

BC CHILDREN'S HOSPITAL

THE MIND BODY CONNECTION AND SOMATIZATION: A FAMILY HANDBOOK

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INTRODUCTION

At BC Children's Hospital, we have learned a great deal from the children who suffer from somatic symptoms. These symptoms can puzzle, frighten, hurt, and disable the children who experience them. Their parents may feel helpless and confused about what to do. We have worked with these children and families over the years and learned from their experiences. They have shown us what helped them to recover. We wrote this handbook to share our learning. We hope it will reduce the suffering of children and help families to find the best care available.

In this handbook, we share:

1. Our understanding of somatization
2. The words that are used to communicate about somatization
3. Strategies to treat symptoms

Our hope is that this handbook will give families the information, resources, and confidence they need to help their children learn better coping skills and move towards recovery.



We have given a summary of resources at the end of the handbook and specific resources are marked with the 'key' throughout the manual.

(Note that in this handbook we use the term 'child' for both children and youth).

PART I: UNDERSTANDING SOMATIZATION

SOMATIZATION AND THE MIND BODY CONNECTION EXPLAINED

WHAT IS SOMATIZATION?

Soma means body in Greek. A **somatic symptom** is a physical symptom you have as a result of stress and emotions. It may occur on its own or with a physical illness or injury.

WHAT CAUSES SOMATIZATION?

Somatization happens because of the mind-body connection – the back and forth communication between your mind and your body. All emotions are expressed in our bodies. For example, when nervous you may feel butterflies in your stomach, when happy you may feel light with joy, or when sad you may have tears. There are a few ways that somatization can start. 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 make your child more vulnerable to somatization.

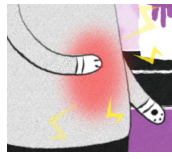
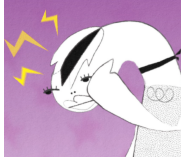
ARE SOMATIC SYMPTOMS REAL?

We all somatize. For example, you may get a headache because of stress or a stomach ache before a test. These somatic symptoms are *normal* and *real*. But, for some people somatization gets in the way of everyday life and needs to be treated. Some somatic symptoms are very powerful, for example, sudden blindness, fainting, extreme fatigue, unusual body movements.

The Mind-Body Connection and Somatization Explained

- Our bodies feel all emotions and stress in a physical way, for example, the lightness of joy, butterflies in your stomach, or the tears of sadness.
- A physical illness or injury can also affect how we think and feel. For example, having a cold can be stressful and can affect our mood.
- Somatization happens because of the mind-body connection.
- “Soma” means body; “somatization” is the word we use for the physical (or body) expression of stress and emotions.
- Everyone somatizes, but for some people it gets in the way of everyday life and needs to be treated
- Somatic symptoms are real and can be very powerful.
- Somatization can occur on its own, or with another medical condition.

DID YOU KNOW... ALL EMOTIONS ARE EXPRESSED IN THE BODY.



SOMAtization:

The word we use to describe the body's expression of stress and emotions

There are many terms used for somatization, for example, Somatic Symptom Disorder or Conversion Disorder (see the boxes below). These terms are used when somatic symptoms interfere with day to day life. The difference between them is in the type of symptom. Body symptoms like pain, dizziness, fatigue, cough, and nausea are part of Somatic Symptom Disorder. Neurological symptoms like fainting, seizures, movements, problems walking, numbness, blindness are part of Conversion Disorder.

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).

