and support for increased developmentally appropriate social interactions also require a paced approach. Encouraging the child to return to participating in their normal daily activities again *without 'overdoing it',* is an important part of recovery. In the absence of a paced approach to symptom management, the child can experience an intensification or the onset of new symptoms. A paced return to day-to-day activities should be implemented even in the presence of somatic symptoms.

When a child experiences symptoms, they simultaneously experience 'outcomes' in their environment (e.g., missing school, non-participation in sports, changes in social or family routines). These outcomes are referred as un-intended secondary gains. Since somatization is usually a response to stress, a pattern can emerge such that children may often be asymptomatic for certain situations compared to others. At this point in time, it is essential to remind family and educators that these symptoms are unintentional, as there is a risk that they may believe that the child is 'faking' the symptoms to achieve a certain outcome.

Balance is integral to our treatment approach. Physical symptom reduction is an important treatment goal that must be balanced with understanding, accommodating and treating some of the common all-or-none thinking patterns and underlying stressors that may have contributed to the somatization. Over-focusing on physical recovery to quickly may place the child or youth 'at risk' for facing the stressors that may have contributed to somatization, before they are fully ready to do so. It is essential to understand, accommodate and treat the underlying stressors and thinking styles simultaneously with symptom reduction so that recovery is 'safe'. The child typically needs to develop emotional resilience and/or coping strategies to fully support their return to participation in day-to-day activities.

Stressful situations should not be avoided altogether. Every child needs to build skills in managing normal/typical levels of stress and resiliency for atypical or more intense experiences of stress and emotion. A finely **balanced** approach to reduce stressors yet encourage **paced** participation in developmentally necessary and appropriate activities is vital.

Actions

- ✓ Educate the child and family about the importance of pacing
- ✓ Teach the child to avoid an 'all or nothing approach' (both cognitive and behavioral)
- ✓ 'Prescribe' the child to take small steps but keep going (e.g., physical therapies)
- ✓ Temporarily limit participation in overly stressful activities or situations
- ✓ Choose one or two target activities at a time and adopt a paced or gradual return plan
- ✓ Teach the child to use their symptom management plan (with behavioural and cognitive coping strategies and tools)
- ✓ Ensure appropriate environmental accommodations and adjustments are in place (e.g., tutoring for school, modified participation in activities, family supports)
- ✓ Plan what 'full recovery' looks like (e.g., Create realistic activity schedules (that may be less than pre-somatic symptoms), with attention to transitions)
- ✓ Elicit and understand the nature of the child and family stressors
- ✓ Support the family to learn to respond to physical symptoms differently including an increased focus on the child's emotional experiences
- ✓ Advocate for a School Based Plan[1] including:
  - a plan for symptom management with school based behavioural coping strategies clearly outlined
  - specific social integration supports
  - academic accommodations
  - information for the school to help facilitate a special needs designation, if appropriate

Outcome

The child and family are able to tolerate ongoing symptoms while the child is concurrently returning to activities so that they can maximize functioning and reduce the need for unconscious secondary gain. Development of the child's emotional awareness, resilience and coping in tandem with their physical recovery through cognitive, behavioral, emotion-focused child and family-based therapies.

See Chapter 5: School Letter Template

Support Healthy Development

Healthy development in childhood and adolescence is characterized by increasing independence within the family, testing boundaries, renegotiating ways of maintaining connections with family, entering supportive peer relationships, engaging in social and recreational activities, progressing academically, experimenting with and developing a sense of identity and belongingness in the world, and learning navigate emotional upheavals. Somatization can interfere with the achievement of some of these milestones, particularly for those children and youth who are very sensitive, conscientious, perfectionistic, and internalizing. For these patients, physical symptoms can become a primary modality of communication with parents, and parents can become very focused on caring for an ill child, unintentionally impeding recovery.

We often start the conversations about returning to developmental normal and appropriate activities (academic engagement, social interactions, family life, extra-curricular activities) with the following sentences: "Now that we know the symptoms are strong but not dangerous, we need to shift from treating them in the acute medical model and shift to a rehab model. This means that instead of responding on a daily basis to the symptoms (going home if the pain is bad), we should make a plan that is balanced and paced and that is achievable regardless of the severity of the symptom." The example of recovering after a broken ankle is useful – once the ankle has healed it is important to slowly start to walk and then run despite initial pain.

Actions

- Provide psychoeducation about typical child and adolescent healthy development.
- Promote patients' independence and decision-making. For those with perfectionist traits, help patients develop insight into the difference been working hard on something they enjoy ("process") versus working to produce a perfect outcome or achievement ("product").
- Support parents to identify accommodations made for their child's symptoms that were helpful initially but are no longer necessary. In particular, support them to think about how some of their responses (e.g., reassurance) increase their child's avoidance rather than coping.
- Help parents understand the difference between nurturing their child (in all areas of development) versus attending primarily to their child's physical symptoms.
- Facilitate parents' understanding of the impact of somatization on their lives (e.g., work attendance, family relationships, social activities), and the potential impact to these areas of life when their child's somatization lessens.
- Prepare parents to be ready for more age-typical emotions and behaviours in their child as their somatic symptoms diminish
- Involve psychologists or counselors to support the family through the recovery process.

Outcome

Empower patients and parents calibrate their expectations about age-appropriate tasks, their respective roles in supporting those tasks, and developing and identity that is not defined by somatization.

See Chapter 5: Supplemental Resources for Families

Promote Emotional Awareness

Emotions are first felt as physical sensations, before they are recognized in our thoughts. These feelings serve an important purpose, informing us about our immediate needs and goals, and physically preparing us to quickly take action. With somatization, there can be confusion about the emotions behind physical sensations or a lack of awareness of the emotional experience itself. An affected person can feel mistrustful, overwhelmed, or immobilized by the physical sensations. Increasing emotional self-awareness is essential for finding relief.

