

BC Children's Hospital Pediatric Somatization: Family 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. Over the years, we have learned a great deal from these children and their families. We have compiled our shared knowledge in this family handbook.

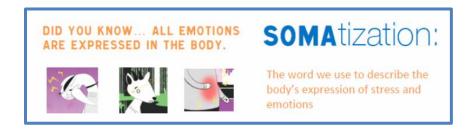
Our goal in writing this handbook is to provide families with the information and resources they need to help their children move through the journey towards recovery and resilience. This handbook outlines: 1) our understanding of somatization and the mind-body connection, 2) the ways we communicate about somatization and the mind-body connection, and 3) treatment strategies.

Specific resources are marked with this 'key' throughout the handbook and summarized in Chapter 3: Resources.

(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).

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.



Somatization happens because of the mind-body connection – the back and forth communication between your mind and body. All emotions are expressed in our bodies. For example, when nervous, you may feel 'butterflies in your stomach', when happy you might feel light with joy, when sad you may have tears. Everyone experiences somatic symptoms during his or her life; somatization is *normal* and *real*. It can occur on its own or with a physical illness, medical condition, or injury.

There are a few ways that somatization can start. Emotions and stress may cause physical symptoms. Having a medical condition or injury can be stressful and this stress may make the physical symptoms associated with the medical condition or injury stronger or more intense.

Some somatic symptoms are quite common, for example you might get a headache thinking about a stressful situation, or a stomachache before a test. Sometimes somatic symptoms are very powerful, for example, sudden changes in vision, fainting, extreme fatigue, or unusual body movements. For some people, somatic symptoms get in the way of everyday life and when this happens, somatization needs to be treated.

The mind-body connection and somatization are often not well understood, even by some health care providers. Children may suffer with somatic symptoms for months and even years, going from specialist to specialist, trying to find answers and treatment. In our work, we focus on integrating care – medical, psychological, and rehabilitation approaches - to help with recovery and resilience.

We use our 'foundation language' to help families and health care providers understand somatization in a way that is transparent, simple and makes sense to everyone.

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 are 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

This animated video called the 'Mind Body Connection at Wildwood High' also helps explain the mind body connection and somatic symptoms. https://www.youtube.com/watch?v=weRg8fwll50



There are a few key terms we use with somatization. Somatic Symptom Disorder (SSD) or Conversion Disorder (CD) are 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.

Diagnostic Criteria for **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).

Diagnostic Criteria for **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 also sometimes use the term *element of somatization*.

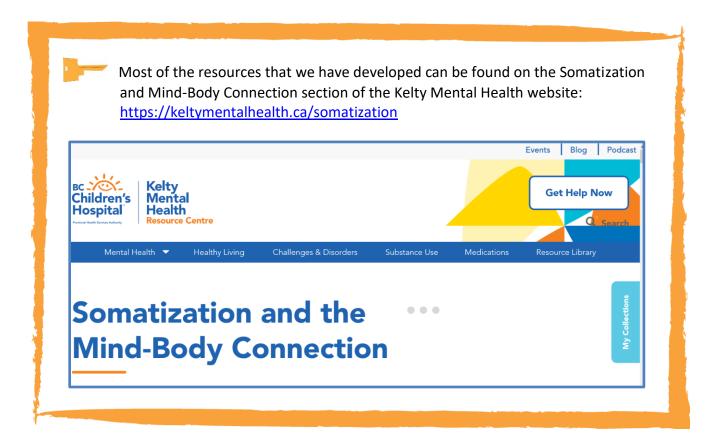
We use the term an **element of somatization** when:

- somatization is present but full criteria for diagnosis of SSD or CD are not met; or
- somatization is occurring along with a medical condition; or
- medical investigations are ongoing and at the same time, stress and emotions seem to be playing an important part in the physical symptoms.

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

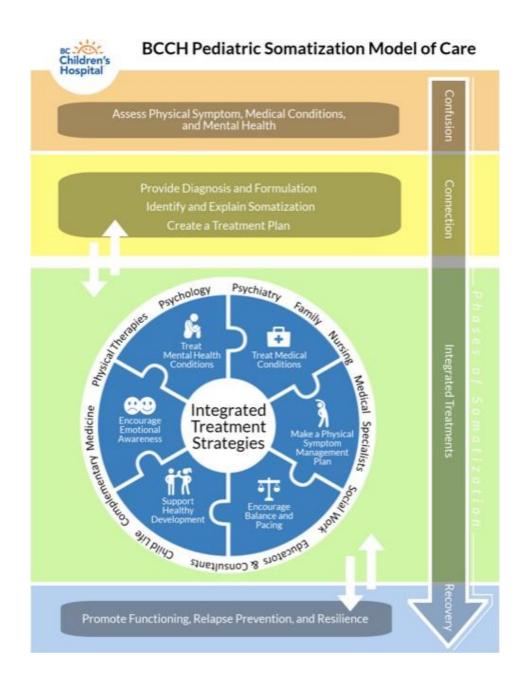
- 1) to explain that the physical symptom is partly caused by somatization,
- 2) to acknowledge the relationship between physiology (how our body functions) and stress or emotions (the mind-body connection); and,
- 3) because we don't always know how much the mind-body connections are part of the physical symptom(s).

Somatization is a mental health condition. There may be other mental health disorders that children experience along with somatization. The most common co-occurring mental health diagnoses are anxiety or mood disorders.



Pediatric Somatization Model of Care

The diagram below shows the care pathway we have developed at BC Children's Hospital. The phases of the journey are shown in the downward arrow on the right. They go from 'confusion' to 'connection' to 'integrated treatments' to 'recovery'. Your child's care providers will work with your family to help create an individualized treatment plan for your child. The six key areas of treatment to think about are shown in the circle.



Phase I – Confusion

The Confusion Phase in the somatization journey is the period of time when physical symptoms have started, and there is uncertainty about what is causing the symptoms and how to make them stop. This phase can last a long time, often because of how the health system works. There may be long wait-lists, on-going medical tests, and mixed messages from different health care providers. The Confusion phase may also last a long time because it can be hard to accept that what is going on might relate to the mind-body connection. You might worry that a medical condition is being missed. If this is how you feel, you are not alone. Many children and parents share this worry.