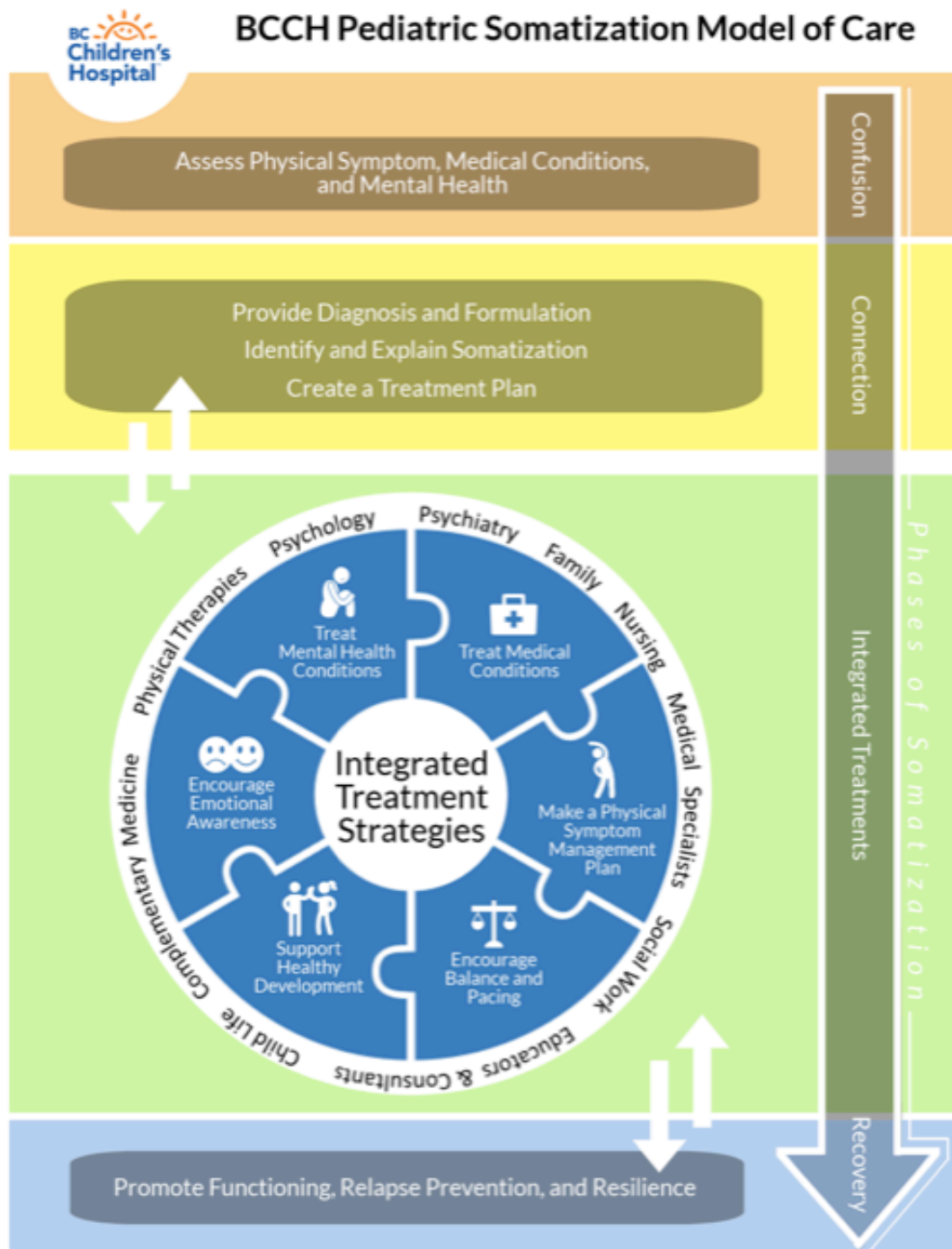
CONVERSION DISORDER

(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.

BCCH PEDIATRIC SOMATIZATION MODEL

The diagram below shows the care plan we have developed at BC Children's Hospital to help children with somatization. The stages 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 a personal treatment plan for your child. The six key areas of treatment to think about are shown in the circle. The plan depends on your family's needs and readiness for these elements of treatment.