Emotional self-awareness has several parts, including attending to the sensation, labelling or expressing the distinct emotion, accepting it is happening, and taking action if needed. These are very complex tasks. The brains of children and adolescents, in particular, are not fully developed or prepared to do these tasks alone. More than in later life stages, children and adolescents especially depend on their caregivers to 1) detect their emotional state from bodily expressions and 2) provide a response that helps them understand and manage that emotion. Over time, this shared process sets a template for emotional self-awareness in the brain, so the young person becomes gradually less reliant on their caregivers for emotional support

ACTIONS

- ✓ Provide psychoeducation about the adaptive role of emotions in survival, and their link to physical sensations and somatization.
- ✓ Involve psychologists or counselors who can provide emotional coaching and psychotherapy to child, the parent, or the family.
- ✓ Help families talk about emotional patterns taking place at home (e.g., emotions that are commonly expressed and avoided by each family member). Identify reasons for these patterns (e.g., genetics, temperament, medical adversities, other stresses, generational trauma, etc.). Support them to decrease self-blame for these emotional patterns.
- ✓ Empower caregivers to tune into their own emotional experiences, articulate them, accept them, and take action if needed. Support them to express both positive and negative emotions in the home. Help them discover they can heal wounds from both emotional expression and emotional avoidance in the family.
- ✓ Coach parents to tune into their child's non-verbal emotional expressions (e.g., tone of voice, body language, actions, and physical symptoms). Help them find ways to "be with" even the most distressing emotions. Support them to label and validate these emotional states. Prepare them to give their child developmentally appropriate independence in solving emotional problems.
- ✓ Coach the child to investigate the connection between their physical symptoms and their emotions. Provide psychoeducation about highly specific words that can be used to label diverse emotional experiences. Support them to turn to trusted adults for help in understanding and organizing emotional experiences.

Outcome

For children to become comfortable recognizing, expressing and regulating the emotional ups and downs of life on their own in a healthy way.

See Chapter 5: Supplemental Resources for Families

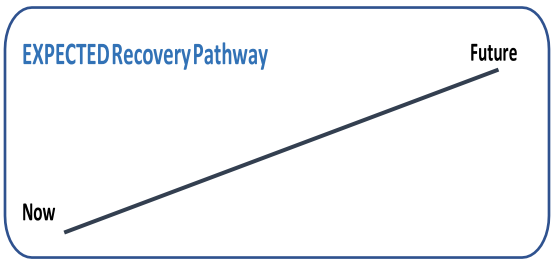
Chapter 4

RECOVERY

Recovery from somatization can take a variable course. Increased **function** and participation in meaningful activities, even in the presence of symptoms, is a key focus of recovery. Through engagement in the integrated treatments, children and families will have an increased understanding of healthy development and emotional awareness to support ongoing **resilience**. Treatment of any co-existing mental health concerns and adoption of a balanced and paced approach are key to **relapse prevention.**

Ongoing collaboration and communication are essential in the recovery stage. Sharing information with children and families about what to expect during this phase and encouraging them to ask questions or raise concerns, is foundational to support function, resilience and relapse prevention. Preparing families with an understanding that recovery is not usually linear, as it might be with other conditions. An overall pattern of symptom reduction is fully expected overtime; however, a pattern of 'flare ups', 'relapses', or 'setbacks' usually occurs along the journey towards long-term recovery.

Body Talk: Stories of Somatization: Part 4 Learning to Listen to your Body



When a 'flare-up' happens, this can be perceived as a setback, yet it can be an important opportunity. When children are able to identify a stressor or emotion and respond with copping strategies to

minimize the impact of a symptom or reduce intensity of the symptom, this is a significant milestone in the path to recovery. Providers have the opportunity to reinforce and validate the child's experience and 'expertise' in their management of somatization and empower them to respond to future symptoms. In discussions about recovery, it can be helpful to let the child and family know that recovery from one symptom can sometimes lead to the emergence of a different symptom. If new symptoms emerge, this can be cue to revisit some of the elements in the Integrated Treatment plan. Assess any new symptoms as needed, and while this occurs support the family in understanding that if the initial symptom was not part of a medical condition, it is unlikely that the new symptom is either.

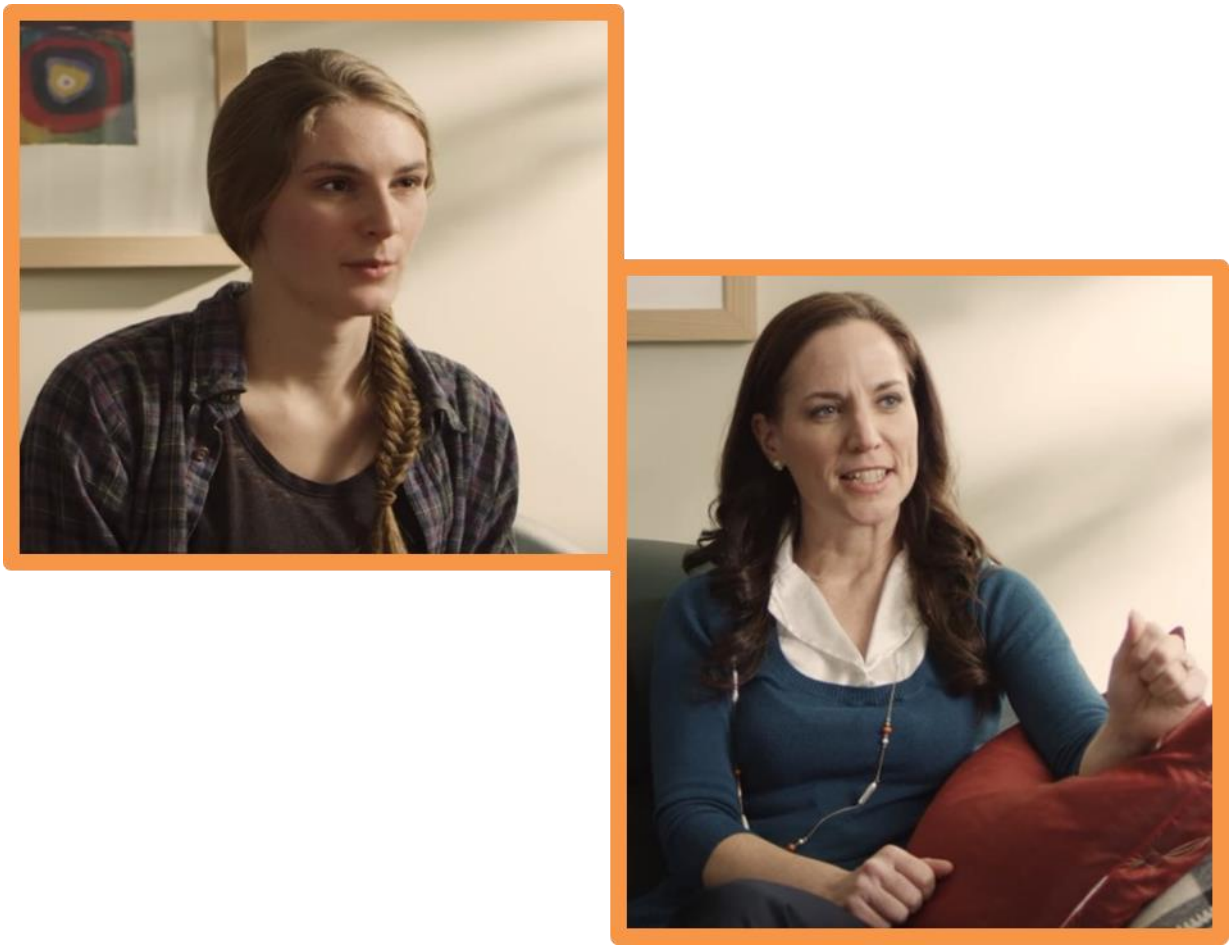
Physical symptoms tend to be less intense or frequent overtime as children and their families develop resiliency and coping skills through participation in integrated treatment. For all cases (regardless of how long treatment has been required or provided), provide follow-up 'wellness check-ups' appointments overtime. 'Wellness check-ups' should be held with medical, psychiatric and psychological treatment providers and should aim to support the child and parents in preventing relapse by highlighting resiliency, emotional and physical wellbeing.