We have developed a video that may be helpful to watch: *"Body Talk: Stories of Somatization"*. Part 1 of the video is about the Confusion Phase and can be found here: <u>https://www.youtube.com/watch?v=KO7cFyjHK6A</u>



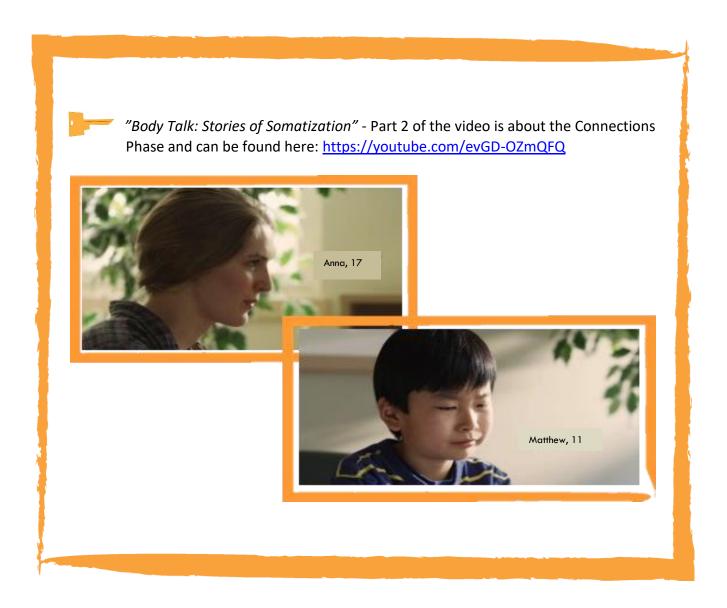
Confusing Symptoms

Searching for answers about what is causing physical symptoms and how to make them go away can be a confusing and frustrating experience. This emotional stress can take a toll, and sometimes even makes the physical symptoms worse.



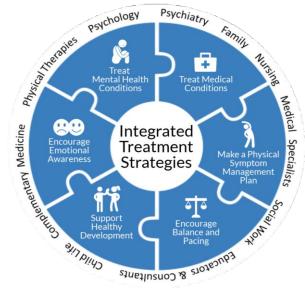
Phase II – Connections

The Connections Phase is very important. Your child will take part in different types of assessments to help understand what has led to their symptoms. The care team will work to build trust and a strong connection with your child and your family. We want to ensure there is a shared understanding of the mind body connection and somatization. A key message for your family in this phase is that we know your child's symptoms are 'real', and not 'all in their head'. We need to acknowledge the suffering that your child has experienced as a result of having somatic symptoms, and the impact of these symptoms in daily life for both the child and family. The team will make time to listen and validate your concerns, as well as encourage you to ask questions. The goal is to support an understanding how the mind-body connection relates to your child's experience.



Phase III – Integrated Treatment

The Integrated Treatment phase involves both planning and participating in treatment activities and supports. Your health care team will work with you to build an individualized treatment plan for your child. In our model, there are six broad treatment components. We have learned that relying on only one component of treatment rarely allows for full recovery from any condition. Successful recovery usually requires a combination of medical, physical and psychological strategies. That said, you do not need to focus on all six treatment components at the same time, and treatment components do not need to happen in a specific order. Indeed, the components can change over time, depending on your child's needs. The communication between you and your health care team is crucial during the Integrated Treatment phase.

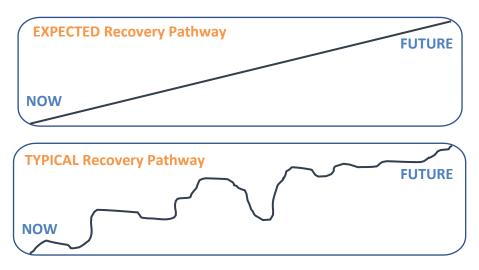


"Body Talk: Stories of Somatization" - Part 3 of the video, about the Integrated Treatments Phase, can be found at <u>Stories of somatization: Part 3 The Work of</u> <u>Getting Better</u>



Phase IV – Recovery

In the Recovery Phase, your child will return to everyday activities. They will have learned skills and activities to help cope with emotion, stress and physical symptoms in everyday life; and what to do if symptoms return. The typical recovery for somatic symptoms usually looks like steady improvement, with some occasional flare-ups or new symptoms overtime. Similarly, it is not unusual for somatic symptoms to come back. If they do flare up during the recovery phase, they are usually less intense and/or shorter-lived.



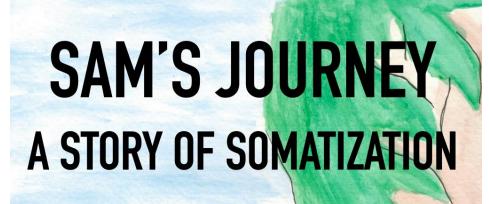
The Pathways of Recovery – Expectations compared to typical recovery

When a flare-up happens, it does not mean that the treatments have not worked. It is a time to think about what strategies and treatments have helped during the Integrated Treatment phase. Children have usually developed new skills and strengths, so a flare-up is a time to recognize what has worked and consider re-visiting some of the strategies that have led to change and recovery. Our patients often tell us that their journey from Connections to Recovery was challenging, but that it also led to important personal development.





This is a book with pictures that goes through the journey of somatization for a child named Sam. The link for the book can be found at: https://keltymentalhealth.ca/sites/default/files/resources/Sam%27s%20Journey.pd



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ILLUSTRATED BY: KATHERINE GREEN

CHAPTER 1 UNDERSTANDING SOMATIZATION Phase I - CONFUSION

Physical Symptoms

Many somatic symptoms are part of the way people frequently experience everyday emotions, for example, crying when sad or blushing when embarrassed. However, some somatic symptoms are unusual and distressing, such as problems with walking, blindness, and seizures (non-epileptic). In the middle, are common somatic symptoms like headaches, stomach pains, tiredness, dizziness or muscle tension. Emotions can show up in different physical ways in different people. For example, before a test some people have a headache, where others have an upset stomach. It can be very confusing because there are so many types of symptoms, and different ways they are experienced. Somatic symptoms can occur on their own or with an illness or injury. Over time, new somatic symptoms may also develop.

When somatization adds to existing physical symptoms:

- The body is familiar with sending signals to alert us of medical symptoms, and it can 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 seizures.
 - Expressing emotions and stress by familiar pathways can also happen with migraines, or with broken bones that have healed, or lots of other medical conditions.

When stress/emotion causes physical symptoms:

- Everyone has stress! But what causes stress is different for each person. We are not always aware of others' stress.
- Everyone's body has a different way of showing and responding to stress and emotion. In a stressful situation, one person might get a headache due to feeling overwhelmed, while another person might faint.
- Sometimes stress and emotional experiences are so private they get 'bottled up' inside without the person recognizing their own stress. Here, the body does the 'talking' for them through physical symptoms.