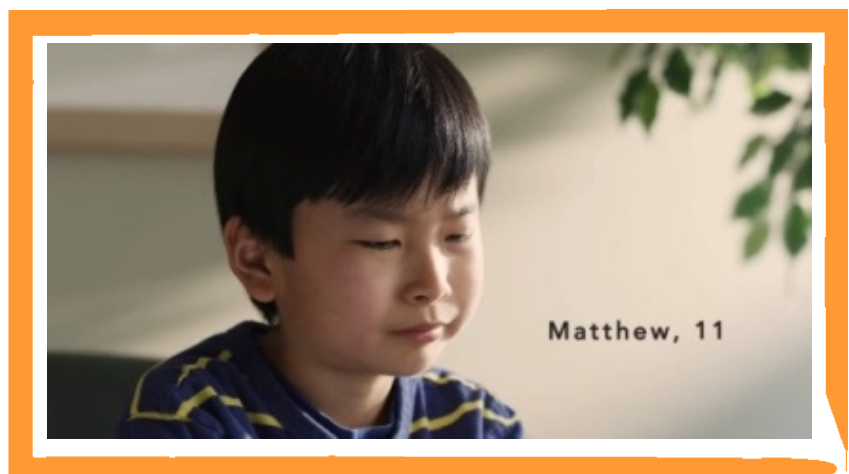
STAGES

The Confusion Stage is when the physical symptoms have started and no one is sure what is going on. You don't know what is causing the symptoms or how to make them stop. This stage can last a long time because of the way the health care system works. There may be long waitlists, medical tests to rule out other illnesses, mixed messages from different health care providers, etc. The confusion stage may also last a long time because it can be hard to accept what is going on. You might be worried that a medical illness is being missed or have a hard time believing that your child's physical symptoms are related to stress and emotions. If this is how you feel, remember you are not alone. Many parents feel this way.



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 Stage and can be found here:

www.youtube.com/watch?v=KO7cFyjHK6A



CONFUSING SYMPTOMS



Searching for answers about what is causing physical symptoms and how to make them go away can sometimes be a confusing and frustrating experience. The stress of it can take a toll on the body and sometimes, make the symptoms worse.

The Connections Stage is very important. Your child will take part in different types of assessments to help understand what has led to your child's symptoms. Your child's team will work with your family to build an understanding of the Mind Body Connection and somatization. Providers will build a strong connection with you so that you know child's symptoms are "real", and not in their "head" and your concerns are validated. You will be encouraged to ask questions and have on-going discussions with your health care team until you understand how the mind body connection relates to your child's experience.

🔑 'Body Talk: Stories of Somatization' video, part #2 can be found here: <https://youtu.be/evGD-OZmQFQ>


THE MIND BODY CONNECTION: THE MIND BODY MESSAGE SYSTEM

The mind and body are amazing, always "talking" to each other and cooperating. The central nervous system (including the brain) connects to organs, blood vessels and muscles (the body) through very complicated back-and-forth signals using many different types of hormones and chemicals. Most of the time, when things are running smoothly, the system of signals between the mind and body is automatic and functions in balance. Some examples:

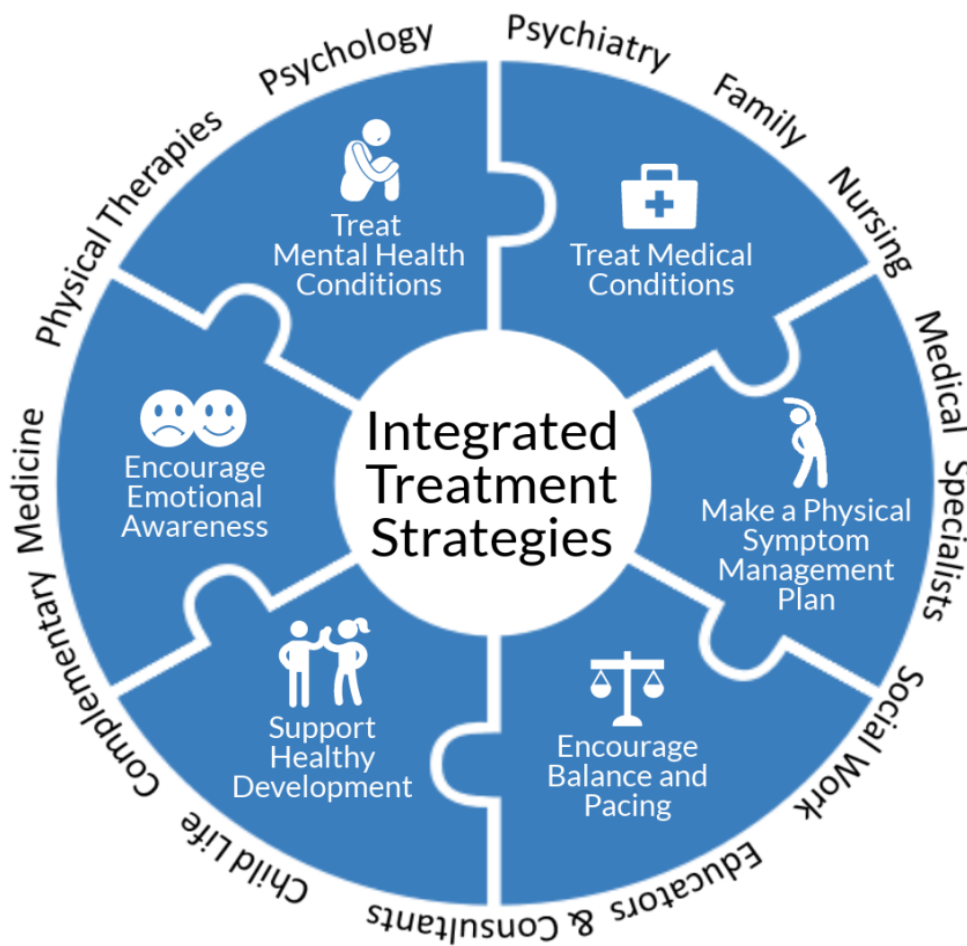


The **Integrated Treatment Stage** is about the plan for treating your child's symptoms.

Your health care team will work with you to build a personal plan for your child. It will include up to six elements. At any particular time, one or more elements may be part of the treatment plan. They do not need to go in a specific order. The elements you include in the treatment plan and the focus at any specific time can change depending on your child's needs. The communication between you and your health care team is very important during this stage.

 'Body Talk: Stories of Somatization' video part #3 can be found here: <https://youtu.be/6Sk6yBtNSr4>

We are learning that relying on only one type of treatment rarely allows for full recovery from any condition. Successful recovery usually requires a combination of medical, physical, and psychological strategies.