The journey through the phases of somatization from **Confusion**, to making **Connections**, to engaging in **Integrated Treatment**, and finally entering and staying in the **Recovery** phase is usually very meaningful for the child and family. Many children and families tell us that the journey was difficult but, in the end, they feel that they have grown as individuals and as a family unit along the way. It is a gift to be able to take place in the journey with them.

Chapter 5

RESOURCES

This chapter includes a collection of practical resources. These resources are found in the Pediatric Somatization: Family Handbook as well. Some of these resources were developed for our Mind Body Connection Group Therapy Program and are included here as they can also be used individually.



The following is an overview of the resources in this section.

i. **Frequently Asked Questions (FAQs)** These FAQs reflect questions that families often have in the initial phases of confusion and connections when they are learning about somatization. The answers are transparent, normalize somatization and provide reassurance that somatization is treatable.

ii. **School Letter Template** The school letter is a generic template that can be modified based on the child's individual context. It provides information to school professionals and suggestions for strategies to help keep children attending and engaged in school.

iii. **Supplemental Resources for Families.** These resources can also be found in the Pediatric Somatization: Family Handbook

iv. **Integrated Treatment Plan Worksheet** This worksheet is used to collaboratively plan an individualized integrated treatment plan for a child that reflects their unique needs and context.

Frequently Asked Questions

Are somatic symptoms real?

Yes. 'Soma' means body. Somatic symptoms are symptoms experienced in the body - physical sensations, movements or experiences. Some examples include pain, nausea,

dizziness, and fainting. All emotions have a physical expression. Somatic symptoms are the physical expression of stress and emotions. Just like tears of sadness are real and a heart racing from excitement is real, so are somatic symptoms. Somatic symptoms can be symptoms that we often associate with stress, such as stomachaches or headaches. Or they can be ones that we don't typically associate with stress, such as blindness, seizures, or numbness.

Are my child's somatization symptoms 'all in their head'?

The answer is 'No' in the sense that 'All in your head' has often been a way of suggesting that someone is 'faking' or 'making up' their symptoms, or that their symptoms are a sign of mental weakness. None of these are the case with somatization.

However, it is very important to know that the brain and body are closely connected – they are partners that are always 'talking' to each other and 'cooperating'. They connect through very complicated back-and forth signals or 'messages' that involve the nervous system, hormones, and brain chemicals. Most of the time, when things are running smoothly, the system of signals between your brain and body is automatic. We call this **the *Mind-Body Connection.***

The brain-body message system allows you to do what you need to do in your daily life. It also works as a warning system by producing symptoms to pay attention to. Your brain and body communicate when you experience emotions. You often experience emotions not only as feelings in your mind, but also as sensations in your body. For example, when you are embarrassed or nervous, blood flow to the skin in your cheeks may increase ("blushing"). Or when you are very stressed, your brain sends signals to increase your heart rate, to breathe more quickly, to tense your muscles, and to empty your intestines. This "fight-flight-or-freeze" response helps you to survive dangerous situations.

Are children with somatization 'faking' their symptoms?

No, somatization is an 'unconscious' (involuntary) process. Somatic symptoms are the expression of an underlying emotion or emotion(s). Just like 'butterflies' in your stomach aren't fake; these symptoms are not made up.

Over time, there may become a pattern in which the somatic symptoms cause a child to avoid or get out of an uncomfortable situation or a distressing emotion. For example, imagine a child is being bullied at school and has a somatic symptom, like a stomachache. If the somatic symptoms continue and/or stressful situations and emotions are not managed, over time a child may learn (consciously or unconsciously) that having the symptom helps them to avoid certain stressful or negative situations.

We encourage parents, teachers and care providers to always work from the belief that the child's somatic symptoms are non-intentional, even in the face of emerging patterns of avoidance. It is rare that a child intentionally produces a symptom.

Do children have conscious (voluntary) control over their symptoms?

No. Children do not have control over when, where and how their symptoms occur. However, there are a few strategies to help a child gain some control over their symptoms. At the beginning of treatment children can be helped to pay attention to their symptom(s) because there may be 'early

warnings' signs that allow them to modify the intensity of the symptom or make themselves safer when experiencing a symptom. Understanding that the symptom is a somatic symptom and not a symptom of a medical illness may reduce a child's worry or stress about the cause of the symptom; and, in turn decrease symptom intensity or frequency. Helping children learn what some of their internal stressors are and expressing them in other ways, helps build control in their lives and over the symptoms. Finally, taking a "rehabilitative" approach – encouraging school attendance, socializing, and extracurricular activities – also helps child take back some control in their life that has been disrupted by the symptoms.

What is the difference between 'complex pain' and somatization?

Pain often has a 'component of somatization' – stress or distress makes any type of pain worse. For example, if you have migraines, stress is one of the factors that worsen them. Other things, like lack of sleep or too much sun, also play a role. Complex pain refers to a pain syndrome that has a component of somatization. Most chronic illnesses, even things like asthma or diabetes, have a component of somatization.

How are epileptic seizures different from non-epileptic seizures?

The movements and behaviours that occur during epileptic and non-epileptic seizures can be similar, but the cause is different. Epileptic seizures are caused by a disruption in electrical communication between neurons in the brain. Non-epileptic seizures are caused by subconscious emotions, thoughts or stress. Sometimes we call them 'stress-seizures'. Both epileptic seizures and non-epileptic seizures are involuntary (not intentionally produced). About 1 in 6 people with non-epileptic seizures also have epileptic seizures or have had them in the past. We now know that non-epileptic seizures are common.

What kinds of stressors are common causes of somatic symptoms?