The following are examples of common 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 known underlying causes for her pain.

Somatic Symptom Disorder <u>with</u> a Medical Condition (an 'Element of Somatization')

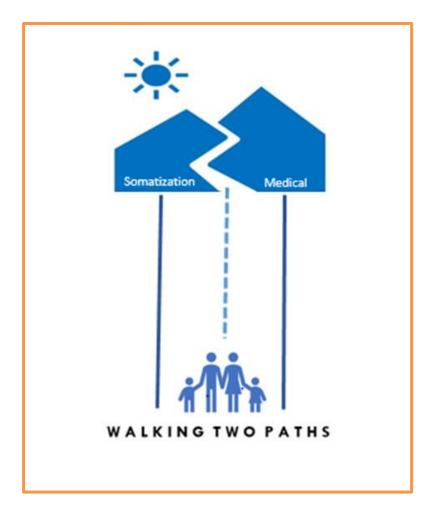
Raj is an athletic teenager who is involved in competitive soccer and hopes to play for a university team. Raj sustained a concussion during the soccer season and subsequently missed a month of school and playing soccer with his team. His concussion symptoms (headaches, sensitivity to light, concentration 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 happen on its own or along with a medical condition or illness. As such, we suggest your health care providers take a 'walking two paths' approach when they are considering somatization as a possible diagnosis. This means we encourage them to assess for possible medical conditions by doing blood tests, scans, etc. and, at the same time, do assessments and start treatments for possible somatization. The 'walking two paths' approach ensures a medical condition is not missed. This also makes sure that treatment for somatization starts as soon as possible, if it is understood to be part of the child's experience.



A detailed review of a child's social, emotional, and mental health is a necessary part of the comprehensive assessment process. This should include questions about everyday activities and stresses in order to understand how a child is functioning. Some children with somatization have anxiety or mood difficulties, but others don't.

Phase II - CONNECTIONS

Getting a Diagnosis

The diagnosis of a Somatic Symptom Disorder or somatization is made based on the medical assessment. In completing the assessment, your child's medical doctor or nurse-practitioner will:

- Interview you and your child, take a history of the symptoms and complete a physical exam
- Order and interpret medical investigations and tests
- Include a mental health professional to complete a social-emotional assessment
- Discuss all the results with the mental health professional(s)
- Make a diagnosis

The diagnosis is based on clinical knowledge of the causes and symptoms of medical conditions. It is not made just because a child has stress, or certain ways of behaving, or past traumas, or abuse, or other mental health issues.

At BCCH, our care providers often use the term an 'element of somatization' when stress and emotions make the symptoms of a medical condition worse. For example, a medical condition like a migraine may have an 'element of somatization'.

We have found that a Team and Family Meeting is very helpful for understanding the diagnosis and starting to make a treatment plan.

The people who attend the meeting can depend on a number of factors. Usually one or, better yet, both parents attend, along with the care providers who are involved in the assessment, diagnosis and treatment. If your child has been seen at the hospital, the team might invite care providers from the community to be involved as well.



We encourage children to attend the meeting, but we often like to give parents the chance to meet with the team before bringing in the child. That way, if needed, parents can ask questions that they might feel uncomfortable asking in front of their child. Often people take part by telephone or virtually to make it easier for everyone to attend.

Talking to Others about the Diagnosis

A child has been rushed to the Emergency Department because of a sudden vision problem after a few weeks of feeling dizzy and having trouble 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 psychologist on the team has been speaking with you and your child about stress. You have been updating other family members and friends about the child's condition and the care 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. The recommended treatment is physiotherapy and counselling.

How do you explain the diagnosis and treatment plan to your family and friends...?

Sometimes friends and other family members will tell parents they should be asking for more tests or not leaving the hospital until they have a better explanation. Even though somatization may start to make sense to the family, it might not yet make sense to others. For these reasons, we have found it very helpful to have a discussion to ask, 'What do you want to tell other people?'

First, we remind each other how complex somatization is, and how difficult it can be to explain to others. We often try to help a child learn to use their own words to explain their condition and treatment. We ask them to think of questions they would want to ask someone who had similar symptoms; and, then we ask them to think about the answers they might give. Once we have supported the child in thinking about they would talk about their symptoms, we find that it is often very helpful for parents to go through the same process. This process can help you ask more questions of the team and clarify your understanding of the diagnosis and the treatment plan. Having a clear, simple explanation to give when others ask questions will help to stop the spread of wrong information or unhelpful rumors. We also suggest to children and families that they don't have to share the same amount of information with everyone. Instead, they can share more information with the people they are closer to, and less information with people that they don't know as well.

Families sometimes tell us that members of their support group or extended family do not 'believe' the diagnosis. This adds more stress to child and family who are working on treatment components. If it happens for you, we suggest that you ask these individuals to consider attending a meeting with your child's health care team and you. This will help them understand how the diagnosis was made and allow your child's health care team to respond to any questions they may have.

Examples of Child and Youth Explanations



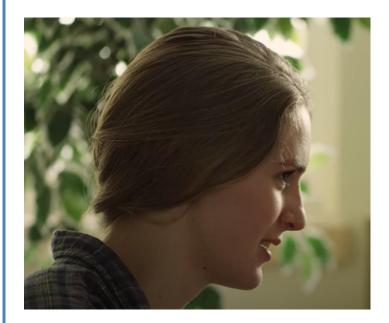
Example 1

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 medical condition or injury. I am doing some physiotherapy to help with walking. I'm also finding out why my body is having these symptoms and learning ways to get better.

Example 2

I went to the hospital because the symptoms from my concussion seemed to be getting worse instead of better. The doctors ran some more tests. They said I am recovering from the concussion; and the symptoms are not caused by my injury.

The symptoms are probably related to the things that are going on in my life, because stress and emotions can be expressed physically. They taught me some ways to manage pain that are helping me. 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.

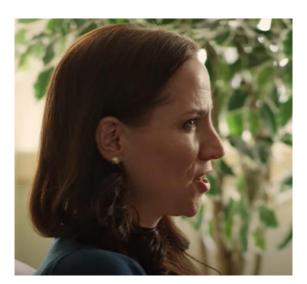


Examples of Parent Explanations

Example 1

We were really worried when our son, Jack, was having trouble walking. The doctors at the hospital asked us 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 Jack was experiencing somatic symptoms – sometimes called Conversion Disorder. These symptoms are not caused by a brain tumor or encephalitis. Instead, it seems like he is experiencing stress and sadness. Since it's hard for him to talk about it, his body is doing the talking for him. Jack is having physiotherapy to help improve his walking and balance and talk therapy to find better ways to deal with his stress. We are all still watching Jack closely.