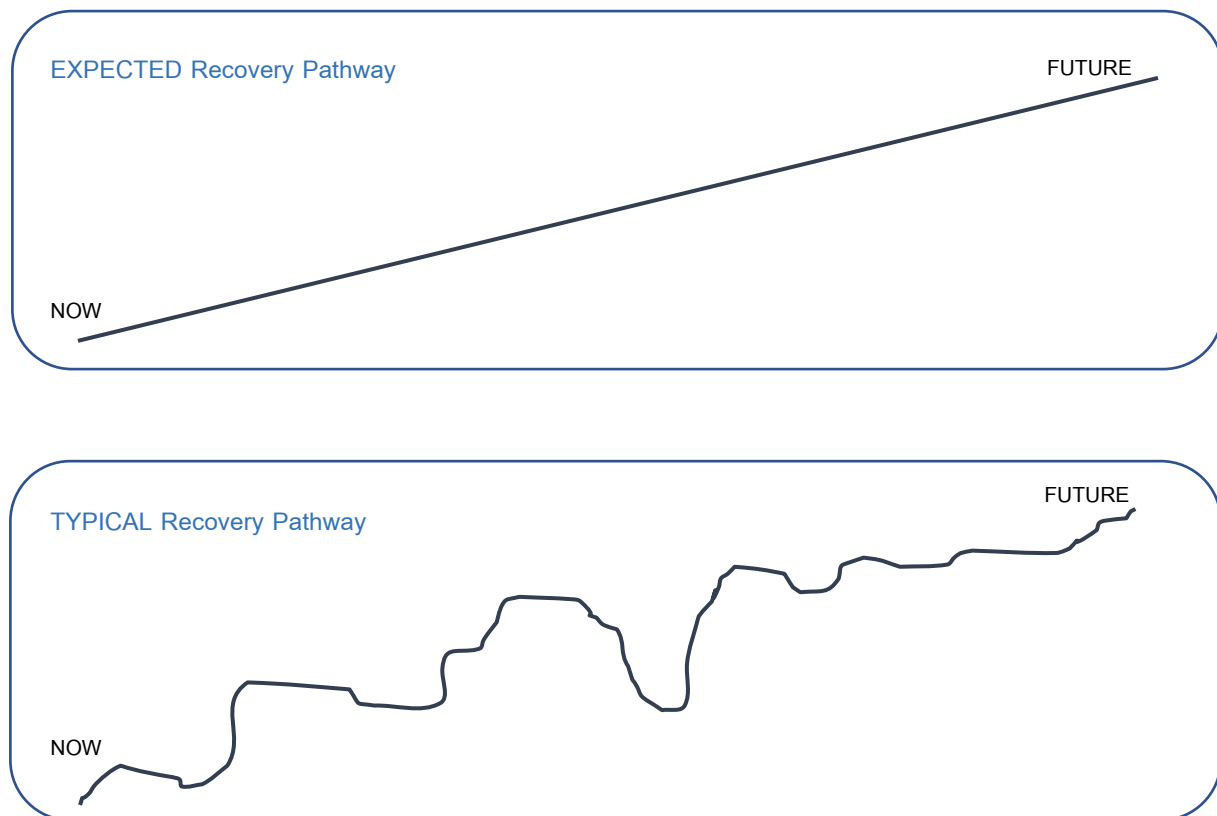


In **The Recovery Stage** your child will return to your usual life and everyday activities. They will have learned skills and activities to help cope with emotion, stress and physical symptoms in everyday life and if symptoms return. The typical recovery for somatic symptoms is steady improvement with some flare-ups or new symptoms. It is not unusual for somatic symptoms to come back. In the recovery phase these symptoms are usually less intense and shorter-lived. This does not mean that your treatment journey has been unsuccessful. It is a time to review what helped during the Integrated Treatment Phase. Our patients often tell us that the journey has been a challenge, but it has also led to personal development.



'Body Talk: Stories of Somatization' part #4 can be found here: <https://youtu.be/fL0JsgMFee4>

The Pathway to Recovery:



PHYSICAL SYMPTOMS

Somatic symptoms are the way people often express everyday emotions, for example, crying when sad or blushing when embarrassed. Some symptoms are more unusual and distressing such as problems with walking, blindness and seizures (non-epileptic). In the middle of this range are common 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 and 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 stress/emotion adds to physical symptoms:

- 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 stress induced seizures.
- Expressing emotions and stress by familiar pathways can also happen with migraines, broken bones that have healed, and lots of other medical conditions.
- 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.

When stress/emotion causes physical symptoms:

- Everyone has stress! But what causes stress is different for each person and is often private to that person.
- 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 gets a headache.
- 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 symptoms.

EXAMPLES:

SOMATIC SYMPTOM DISORDER WITHOUT A MEDICAL CONDITION:

Brenda has always been kind and caring. She has many friends at elementary school and is close with her family. Her mother is currently on sick leave from work. Brenda enjoys being in the school band, but she struggles with math and reading comprehension. During the school year, she felt a lot of pain in her right arm from her elbow to her fingers. Because of her pain, Brenda was not able to take part in academic or school band activities. The results of the medical assessment did not show any causes for her pain.