Any kind of stress or psychological distress (anxiety and worry, sadness and grief, anger and frustration) can cause somatic symptoms. Every child has stress in his or her life. Children experience stress differently and what causes stress in one child may not cause it in another. Children also show their stress in different ways. Some children yell, cry, or talk when they are stressed, while others keep their stress to themselves. Some children are more likely than others to have somatic symptoms as a result of stress and emotions.

Examples of common childhood stressors that can cause somatic symptoms include being disappointed or worried that they are not doing well enough at school or in other activities, being bullied, worrying about friends and parents, the loss of pet, puberty, changes with friend groups, illness in the family, etc.

How can my child have somatization when I don't think they are stressed?

Everyone has stress and everyone somatizes. Somatization needs treatment when the physical symptoms are getting in the way of life. Children who have strong or frequent somatic symptoms are often (but not always) described as children who are sensitive, have high expectations for themselves, and tend to keep their emotions to themselves ('internalize', sometimes described as 'stoic'). When stress is kept 'internal' and not expressed through talk or behavior, it can become very hard for a child

to recognize or fully be aware of their stressors. It is common that parents also may not be aware of the internal stress that their child is experiencing or the reasons for it.

Do all children with somatization have a history of trauma or abuse?

No. Trauma and abuse are *one* source of stress and can be the cause of somatic symptoms in some children. However, most of the children that we treat have not been abused nor had a significant traumatic event in their lives. Instead, we see children where a relatively 'minor' stressor might occur (e.g., poor performance in exams, a minor sport injury, illness of a friend or family member, changes in peer relations, changes in family situation) that seems to be the trigger for somatization. Often that single situation represents a longer accumulation of stresses that have not been recognized or dealt with.

We also see children in situations in which their abilities do not meet the increasing demands of the situation – e.g., children who have been strong students in elementary school who are now struggling in high school, youth who perform well at a certain level of extracurricular activity but struggle when the demands of the extra-curricular activity increase or become more complex, etc. Children can suffer when their perceived sense self and competency, as defined by their activities, becomes challenged (e.g., I thought I was going to be a professional hockey player, I am not an honour roll student).

If my child is stressed, why are they having physical symptoms instead of emotional difficulties?

Somatization is the severe/intense form of physical expression of stress and emotions. There is usually not a single reason for somatization – instead, a combination of factors including personal temperamental styles, experiencing difficult or stressful circumstances, and/or having trouble expressing or describing emotions can all contribute to children developing somatic symptoms. Children may also have a physical vulnerability and that becomes the path for how their stress is experienced. For example, a child who is prone to headaches might get a headache during a stressful situation or a child with epilepsy might get a non-epileptic seizure in response to stress. Children may also start experiencing somatic symptoms in the same area as a previous injury. By learning about and developing the connection between the mind and body, children can start to recognize, express, and learn to deal with the underlying emotional components of stressful, difficult experiences.

How is the diagnosis of somatization made?

The diagnosis is made based on the medical assessment. Your child's medical doctor will take a history about the symptom(s), complete a physical exam, order and interpret investigations and tests, and will make the diagnosis based on their extensive knowledge about medical conditions. The diagnosis is <u>not</u> made because the patient has psychosocial stressors, certain temperamental styles or personality traits, or other psychiatric disorders. Usually, the diagnosis of somatization is not a "diagnosis of exclusion" (e.g., the doctors couldn't find anything else, so they called it somatization).

Can my child have a medical illness and somatization?

Yes, it is common to have a medical condition along with somatization. This is why we use the term 'a component of somatization'. Other children may have somatization without a medical condition, and these children may meet criteria for Somatic Symptom Disorder or Conversion Disorder.

What should I do if disagree with the diagnosis - I just don't buy it?

You aren't alone! Many families struggle with the diagnosis of somatization. If your child has sudden and severe symptoms, it is natural to fear that something is being missed. If your child has suffered with symptoms for a long time and had a lot of medical appointments and you haven't received any answers, it makes sense to question a new diagnosis of somatization. We respect family's concerns and uncertainty about the diagnosis.

If the diagnosis of somatization has been made by medical doctors who have done a thorough investigation, we work with families who are uncertain about a somatization diagnosis with 'walking two paths. The term 'walking two paths' refers to moving forward with treatment in two directions at the same time:

1. Continuing to engage in medical assessments, investigations and treatment as appropriate over time (in fact, ongoing medical monitoring and check-ins are highly recommended); and,
2. at the same time, starting psychological and rehabilitation treatments and strategies to help manage the somatic symptoms and increase the child's coping.

This 'walking two paths' approach allows families and teams to start working closely together. It also helps families be more confident about starting psychological and rehabilitation treatments for somatization even if they believe there might be another medical diagnosis that hasn't yet been made.

Why is my child not having more medical diagnostic tests?

Families often ask this question. After the initial medical tests are completed, the focus turns to helping the child cope with and minimize the stress relating to the physical symptoms. Waiting for more tests before starting to provide treatment can sometimes lead to a delay in children learning coping strategies and emotional skills that can help them get back to participating in day-to-day activities. This approach requires trust between the family and the providers and a lot of communication. When medical doctors remain connected with the family and other health care providers after the diagnosis of somatization has been made this makes it easier to assess any changes in symptoms or new symptoms. Having the medical doctor(s) stay involved does not prevent the child from starting treatment and 'walking two paths' towards recovery.

We have heard different words used to describe our child's symptoms and different diagnoses. Why?

When children first experiences somatic symptoms, they are usually seen by different medical specialists who have different ways of explaining the symptoms. Words such as functional, psychogenic, psychosomatic, medically unexplained, amplified and non-organic are all medical terms that have been used. These different terms can create confusion for everyone. We see part of our work as helping providers across medical specialties to work together and consistently use the term 'somatization'; the goal of using consistent language is to support the understanding that different somatic symptoms are all connected.

If the symptoms continue after a diagnosis has been made, does this mean the diagnosis is wrong?

No. This is very typical. The process of understanding, reducing and removing a child's stressors can take time. Symptoms will continue in the context of stress until a child has developed the necessary coping skills and a way to understand and express their emotions. Sometimes, the symptoms remain

even when work has been done to reduce or remove the child's stresses. In this situation we understand that there is more work to do to help the child's emotional and behavioural coping.

My child's symptoms have changed over time. Does this mean that the somatization diagnosis is wrong?

No. The body has many ways to physically express stress and emotions. Children who have somatization can have a number of different kinds of somatic symptoms over time

What is the typical course of recovery?