Example 2

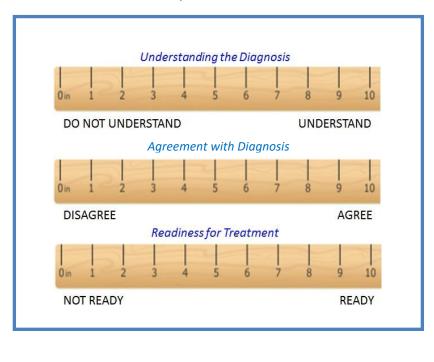
We were concerned that our daughter Emma's concussion was not healing, and that her symptoms seemed to be getting worse instead of better. We took her to emergency, and they ran some more tests. They went over the symptoms and asked about any stress in Emma's life. They explained that she has probably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

Checking-In About Understanding the Diagnosis and Readiness for Treatment

Before treatment planning, it is often helpful to do a self-check to see where you are in terms of understanding and agreeing with the diagnosis and readiness for treatment.

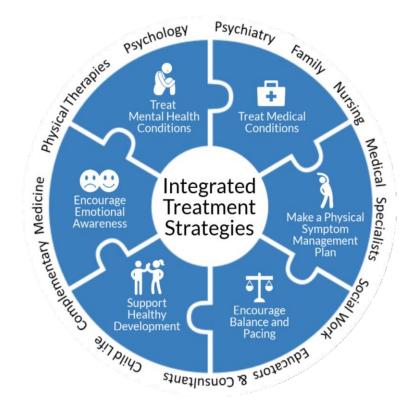
Self-Check: Understanding Diagnosis and Readiness for Treatment

Take a few minutes for you and your child to separately do the self-check. Share this information with your team or provider so they can understand what you or your child might need in the diagnostic and treatment planning process. For example, you may be ready to start treatment planning AND still have questions or concerns that your provider can help answer. This self-check tool can help the keep the flow of open communication between families and providers.



Making a Treatment Plan with Your Team

Once somatization has been identified as being an element of your child's condition or as a diagnosis, the next step is to make an individualized treatment plan. We use the BCCH Pediatric Somatization Model of Care as a guide.



Some children and families feel ready to start the treatment process right after the diagnosis has been given. Others, however, feel more hesitant because they are still struggling with the somatization diagnosis. In either case, we like the concept of 'walking two paths'. The 'two paths' idea means your child will continue to have medical assessments, investigations and treatment if these are needed, *and*, at the same time, can start treatments that reduce their suffering.

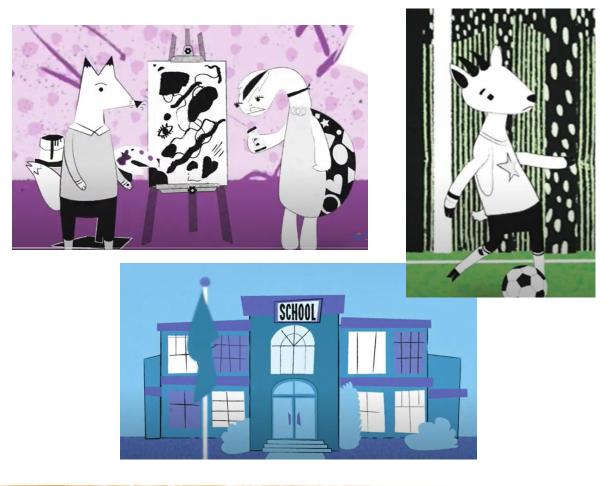
Different care providers are often involved in different components of care. It is important that all team members communicate and work to develop the treatment plan.

Examples:

- A school counselor may help manage school scheduling and progress
- A physiotherapist can help with movement and returning to activity
- A counsellor or psychologist can help with understanding stress and the mind body connection

We focus on increasing function so that children can have a meaningful and rewarding life, even if they continue to have symptoms. We find that when children get back into routines, even if they continue to require supports, it helps their overall recovery. When children are away from activities and they worry about getting behind in schoolwork or in their social lives, their symptoms often become worse.

In the next part of the Handbook, we will walk through each Integrated Treatment Strategy with a description of the components that make up the integrated treatment. We also include a list of actions and goals for each strategy.



'Integrated Treatments Family Worksheet'

At the end of this Handbook there is an 'Integrated Treatments Family Worksheet' you might find helpful to use when you are developing your child's individualized treatment plan.

CHAPTER 2 TREATING SOMATIZATION Phase III – INTEGRATED TREATMENTS

Treat Medical Condition(s)

As we mentioned above, we recommend a 'walking two paths' approach. This means that we encourage medical assessments and treatment for any known medical condition(s) at the same time as ensuring helpful treatment for symptoms is happening.

If your child has physical symptoms(s) related to a medical condition, it's clearly important to treat the medical condition. This is true for many medical problems, such as concussion, inflammatory bowel disease, or asthma. It other cases, such as migraines, post-concussive syndrome, and abdominal pain, it can be difficult to distinguish between the medical and somatic symptoms. And it's also important not to use medications or treatments that won't be helpful or may even cause harm.

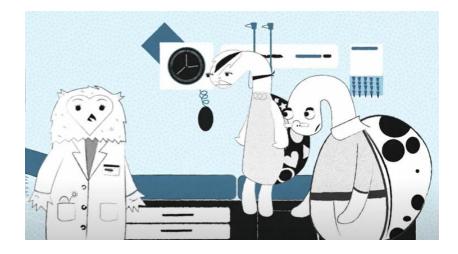
If a medical condition is not diagnosed, we would still recommend that your child has regular appointments with a medical provider. The ongoing care may range from weekly check-ins, to visits a couple times a year. If new symptoms arise, they should be assessed.

Actions

- ✓ 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.

Outcome

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.



Treat Mental Health Condition(s)

Somatization may occur on its own, with a medical condition, or with a mental health condition. The most common mental health conditions that co-occur with Somatic Symptom Disorder include adjustment, anxiety and mood disorders, as described below.

Co-Existing Mental Health Disorder: Children can have a mental health disorder such as Generalized Anxiety Disorder or Major Depression in addition to somatization, for example, a child may have symptoms of depression, as well as non-epileptic seizures.