SOMATIC SYMPTOM DISORDER WITH A MEDICAL CONDITION (A 'COMPONENT OF SOMATIZATION'):

Raj is an athletic teenager. He plays competitive soccer and hopes to be on a university team in the future. During the soccer season, Raj suffered a concussion. As a result, he had headaches, problems concentrating, tiredness and sensitivity to light. He missed a month of school and playing soccer with his team. The symptoms went away, but during spring break, his headaches returned. Raj was not able to 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. She has a small and close group of friends. She recently started middle school and was put in an enriched class for students with strong academic skills. In October, Sarah began having fainting episodes; she would slump over in her desk or fall to the ground. These episodes happened up to twenty times a day. No medical cause was found. Sarah kept going to school, but spent much of the day in the nurse's office. Two of her friends often left class to be with her.

ASSESSMENTS AND INVESTIGATIONS

As was mentioned above, somatization may happen on its own or along with a medical condition like an injury or illness.

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 check for possible medical conditions by doing blood tests, scans, etc., and, at the same time, do assessments and treatments for possible somatization. The “walking two paths” approach ensures a medical condition is not missed and also makes sure that treatment for somatization starts as soon as possible if it is part of the problem.

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

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
- complete a physical exam
- order and interpret medical investigations and tests
- include a mental health professional to complete a social emotional assessment
- discuss the all the results with the mental health professional(s)
- make a diagnosis

The diagnosis is based on an extensive knowledge about medical conditions. It is not made just because a child has stress, certain ways of behaving, past traumas, abuse, or other mental health issues.

At BCCH, our care providers often use the term a “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 vary. Usually one or, better yet, both parents attend, along with the care providers who are involved in the diagnosis and treatment. We encourage children to attend the meeting, but we like to give parents the chance to meet with the team before bringing in the child. That way parents can ask questions that they might feel uncomfortable asking in front of their child. Often people take part by telephone to make it easier for everyone to attend.

TALKING TO OTHERS ABOUT THE DIAGNOSIS

***Example:** You rush to the Emergency Department because your child has 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.*

This example occurs at hospitals on a regular basis. Sometimes friends and other family members will tell parents they should be questioning or asking to get more tests or not leaving the hospital until they have a better explanation, etc. The family might feel pressure to follow these suggestions. Even though the somatization explanation 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 about ‘What do we tell other people?’

First, we remind children and families how complex somatization is, and how difficult it can be to explain to others. For the child, we often help them learn to use their own words to explain their condition and treatment. We ask children if they are comfortable sharing more information with the people they are closer to and less information with people that they don’t know as well. We ask them to think of questions they might ask someone who has had the same kind of symptoms and let them think of answers to give if they are asked similar questions. We follow the same process with parents. This gives them a chance to ask more questions and clarify their understanding of the diagnosis and the treatment plan. We remind families that having a clear, simple explanation to give when others ask questions will help to stop the spread of wrong information or unhelpful rumors.

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 (bad) medical condition or injury. I am doing some physiotherapy to help with walking and I’m 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 and talking. 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. So these symptoms are not caused by a brain tumour or encephalitis. Instead, it seems like he is experiencing stress and sadness; and, since it's hard 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.

Families often tell us that members of their support group or extended family do not 'believe' the diagnosis and this adds more stress to child and family who are working on treatment elements. We suggest that you ask these individuals to consider meeting with the provider or team to allow them to hear how the diagnosis was made and to respond to any questions they may have.

UNDERSTANDING DIAGNOSIS AND READINESS FOR TREATMENT

Families might want to take the time to do a self-check to see where they are in terms of understanding and accepting the diagnosis. You may still have questions and concerns that your providers can help answer AND also be ready for treatment planning.



Families might want to take the time to do a self-check to see where they are in terms of understanding and accepting the diagnosis. 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 flow of open communication between families and providers.