The course of recovery is different for each child. In general, the earlier the somatic symptoms are treated with appropriate treatments, the faster the recovery. We often see 'functional' recovery before we see an actual change in the somatic symptoms. That means that the child is attending school, spending time with friends, engaging in some extra-curricular activities; their functioning has improved. A fuller recovery (involving reduction of somatic symptoms and expansion of emotional functioning) can occur within days or can last for years.

If my child's symptoms are no longer occurring – will they return?

It is not unusual for children's symptoms to re-occur (or for new somatic symptoms to present) in times of stress. The first time this happens is a critical time in treatment. Getting through the first re-occurrence is a real test of the child and family stress coping skills and an opportunity to reinforce the child/families' ability to identify stresses in their life and solidify previously successful coping skills.

Can medications be helpful?

Sometimes, depending on whether or not there is also an existing medical condition and/or a co-occurring mental health issue (e.g., anxiety or depression).

What do we do if our child does not want to see a counselor or therapist?

For many children with somatization, talking about stress is very uncomfortable. Work with your medical care team to find a professional who has training in working with somatization. At first, it is often helpful to focus on 'practical' supports that decrease stress and promote symptom management and as a therapeutic relationship is developed work can start to help the child start talking about stress and emotions. Never push 'talk therapy' to the point that the child feels so stressed that this compounds the stress that is underlying the somatization.

After diagnosis and initiating new supports (e.g., therapy) my child's symptoms got worse. Is this typical? Why would this happen?

This can happen when children are first beginning to talk about stress and emotions. It's scary and new. It is important to help parents and children know that this may happen at the outset of therapy.

My child has non-epileptic seizures and keeps getting sent home from school when they have an episode – is this a good idea?

Since these seizures are not a medical emergency, it is not necessary to send the child home from school. Generally, we try to minimize the amount of time children miss school. What is important is the

developing of a coping/safety plan for the child both during and after an episode that includes the appropriate supports and allows for the child to remain at school.

What should I do when my child is experiencing a somatic symptom?

Symptom type and severity are different across all children and families. It's important for families to work with their medical providers and mental health support staff to have a specific symptom management plan. However, in general, the following principles should apply:

i. Remain calm. Recognize that this is a somatization experience, that the symptoms are normal and not dangerous. Families that become very scared or anxious when symptoms occur often inadvertently worry their child. Keeping your cool will ultimately lead to de-escalation in symptom severity/intensity.
ii. Validate the symptom and stressful experience. For example, you can say "I can see that you're feeling worried right now by your arm shaking." These kinds of comments help the child make the connection between emotional events and their physical symptoms.
iii. Provide support as needed and help the child implement the symptom management plan (e.g., using distraction).
iv. Don't over support. Sometimes well-meaning families may inadvertently provide a great deal of attention around a symptom (e.g., videotaping a child in an NES event; recruiting siblings/extended family to help support during a somatization event), but this may increase both parent and child stress levels and can lead to further symptom escalation. It can often be enough to assure the child that you recognize they are stressed, that you will remain close by and ready to help if needed, and to remind them of a coping strategy (e.g., "I can see you're stressed. I'm right here making dinner. You have your book to read. I'll be right over there ready to help you if you need anything").

How can we tell the difference between a new somatization symptom and a physical symptom?

We recommend that families treat new symptoms as they typically would; see your health care provider to a reassessment unless it is clear that the symptom is a somatic one.

Is it common to have to review the diagnosis with the family many times?

Yes. Somatic Symptom and Related Disorders are complex conditions. The physical symptoms themselves can be frightening and confusing. Additionally, families have been told that there is a psychological component to their symptoms, which may be unsettling and/or surprising. Reviewing the diagnosis with a family more than one time and at different times during the course of treatment is common and can be very helpful to support the therapeutic relationship and understanding of the condition.

My patient with conversion/somatization doesn't endorse any or few negative emotions. Is this common?

Yes. Although there is not singular profile for children and youth who suffer from somatization, we find that these children have a difficult time with emotional expression. In particular, recognizing and expressing negative emotions (e.g., anger, frustration, disappointment, etc.) is particularly challenging and, at some level can be 'threatening'. These children are often very perceptive, sensitive and

sometimes perfectionistic and the combination of these characteristics with challenges in expression of negative emotions can result in a higher risk of somatization.

School Letter Template

[Date]
Dear School Team,
I am writing this letter to assist in the school plan for [patient]. I am involved through my role as [e.g., Psychologist with the Medical Psychology team] at BC Children's Hospital. [Patient]'s medical care is currently provided by [healthcare professionals].
[Patient] has been diagnosed with [somatization, a Somatic Symptom Disorder, a Conversion Disorder, or as having a component of somatization]. *(Note to writer: if patient has been diagnosed with a medication condition, provide a brief summary here.)*

What is somatization?

- All emotions have a physical component, for example, the lightness of joy, the flush of shame or the tears of sadness.
- "Soma" means body.
- "Somatization" is the word we use to describe the physical (or body) expression of stress.
- Stress can be positive or negative.
- Everyone somatizes.
- Somatic symptoms are real.
- Although everyone experiences somatization, for some people somatization gets in the way of everyday life and requires treatment.

See http://keltymentalhealth.ca/Somatization-Disorders for more details on pediatric somatization. There are two types of DSM5 somatization disorders: Somatic Symptom Disorder and Conversion Disorder. In Somatic Symptom Disorder, common symptoms include pain, dizziness, and fatigue. In Conversion Disorder, symptoms involve sensory or motor systems, such as fainting, convulsions, difficulty walking and numbness. Sometimes, medical condition can be accompanied by a strong component of somatization.

[Patient]'s symptoms include [list]. There has been a significant impact on [Patient]'s functioning. It is essential that [Patient] attend school [part-time, full-time, through distance education]. Although [Patient]'s somatic symptoms are powerful at times, it is possible and important for symptoms to be managed at school. I recommend that the school develop a symptom management plan that includes:

- List of typical triggers
- List of warning signs for symptom escalation
- Strategies to prevent symptom escalation (e.g., relaxation breathing)
- Strategies to manage symptoms when present (e.g., rest/recovery locations at school)
- Strategies for re-entry back to class as soon as possible
- List of support team members at school

School Letter Template Cont'd

School counselors play an important role in successful participation in school and the recovery process. If possible, it would be very helpful for [Patient] to work with a school counselor to further develop the following skills:

- Being an 'early detector' of stress triggers and physical symptoms
- Proactively pacing activities throughout the day/week.
- Practicing stress and symptom coping skills (e.g., relaxation breathing, taking a break to lie down, going for a short walk)
- Developing emotional awareness and expression (e.g., being aware of stressors and emotional responses, and talking about them)

Support relating to social integration is often as important as support for academics. It is useful to figure out what school activities [Patient] enjoys/might enjoy (e.g., drama club, peer tutoring, sports) and to help prioritize these as part of [Patient]'s week at school. Initially, [Patient] may require adult facilitation to support social engagement both in and outside of school.