Emerging Mental Health Disorder: Children can have somatic symptoms without any obvious mental health concerns. Over time, as somatization is treated and the physical symptoms improve, the mental health symptoms can become more obvious. For example, consider a child who has a somatic symptom such as pain in the abdomen. As the child learns to identify their feelings, the somatic symptom (the pain) decreases, and the mood symptoms become more obvious. In these situations, as the child learns the skills to understand and communicate their feelings, their body no longer needs to do the 'talking' or expression of emotions. However, parents may feel quite worried and discouraged as they see emotional symptoms increasing.

Somatic Symptom Presenting as Psychiatric Symptom: It is possible for a child to have a symptom that at first appears to be a mental health symptom but is in fact a somatic symptom. For example, a child has a psychotic-like experience, such as a visual hallucination, without other symptoms of psychosis. In this case, the hallucinations may be a Conversion Disorder symptom, and not a symptom of a mental health condition such as schizophrenia.

High Risk Symptoms: Sometimes somatic symptoms that last a long time and/or are very intense may cause or worsen serious, high risk mental health symptoms such as self-harm and suicidality.

Actions

- ✓ 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.

Outcome

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

Develop a Physical Symptom Management Plan

It is really helpful to make a plan to manage any physical symptoms, especially in the beginning stages of treatment. When families work with providers to make plans to reduce symptoms, children often feel their pain and suffering is understood.

Actions

- ✓ 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., ice-packs, 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)

*Remember: Coping strategies are work differently for each person. What works for one person may not be best for someone else.

- 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. It helps to explain to others how they should respond to your child at these times. These plans can even be used when your child is out in the community or at school.
- ✓ Consider seeking physical and/or occupational therapy if your child is having difficulties with walking, coordination, or sensory impairment. (Sensory impairment is when one of the senses; sight, hearing, smell, touch, taste, and spatial awareness is not working the way that would be expected for your child.)
- Consider physical and/or occupational therapy, to prevent any long-term problems that can result from being physically inactive.
- ✓ 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.

Outcomes

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.



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 can make a difference.



Encourage Balance and Pacing

Somatization can lead to children withdrawing from school attendance, spare time activities, and social contacts. After they are absent for a time, it may seem stressful and overwhelming to go back to these activities. In fact, sometimes there are unintended advantages to being absent from these day to day activities. For example, missing school can mean avoiding stressful schoolwork or tests. Because somatization is usually a response to stress, parents might notice a pattern. Parents and/or teachers may see the symptoms come up in some situations and not others. However, just as child's symptoms are not produced on purpose, these 'advantages' or outcomes of symptoms are also not developed on purpose. It is very rare that a child produces symptoms on purpose.

It can be tempting to rush back into things, especially activities that your child has really been missing. However, a gradual approach is more likely to result in success. It's also important to include plans for coping with stress, dealing with unhelpful thoughts, and increasing your child's resilience (their ability to 'bounce back' after a set-back).

Pacing is a step-by-step way for your child to return to activities, without overdoing it. Pacing reduces the risk that your child will experience new or more intense physical symptoms. It is important to take the first steps early, even if the symptoms are still present. Involving your child to help develop the steps in a 'paced return to activity plan' will help move them towards recovery.

Actions

- ✓ 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 could 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
 - \circ $\;$ Give support for getting back into social activities at school
 - Adapt and help with schoolwork
 - \circ $\;$ Apply for a Ministry of Education Special Needs Designation, if appropriate

Outcome

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.

Sample School Letter

Ask your child's health care team to write a letter to your child's school team to help with Symptom Management, and Balance and Pacing at school. Below is an example of a part of a school letter for a child named Sam.

Dear School Team,

Sam has somatization and been diagnosed with a Somatic Symptom Disorder.

There are two types of 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 element of somatization.

What is somatization? All emotions have a physical component, for example, the lightness of joy, the flush of shame, or the tears of sadness. "Somatization" is the word we use to describe the physical (or bodily) expression of stress and some emotions – it's the medical term for mind-body connection. Everyone somatizes. In fact, up to 12% of doctors' visits are due to symptoms affected by somatization. Somatic symptoms are very 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.

How does somatization happen? There are a few ways that somatization can start. It can happen on its own or as part of a medical condition. Emotions and stress may cause the physical symptoms, or emotions and stress may make the symptoms of a medical condition stronger or more intense. Having an illness or injury can sometimes cause anxiety and distress, which then leads to somatic symptoms. This connection between emotions and physical symptoms is called the mind-body connection.

Sam's symptoms include stomachaches and nausea. As part of his recovery, it is essential that Sam attend school. Although his somatic symptoms are powerful at times, it is possible and important that they be managed at school. It will be important for Sam, family and the school team to develop a plan. We recommend a plan that allows Sam extra time to transition from classroom to classroom. Initially it may be important for Sam to have a reduced course load.

A Symptom Management Plan may be useful. A symptom management plan may include things like:

- 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 counselors play an important role. If possible, it would be very helpful for Sam to work with a school counselor to further develop the following skills:

- Be an 'early detector' of stress triggers and physical symptoms
- Proactively pace activities throughout the day/week.
- Practice stress & symptom coping skills, e.g., relaxation breathing, take a break to lie down, go for a short walk
- Develop emotional awareness and expression

(...letter continues...)

Support Healthy Development

As part of growing up, children become more independent. They test parents' boundaries, depend more on friends and peer groups, and change the ways they connect emotionally with parents. They also learn more about themselves, and how they belong in the world. And they discover their strengths and weaknesses at home, school and in the community. During all of this, they learn how to manage emotional ups and down. Somatization can interfere with all of these milestones.

For somatization symptoms, it is important to shift from an injury treatment model to a rehab treatment model. Now that we know the symptoms are strong but not dangerous, it is important to plan out normal activities (academic engagement, social interactions, family life, extra-curricular activities) regardless of the symptoms. Instead of responding on a daily basis to the symptoms (going home if the pain is bad), you can make a plan that is balanced, paced, and achievable, regardless of the severity of the symptom. This is similar to other injuries, like a broken ankle. After the initial period of rest and healing, it is important to start moving and walking again even if it is painful at first. It can be hard to take part fully in normal daily life when they are suffering from strong physical symptoms but having some plans for a somewhat more 'normal' day is helpful in the long run.