Other specific symptom management strategies that may be helpful to ensure successful school participation include:

- Use of medication
- Plan for how to move between classes (e.g., locker location, reduce books to carry, use of walking aids only if needed)
- Use of seating support
- Consideration of lighting and use of sunglasses/caps
- Scheduled meetings with a counselor or an educator for proactive check-ins even when somatic symptoms are not present

(Note to writer: these recommendations will vary depending on the patient. Delete as appropriate.)

Based on [Patient]'s profile and learning needs, the following is strongly recommended. Please note that these recommendations are respectfully offered.

- Designation: Consider a Ministry of Education Special Needs designation category.
- Learning Plan: Develop a learning plan or IEP to help document [Patient]'s learning goals.
- Psychoeducational Assessment: I recommend that [Patient] receive an updated learning/psycho-educational assessment to help better understand [Patient]'s learning profile.
- The school team will be in the best position to determine the timing and professionals who should be involved with this assessment. Additional learning adaptations may be apparent after such an assessment is complete.

School Letter Template Cont'd

- Additional specific academic accommodations may include:
  - Being excused from oral presentations.
  - Extra time for assignments and examinations.
  - Reduced workload in subjects of specific challenge.
  - Access to class notes in order to follow along.
  - Modified expectations in PE class (e.g., access to the course on-line, individual activities rather than group classes). Note: This should be assessed regularly, with the goal to be to help the student move actively towards increased participation over time.

We would be pleased to offer a phone consultation to the school-based team with the family's consent. [Provider contact information]
Sincerely,

Supplemental Resources for Families

Develop a Symptom Management Plan

MINDFULNESS

Mindfulness is a tool that can be included in a symptom management plan.
Mindfulness means:

- Being in control of your mind, rather than letting your mind be in control of you.
- Being aware of the present moment without trying to change it.
- Staying focused on one thing at a time, and not 'multi-tasking.'

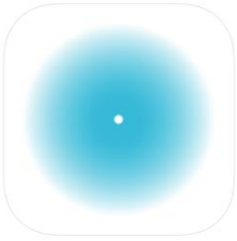
People usually want to avoid pain and uncomfortable sensations. This is very understandable. In mindfulness, instead of focusing on how badly you want the painful or uncomfortable sensation to stop, you pay attention to the symptoms with curiosity and without judgment. In turn, this can help:

- Lessen pain, tension, and stress, and improve your health.
- Give you more choices over how to respond to things that happen.
- Increase well-being and reduce emotional suffering.

Mindfulness can be done anytime, anywhere, without anyone else knowing. For example, you can focus on your breath, your surroundings, or on an activity you are doing.

Mindfulness is something that takes a lot of practice. Work on practicing mindfulness for 30 seconds, and then gradually increase your mindfulness practice to longer periods when you are ready. Having a mindfulness 'teacher' or online tool

Breathr App:
https://keltymentalhealth.ca/breathr



Breathr: Mindful Moments 4+
PHSA
2.1, 7 Ratings
Free

Mindshift App:
https://www.anxietycanada.com/resources/mindshift-cbt/

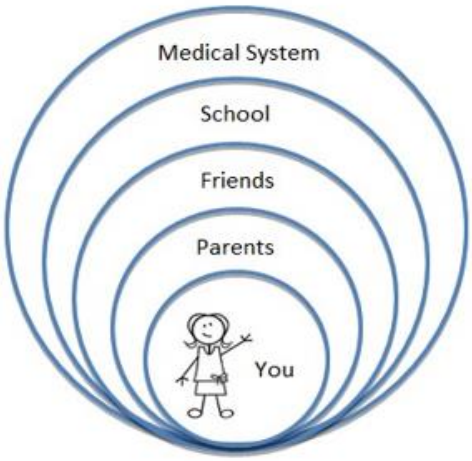
MindShift CBT - Anxiety Canada 4+
Proven Mental Health Relief
Anxiety Canada Association
#67 in Health & Fitness
4.4, 253 Ratings
Free

Support Healthy Development

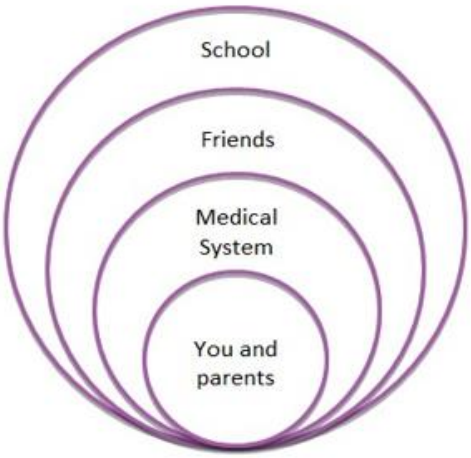
SOMATIZATION and CIRCLES of INTERACTION

Forming relationships is part of healthy development. Relationships range from people we see often who have a strong influence on us to people we do not interact with very often. Experiencing somatization can change how much and who we interact with and this might get in the way of building or maintaining friendships, going to school and other typical activities. For example, youth who would typically be spending more time with friends becomes more reliant on parents or health care professionals.

Without Somatization:



With Somatization:



For youth, this change in relationships can be stressful since they are not doing all the things they want to do (or see their friends doing). This can also be difficult for parents, who find themselves devoting a lot of time to support their child and also changing the nature of their relationships. Recognizing the 'risks' of these changes in relationships gives youth and families the opportunity to consider ways, even in small steps, to help support healthy development.

Support Healthy Development

DEVELOPMENTAL PATHWAYS OF ADOLESCENCE

The information in the box below reviews developmental pathways, especially the 'tasks' of adolescence. Consider this as you discuss with your child their individual priorities and goals.

Adolescents experience changes on many fronts all at once: physical, neurological, emotional, and social. It can be a very exciting time, but also very a stressful one. Some people think this is a stage simply to 'get through.' But actually, we need to fulfill the tasks of this stage in order to become ready for later life stages. So, there are some normal pathways we must all travel along, regardless of culture, gender, personality, etc. The pathways include:

Each pathway has tasks that are necessary (even if they appear negative) for typical development. Scientists are learning that experiencing normal levels of conflict, stress, uncertainty, and emotions during this stage of life makes us stronger. We become better able to handle these things when they come up (and they will!) at older ages. It is especially good to get practice in these areas now, during a time of life that important people (like caregivers and friends) are watching out for us.

Promote Emotional Awareness

Emotional Awareness & Expression in the Family

The information in the box below reviews ways to think about emotional expression patterns in your family, and the importance of parents understanding their children's emotions.

Individuals in the Family – Emotional Awareness and Expression:

Experiencing emotions can happen with or without us being aware of it.

- Some emotions are easier be aware of and pay attention to and others are more difficult.
- Usually, the emotions that are difficult to experience are ones that feel unpleasant or confusing.
- However, which emotions are easy or difficult to experience can be different for different people.

The Importance of Emotional Awareness and Expression of Difficult Emotions:

If we find certain emotions difficult to experience, we can sometimes become so good at ignoring them that we don't even notice that we are feeling them.

- This can be a helpful strategy in the short-term because it helps us avoid or get through a difficult experience.
- This strategy can be problematic in the long-term if it prevents us from expressing the emotion and solving an ongoing issue that has bothered us for a while.

The good news is that we can learn which emotions are difficult for us to experience and to become more aware of these emotions. By finding the links between our emotions and physical sensations and symptoms, we can start to uncover what our bodies are 'telling' us, and we can start to feel more capable, effective, and resilient in the long-term.

Family Patterns:

Families can be similar in how they attend to emotions. For example,

- In some families, sadness or tenderness is more difficult to experience because people feel vulnerable.
- In some families, anger is more difficult to experience because it can lead to conflict with others and/or people feeling unsafe.
- In some families, happiness and pride is difficult to experience because people feel guilty for their success.

In all of these examples, holding back certain emotions can help people feel more 'in sync' and connected to others in the family, yet at the same time, can cause people to feel 'disconnected' from themselves as individuals.

Continued on next page……..

Promote Emotional Awareness

Emotional Awareness & Expression in the Family

The information in the box below reviews ways to think about emotional expression patterns in your family, and the importance of parents understanding their children's emotions.

Supporting Your Child's Emotional Development through Reflective Responding

Parents play a big role in helping their child attend to, identify, label, accept, and express their emotions. One way to support your child's emotional development is to try to understand what your child is feeling, and then offer it back to them (e.g., *"you seem disappointed").* This is called 'reflective responding.'

When children are experiencing and expressing intense or difficult emotions, reflective responding often seems hard to do because parents also often feel that they must come up with ways of 'protecting' the child from the difficult emotion or that they need to try and 'fix' the situation that caused the child's difficult emotion. However, reflective responding simply involves being able to see something through the child's eyes, to sense what the child senses, and to feel what the child feels.

When parents 'reflect' their understanding back to the child, the child feels validated and accepted. Children can become more comfortable sharing some of the hard parts of their lives with parents. Most importantly, they can also become responsible for deciding what to do with that emotion. If an emotion is expressed and goes unrecognized, a child may think that expressing that emotion is not acceptable.

Promote Emotional Awareness

WAYS of RESPONDING

Always helpful:	✓
Being with	Nodding Matching facial expression Holding hands
Reflection	"You're frustrated that…" "This is upsetting to you" "You're anxious about…"
Validation	"I would be sad too" "This is an overwhelming situation" "It makes sense that you feel this way"

Sometimes helpful:	✓	✘
Questioning	"What was that like for you?" "What happened next?" "How did that feel?"	"Are you okay?" "Did you have a good day?"
Reassurance	"I am here with you" "You've gotten through this before"	"Everything is going to be okay" "You'll be fine"
Cheerleading	"I am proud of you for…" "You are a strong person" "You are coping with this well"	"You're so pretty" "You can do anything you want" "At least you're good at other things"
Problem solving	"What has worked in the past?" "May I give you some advice?" "What has helped me is…"	"The answer is simple" "You should just…" "Why don't you just…"
Distracting	"Would you like me to distract you?" "What would you like to do instead?" "What might help you to feel better?"	"Let's take you mind off of this" "Let's talk about something else" "Think happy thoughts"
Downplaying	"How likely is that to occur?" "If _____were to occur, what would happen then?"	"This isn't a big deal" "You're over-reacting" "What's the worst that can happen?"
One-upping	"You are not alone" "I have had to cope with a similar experience"	"I had it worse when…" "You think this is bad?" "Other people have it much worse"

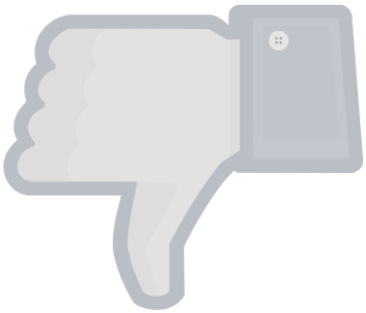
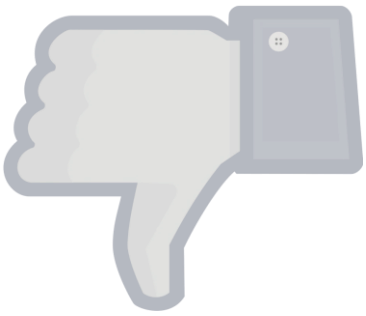
Rarely helpful:	✘
Avoidance	Ignoring emotions Focusing only on physical symptoms "Don't think/talk about that"

Adapted by E. Baker (University of Toronto) and Y. Ichikawa Baker (St. Michael's Hospital, Toronto)

Recovery & Resilience

PRO's and CONS of RECOVERY

Experiencing symptoms has an impact on a child and everyone in their family. Activities (social, school, work, sports) and relationships (friends, family) change. The child and family may be doing more, or less or different activities, and relationships may become closer or more distant. Along with the good things about recovering, there may be some not-so-good things. Imagine a time when symptoms are gone and consider some of the pros and cons of recovery. Make some notes in the boxes below.

Good Things about Recovering	Not-So-Good Things about Recovering
	
Good Things about Staying the Same	**Not-So-Good Things about Staying the Same**
	

Kelty Mental Health Website

We have developed some on-line resources to support families.

Please go to www.keltymentalhealth.somatization.ca to check out the following:

- **Somatization Brochure:** This two-page brochure gives an overview of what somatization and somatic symptoms are, and why we all somatize.

- ***"Body Talk: Stories of Somatization"* Video:** This 20-minute video is based on the words of two children and two parents. It shows how they found their way through intense physical symptoms to recovery. The video is in four-parts, following the four phases of Confusion, Connection, Integrated Treatments and Recovery.