It's important for your child to regain or build aspects of 'healthy development' that somatization has interfered with. For example, you can help your child find ways to:

- Attend school even when they are experiencing physical symptom(s)
- Participate in family activities, e.g., family meals
- Spend time with friends even when they have physical symptoms.

Actions

- ✓ 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.

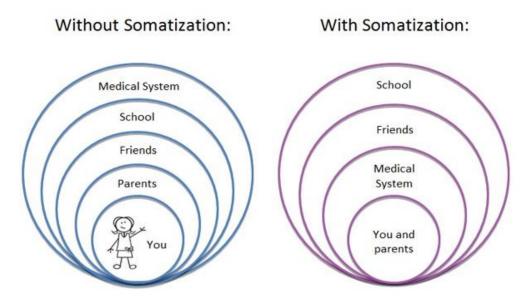
✓ Consider involving psychologists or counselors to support your family during the recovery process.

Outcomes

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.

Parent-Child Activity: 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.



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.

Parent-Child Activity: 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:

Testing Boundaries Explore and Experiment Be Creative Become Independent Push Away From Caregivers (And Seek Out Caregivers) Break Rules Take Risks Connecting Socially with Peers Hang out in Groups Care What Others Think Desire to be Liked Have Conflicts Have a Crush Go Out with Individuals Fall in Love

Searching for Identities Find Out What You Are Good At Find Out What Makes You Happy Develop Self-Esteem Care About Appearance Care About Health and Well-Being Make Choices About the Present Set Goals for Future Experiencing Emotions Be Affected By Stress Complain About Stress Be Confused Experience Both Highs and Lows Swing Between Highs and Lows Find Ways to Cope Learn to Manage Stress/Emotions

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.

Promoting Emotional Awareness

Often, we feel emotions in our bodies before we even recognize them in our thoughts. These sensations have an important purpose. They tell us what we need and what we want and get us ready to quickly take action. They also warn us of danger and help us to survive. Sometimes, it is easy to know what emotions are behind our physical experiences, for example, we have tears because we're sad, or a racing heart when we're afraid.

At other times it is hard to know what emotions are related to certain physical sensations. You might feel butterflies in your stomach and wonder if you're nervous, excited or afraid. Not everyone has the same types of emotions related to their physical symptoms, and sometimes emotions make the symptoms of a medical condition easier or harder to manage. When trying to understand the mind body-connection and how emotions are related to physical symptoms, it helps to explore what these emotions might be.

Emotional awareness includes:

- Paying attention to the sensation and feeling.
- Expressing what you feel in words.
- Accepting the feeling that is happening taking action if needed.

This is not easy as it sounds. In children, youth and sometimes adults, emotional awareness is a skill that needs practice. Parents can help by:

- Providing emotional cues that seem to relate to physical symptoms or what is happening in your child's body, e.g. 'It looks like you are feeling sad today and your stomach is hurting...'
- Giving your child a comforting response that shows them you understand their emotions.
- Reflective listening and providing validation help children understand their own emotions better, and also helps them learn to manage them over time.

Over time, you can help them become more aware of their emotions and recognize how their mind and body work together.

Actions

- ✓ 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.

Outcomes

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.

Parent Handout: Ways of Responding

Always helpful:

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	\checkmark
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:

	\checkmark	×
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?" "Ifwere 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)

Parent Handout: Emotional Awareness and 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.
- But 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.



Parent Handout Continued...

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.



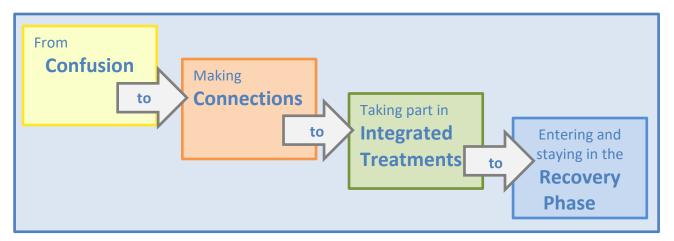
Phase IV – RECOVERY, RESILIENCE & RELAPSE PREVENTION

In the Recovery Stage there is a shift away from a focus on physical symptoms toward 'functional recovery'. For example, a child may still have headaches, but start to do things like go to school, spend time with friends, and eat meals with the family.

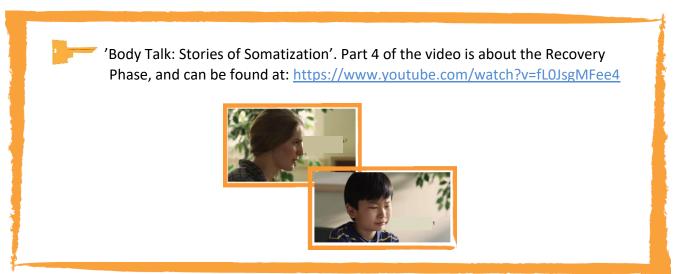
The physical symptoms are likely to flare-up even if things have been going well. When this happens, it's normal for a parent to be worried. But please remember that you are not back where you started. A flare-up gives you and your child a chance to practice the skills you have learned. At this stage it is helpful to:

- Review the mind-body connection
- Explore feelings and stressors
- Use coping skills
- Have an appointment with a health care team member

Many families say that they have found meaning as they go through the stages of somatization:

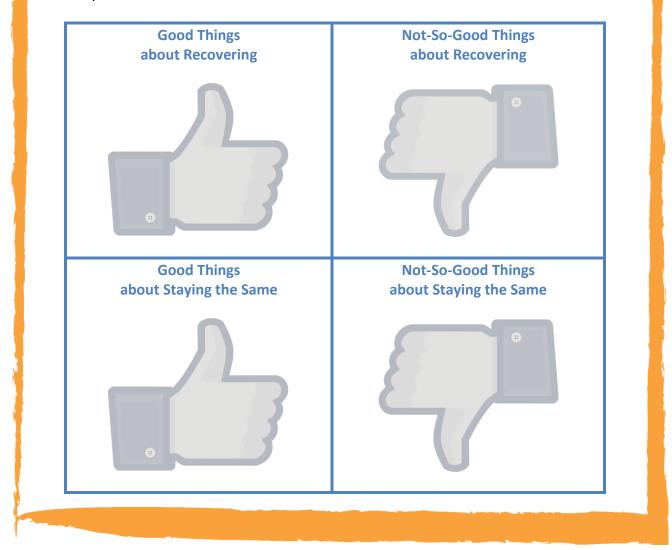


Also, many children and families tell us the journey was hard, but they have grown as individuals and as a family along the way.



Parent and Child Activity: Pro's and Con's of Recovery

When a child experiences somatic symptoms, they are not the only one that is affected. Experiencing symptoms has an impact on a child and 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.



CHAPTER 3 – RESOURCES RESOURCE LIBRARY

Kelty Mental Health Website

We have developed some on-line resources to help your family. Many youth and families, volunteers and staff at BCCH have helped to develop these resources.

Please go to <u>www.keltymentalhealth.somatization.ca</u> 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

FREQUENTLY ASKED QUESTIONS (FAQ's)

What is somatization?

All emotions affect the body, for example, the lightness of joy, the flush of shame, or the tears of sadness. "Soma" is the Greek word for body. "Somatization" is the word we use to describe the physical (or body) expression of stress and some emotions – it's the medical term for the mind-body connection. Everyone somatizes. For some people, somatization gets in the way of everyday life and requires treatment. Many doctors' visits are due to somatization.

How does somatization happen?

There are a few ways that somatization can start. It can happen on its own, or as part of a medical condition. Emotions and stress may cause the physical symptoms, or emotions and stress may make the symptoms of a medical condition stronger or more intense. Having an illness or injury can be stressful and increases vulnerability to somatization. This connection between emotions and physical symptoms is called the mind-body connection.

What is the mind-body connection?

The mind and body are connected through back-and-forth pathways that involve nerves, neurotransmitters and hormones. The fight-fight-or-freeze response is a great example of the mindbody connection. When we sense that we are in danger, a very powerful physical response is triggered. This can happen when we feel scared and there is a major perceived danger present (see the Kelty Mental Health Somatization Brochure for more information on the mind body connection).

Are somatic symptoms real?

Yes. 'Soma' means body. Somatic symptoms are experienced in the body as physical sensations, movements or experiences. Some examples include pain, nausea, dizziness, and fainting. Just like tears of sadness are real and a racing heart from excitement is real, so are somatic symptoms. It can be easier to recognize common symptoms that relate to stress, like stomachaches or headaches. More unusual symptoms, like blindness, seizures, or numbness, can be harder to recognize as stress-related.

How is the diagnosis of somatization made?

The diagnosis is based on the medical assessment. Your child's medical doctor will take a history about the symptom(s) and do a physical exam. Then the doctor will order investigations and tests, and make the diagnosis based on an extensive knowledge about medical conditions. The diagnosis is never made just on the basis of mental health. Instead, the doctor works together with kids, families, and multidisciplinary health professionals to understand the role of emotions and stress in symptoms.

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

Your child may have seen different specialists who have different ways of explaining the symptoms. They may have used words such as 'functional', 'psychogenic', 'psychosomatic', 'medically unexplained', 'amplified' and/or 'non-organic'. These terms can be confusing for everyone. Part of our work is to help different medical specialists work together and we feel it helps when everyone uses the term 'somatization'. The goal of using the same language is so everyone will understand that different somatic symptoms are all connected.

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 speak about an 'element of somatization' affecting symptoms.

How are somatic symptoms different from non-somatic symptoms?

Epileptic and non-epileptic seizures may be good examples. The movements and behaviours that occur during epileptic and non-epileptic seizures can be similar, but the cause of the movements is different. Epileptic seizures are caused by changes in electrical communication between brain neurons. Non-epileptic seizures are caused by emotions or stress, but do not involve changes in the electrical communication in the brain. Both kinds of seizures are involuntary; they are not produced on purpose. Many people with non- epileptic seizures also have epileptic seizures or have had them in the past. It is also possible to have non- epileptic seizures and to not have epilepsy. We now know that non-epileptic seizures are common.

What should I do if disagree with the diagnosis?

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, 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 a family's concerns and uncertainty about the diagnosis of somatization. If a family is still uncertain about the diagnosis after medical doctors have done a full investigation, we will work with those families to start 'walking two paths' – the medical and somatization paths.

What does 'walking two paths' refer to?

We encourage families and their health care team to use a 'walking two paths' approach; meaning that medical assessments and investigations can occur at the same time as starting treatments for somatization. Somatization treatments are conservative, and do not interfere with other medical treatments. This allows families and teams to start working closely together with a unified goal to reduce the child's suffering. Families can pursue treatment in two directions at the same time:

1. Continue to engage in medical assessments, investigations and treatment as appropriate **AND** -

2. At the same time, help manage the symptoms and increase the child's coping by using rehabilitative and psychological strategies.

Why is my child not having more medical diagnostic tests?

Families often ask this question. After the first medical tests, the focus is to help children cope and to lessen the stress related to their physical symptoms. If they have to wait for more tests before starting treatment, this may delay the child learning coping strategies and emotional skills. If delayed, it may take them longer to get back to their day to day activities. Getting started with mind-body treatments requires trust and a lot of communication between the family and the providers. Throughout the treatment process, it is easier to understand changes in symptoms or new symptoms if doctors remain connected with the family and other health care providers. Being involved in mind-body treatments while staying connected with the doctor(s) is what it means to 'walk two paths' towards recovery.

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

No. In fact, it is very common for symptoms to continue. It takes time for children to understand and learn the skills to manage stress and difficult emotions, especially if they are sensitive and didn't recognize their emotions or keep their stress to themselves. The symptoms will often continue until a child finds a way to understand and their express emotions and develop the coping skills they need to manage their physical symptoms and stress. Sometimes, the symptoms remain even after the child has worked on reducing or removing stress. In these cases, we understand there is still more work to do to help the child cope. It does not mean the diagnosis is wrong.

If the symptoms change over time, does this mean that the somatization diagnosis is wrong?

It is very common for new symptoms to appear with somatization. The body has many ways to physically express stress and emotions. Children who have somatization can often have a number of different kinds of somatic symptoms over time. It does not mean the diagnosis is wrong.

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

No. When people hear the term 'all in their head,' they can wonder if others think they are 'faking' or 'making up' their symptoms, or that their symptoms are a sign of mental weakness. None of these are the case with somatization. It is important to know that the mind and the body are closely connected – we call this the mind-body connection. The mind-body connection is responsible for somatization symptoms (see "What is the mind-body connection?" above).

Are children with somatization 'faking' their symptoms?

No, the child is not doing it on purpose. Somatic symptoms are 'unconscious' and involuntary. They suggest a child is distressed. Just like 'butterflies' in your stomach aren't fake, these symptoms are not made up. Over time, the experience of symptoms may lead a child to escape 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, so the child stays at home. If symptoms continue or the stressful situations and emotions are not managed, a child may learn, consciously or unconsciously, that having the symptom helps them to avoid a stressful or negative situation. We encourage parents, teachers and care providers to always work from the belief that children's somatic symptoms are not intentional, even when it appears that they use the symptoms to avoid something.