- ***"Mind-Body Connection at Wildwood High"* Video:** This 5-minute animated video uses a story to explain the science behind the mind body connection.

- ***"Sam's Journey: A Story of Somatization"* Book:** This is a story book with pictures that tells the journey of a young boy named Sam.

- **Pinwheel Podcast Series *"Connecting Mind and Body: What Parents Need to Know about Somatization"*:** This one-hour talk involves a discussion with two youth and their parents describing their somatization experience and the journey to getting better.

- ***"Pediatric Somatization Professional Handbook"*:** This is a handbook for professionals who are working with children with somatization and their families. The Professional Handbook offers practice information and resources for all stages of the journey from Confusion to Recovery.

Other Resources

- **American Academy of Child and Adolescent Psychiatry's *"Facts for Families" on Somatization*:** This handout gives an overview of somatic symptoms, diagnosis, and treatment.

  https://www.aacap.org/AACAP/Families_and_Youth/Facts_for_Families/FFF-Guide/Physical_Symptoms_of_Emotional_Distress-Somatic_Symptoms_and_Related_Disorders.aspx

INTEGRATED TREATMENTS FAMILY WORKSHEET

Patient & Family Workbook
Planning Integrated Treatment for Somatization

Child's Name_____ **D.O.B.**_____

Parent/Guardian/Caregiver **Contact Information**

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_____ _____

Care Provider	Role	Contact

How to Use the Worksheet: *It is best if the child, parent(s), and a primary care team member complete the worksheet together. The worksheet is intended to help monitor the range of treatment activities education, and strategies that the child, family and providers can be involved in. The worksheet can help structure ongoing team/family meetings and be a source of information about progress and sharing information between different treatment providers.*

INTEGRATED TREATMENT COMPONENTS:

Treat Medical Condition(s)

Appropriate treatment of an identified medical condition so that the treatment for somatization can be started with confidence without concerns that medical issues have been missed.

- ☐ Ask questions if needed to understand why a certain medical assessment is or is not being done.
- ☐ Make sure your child is treated for any known medical condition.
- ☐ Arrange for a medical provider to be involved and do routine follow-up visits.
- ☐ Arrange for further medical assessments for new symptoms or changes in symptoms.

Plan/Notes:_____

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Treat Mental Health Condition(s)

Support your child's healthy recovery by being aware of and treating any co-occurring or emerging mental health conditions.

- ☐ Learn about the relationships between different mental health conditions and somatization.
- ☐ If your child has a mental health condition, seek treatments for the mental health conditions using education, psychotherapy and, if necessary, medication.
- ☐ Make a safety plan to deal with suicidal or self-harm behaviours, if needed.

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Develop a Physical Symptom Management Plan

Develop ways to help relieve or lower your child's symptoms. Increase your child's participation in activities. Encourage your child's sense of control through using self-management strategies.

- ☐ Work with your child's health care team to learn ways to watch for symptoms and 'catch' them early.
- ☐ Talk with your child's medical provider to see if medication can help with your child's symptoms (e.g., pain, insomnia, etc.).
- ☐ Try home remedies (e.g., icepacks, stretching, and exercise to treat symptoms).
- ☐ Learn coping strategies* such as:
  - Relaxation breathing
  - Muscle relaxation
  - Visualization techniques
  - Distraction activities
  - Mindfulness
  - Cognitive strategies (e.g., ways to reframe negative or anxious thoughts)
- ☐ Pay attention to situations that tend to make physical symptoms more likely to happen (e.g., not getting enough sleep). Take steps to prevent or manage these situations.
- ☐ Develop plans for what your child can do when symptoms get worse or really interfere with their day-to-day activities.
- ☐ Consider seeking physical and/or occupational therapy.
- ☐ Make sure your child's treatment team knows about any complementary therapy (e.g., acupuncture) that your child is doing so this can be coordinated with other parts of the symptom management plan.

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Encourage Balance and Pacing

A focus on gradual recovery helps your child achieve success, mastery, and independence as they take part in balanced everyday activities that are typical for same-aged children.

- ☐ Work with a professional (physiotherapist, psychologist) to learn more about the 'why's' and 'how's' of step- by-step pacing.
- ☐ Support your child to avoid an 'all or nothing approach' in their thinking and planning and activities. Increase your child's participation in only one activity at a time.
- ☐ Make activity schedules that are realistic and that may not be as busy as your child's schedule was before the somatization.
- ☐ Remember some activities are more stressful than others and may take longer to get back into and/or need smaller steps.
- ☐ Have a back-up plan of ways that your child can still take part in activities even on days where symptoms seem worse. For example, take a 10-minute rest break and then go back to class, rather than coming home.
- ☐ Speak up for a clear school-based plan that includes how your child and school staff will:
- ☐ Respond to symptoms that occur at school
- ☐ Give support for getting back into social activities at school
- ☐ Adapt and help with schoolwork
- ☐ Apply for a Ministry of Education Special Needs Designation, if appropriate

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Support Healthy Development

Help your child take part in at least some of the everyday activities and tasks that other children their age do. Help your child have an identity that is not defined by physical symptoms.

- ☐ Learn more about the stages all children must go through on their way to adulthood, including each stage's typical ups and downs. Learn about parenting strategies to support children through these stages.
- ☐ Focus on efforts (e.g., the process of working towards something) rather than achievements (e.g., winning games in sports, getting top grades, etc.). This will support your child's feelings of mastery and independence.
- ☐ Limit or begin reducing adaptations that were made for your child's physical symptoms that were helpful in the beginning but are no longer necessary.
- ☐ Also, think about what makes your child more likely to avoid activities, and what strategies increase the child's attempts to cope with activities.
- ☐ Think about ways to support your child's growth across a range of developmental areas. Developmental areas to think about include your child's physical health, social relationships, hobbies and interests, and academic education.
- ☐ Consider how your child's somatization has affected your life (work, family relationships, and social activities). Think about how these areas of life might change again when your child's somatization improves.
- ☐ Consider involving psychologists or counselors to support your family during the recovery process.

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Promote Emotional Awareness

Help your child learn to listen to and trust their emotions. Also help your child to express a range of emotions in a healthy way. This can often help reduce somatization symptoms and promotes healthy development.

- ☐ Arrange for counselling or psychological support to help your child learn about emotional awareness and expression.
- ☐ Model to your child how to recognize and express different emotions: share some of your own feelings in response to situations and where you notice them in your body.
- ☐ Understand that no one is to blame if you find emotional awareness hard. Learn about the many reasons that can make it hard: genetics, temperament, medical illnesses and injuries, other stresses, and trauma, etc.

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