Do children have voluntary control over their symptoms?

No. Children do not have control over when, where and how their somatic symptoms happen. But there are strategies that they can learn to get some control. To start, we help children learn to pay attention to their symptom(s). There may be 'early warning' signs that allow them to weaken a symptom, or to be safer when experiencing it. When children understand that a symptom is somatic and not a sign of danger, it may reduce worry or stress about the cause of the symptom. And a decrease in stress may affect how intensely or often they experience symptoms. If children can learn more about their distress and find new ways to express it, it will help them feel a sense of internal control in their lives, and over the symptoms. It's also important to encourage your child to attend school, spend time with friends, and take part in spare time activities. This will help your child take back some control in a life that has been disrupted by the symptoms.

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

There isn't usually a single reason for somatization. A number of factors can contribute to children developing somatic symptoms, including their biology, the way they approach and react to their world, encountering difficult or stressful situations, or difficulties expressing or describing their emotions. Children may also have a physical vulnerability that may relate to the way that they experience stress physically. For example, a child who is prone to headaches might get a headache during a stressful situation, or a child with epilepsy might have a non-epileptic seizure in response to stress.

What kinds of stressors are common causes of somatic symptoms?

Any kind of stress or psychological distress, such as anxiety and worry, sadness and grief, anger and frustration, can cause somatic symptoms. All children have stress in their lives. Each child experiences 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. Examples of 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 a pet, puberty, changes with friend groups, or illness or death in the family.

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

No. Trauma and abuse are one source of stress and can cause somatic symptoms in some children, but most children that we treat have not been abused or severely traumatized. Instead, we most often see children where a more common stressor seems to be the trigger for somatization, for example: poor marks on exams, a minor sport injury, the illness of a friend or family member, a change in peer relations, changes in a family situation. It's often "the straw that broke the camel's back": a single situation that triggers the physical somatic symptoms is the culmination of a longer buildup of stresses that have not been fully recognized or dealt with. We also see children in situations where they do not have the ability to meet the increasing demands of their life situation, for example, students who got good grades in elementary school but are now struggling in high school. Similarly, it may be the story of a youth who starts out doing well at a spare time activity like hockey or chess but struggles when it gets harder or becomes more complex. Examples include: *"I thought I was going to be a professional hockey player, but I'm not the best on the team anymore;"* or *"I used to be a great student, but I am not an honour roll student now."*

How can my child have somatization when they don't appear to be stressed?

Everyone has stress, and everyone somatizes. Somatization needs treatment when the physical symptoms are getting in the way of life. Children with strong or frequent symptoms are often (but not always) described as children who are sensitive. They usually expect a lot of themselves and tend to keep their emotions to themselves. It can be very hard for a child to be aware of stress if they 'internalize' the stress, and do not express it through their talk or behavior. Parents may not be aware of the internal stress that their child is experiencing or the reasons for it. Children often don't have the same coping, reasoning, or problem-solving skills as adults, so stressors that seem minor to adults can be overwhelming for children.

What is the usual path of recovery?

The path of recovery is different for each child. Usually, the sooner the somatic symptoms are treated with appropriate treatments, the faster the recovery. We often see 'functional' recovery before we see a real decrease in the somatic symptoms. This means that the child is going to school, spending time with friends, taking part in some spare time activities but still has some physical symptoms – in other words, their functioning has improved although they still have somatic symptoms. We have seen a full recovery happen within days of diagnosis and treatment, but it usually takes much longer for a child to learn to deal differently with emotions and stress and then for physical symptoms to decrease.

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

The type of symptom and severity are different in every child. It's important for families to work with their care providers to plan how to manage symptoms. These plans will usually say:

- Stay calm. Remember this is a somatic experience and the physical symptoms are not dangerous. Families that show fear or anxiety when symptoms occur will likely worsen the child's worry. If you keep calm, the symptom will often become less severe and intense overtime. It's still important to validate the symptom and the stressful experience. For example, say "I can see that your arm is shaking, and your body is having a stress response." These kinds of comments help the child make the connection between emotional events and their physical symptoms.
- **Give support as needed and help your child use their symptom management plan**. For example, after recognizing the physical symptom, encourage coping by setting up a distracting activity for your child to do until the symptom passes.
- **Don't 'over support'.** Sometimes a well-meaning family may give too much attention to a symptom. This may increase both parent and child stress levels and can lead to an increase in symptoms. It can often be enough to assure the child that you recognize they are stressed, and you will remain close by and ready to help if needed. Then, remind them of a coping strategy, for example, "I can see you are shaking and that 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."

Can medications be helpful?

Sometimes. It depends on whether or not the child also has an existing medical condition or mental health issue, for example, anxiety or depression.

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

Somatic episodes are not a medical emergency, and so it is not necessary to send the child home from school. We usually try to lessen the amount of time children miss classroom time. It is important to develop a plan with your child's school care providers that helps the child to cope and be safe during and after a non-epileptic seizure and allows for the child to stay at school.

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

Many children with somatization are uncomfortable talking about stress. Ask your medical care team to help you find someone with training in working with somatization. For some children, it can be helpful to focus on 'practical' supports that decrease stress and promote physical symptom management. As a therapeutic relationship is developed, work can start to help the child start talking about stress and emotions.

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

This can happen when children first begin to talk about stress and emotions because it's new and stressful. Parents and children need to know that this often happens at the start of therapy. The child will become less afraid to talk about stress and emotions as time passes. As they build their resilience and coping, the symptoms will usually improve.

How can we tell if a new physical symptom is affected by somatization?

We recommend that families see their health care provider for a reassessment unless they are sure the new symptom is due to somatization.

If my child stops having symptoms, will they return?

It is not unusual for children's symptoms to return, or for new somatic symptoms to appear in times of stress. The first time symptoms return is an extremely important time in treatment. It is a real test of the coping skills that the child and family have learned for dealing with stress. It is a chance to show they can identify stresses in their life and practice successful coping skills.

INTEGRATED TREATMENTS FAMILY WORKSHEET

Patient & Family Workbook Planning Integrated Treatment for Somatization

Child's Name	D.O.B
Parent/Guardian/Caregiver	Contact Information

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:

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.

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., ice-packs, 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.

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 could 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

Plan/Notes:_____

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.

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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