Understanding the Diagnosis

DO NOT UNDERSTAND UNDERSTAND

Acceptance of Diagnosis

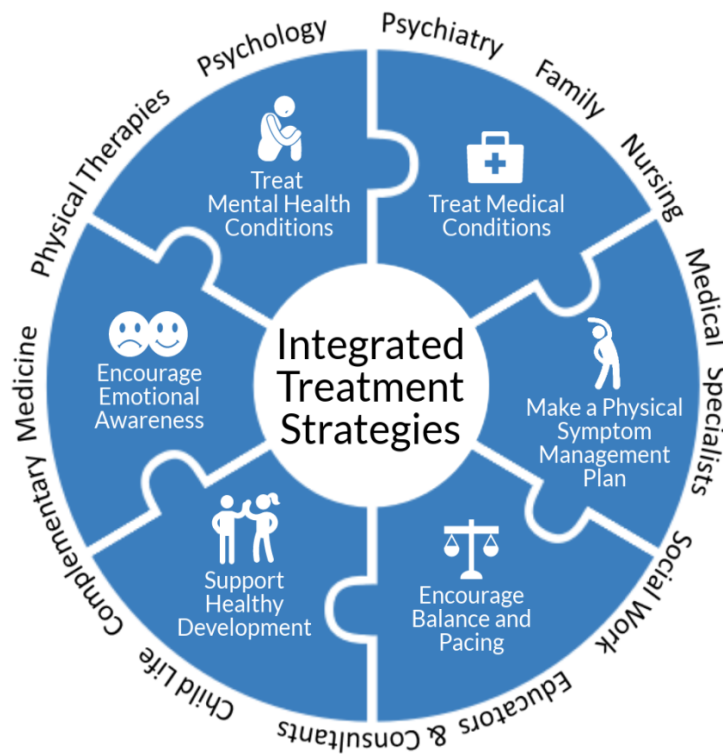
DISAGREE AGREE

Readiness for Treatment

NOT READY READY

MAKING A TREATMENT PLAN WITH YOUR TEAM

Once a diagnosis has been made or we understand there is an element of somatization, it's time to make a treatment plan. We make a personal treatment plan for each child and use Integrated Treatment Strategies section of the BCCH Pediatric Somatization Model of Care as a guide.



Some children and families feel ready to start the treatment process after the diagnosis has been given and others feel more hesitant because they are still struggling with the somatization diagnosis. In either case, we like the concept of ‘walking two paths’ that we talked about earlier. ‘Walking two paths’ means your child will continue to have medical assessments, investigations and treatment if these are needed, *and*, at the same time, start treatments that are useful for possible somatization. It is important for *everyone* to learn about the mind-body connection and how to manage stress. It is important that all team members communicate and work together.

Your child's treatment plan is made especially for your child. It is highly individualized and it will change over time as needed. Different care providers are often involved in different elements of care.

EXAMPLE:

- a school counselor may help manage school work
- a physiotherapist can help with movement and returning to activity
- a counsellor or psychologist could help to understand stress and the mind body connection

We focus on recovery so that children can return to or build a meaningful and rewarding life, even if they continue to have symptoms. We find that when children get back in their 'normal' routine, (even if they continue to require some supports), it helps their overall recovery. When children are away from their friends and activities and they worry about getting behind in schoolwork, their symptoms often become worse.



At the end of the handbook there is an 'Integrated Treatment Family Worksheet' you might find helpful.

In the next Part of the handbook, we will walk through each Integrated Treatment Strategy with a description of what that strategy is all about. We also include a list of actions and goals for each strategy.

PART II: TREATING SOMATIZATION

TREATING THE MEDICAL CONDITION(S)

DESCRIPTION

As we have mentioned, we take a “walking two integrated paths” approach. This means that we encourage medical assessments and treatments for any known medical condition(s) at the same time as ensuring appropriate treatments for a somatization element. If your child has a medical condition connected to the physical symptom(s), it’s clearly important to treat the medical condition (e.g., a concussion, inflammatory bowel disease, asthma, etc.). And it’s also important not to use medications or treatments that won’t be helpful or may even cause harm. Even if we cannot find a medical condition, we still like the child to have regular appointments with a physician. This ongoing care may range from checking in a couple of times a year and doing a re-assessment when new symptoms emerge, to weekly check-ins. 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.

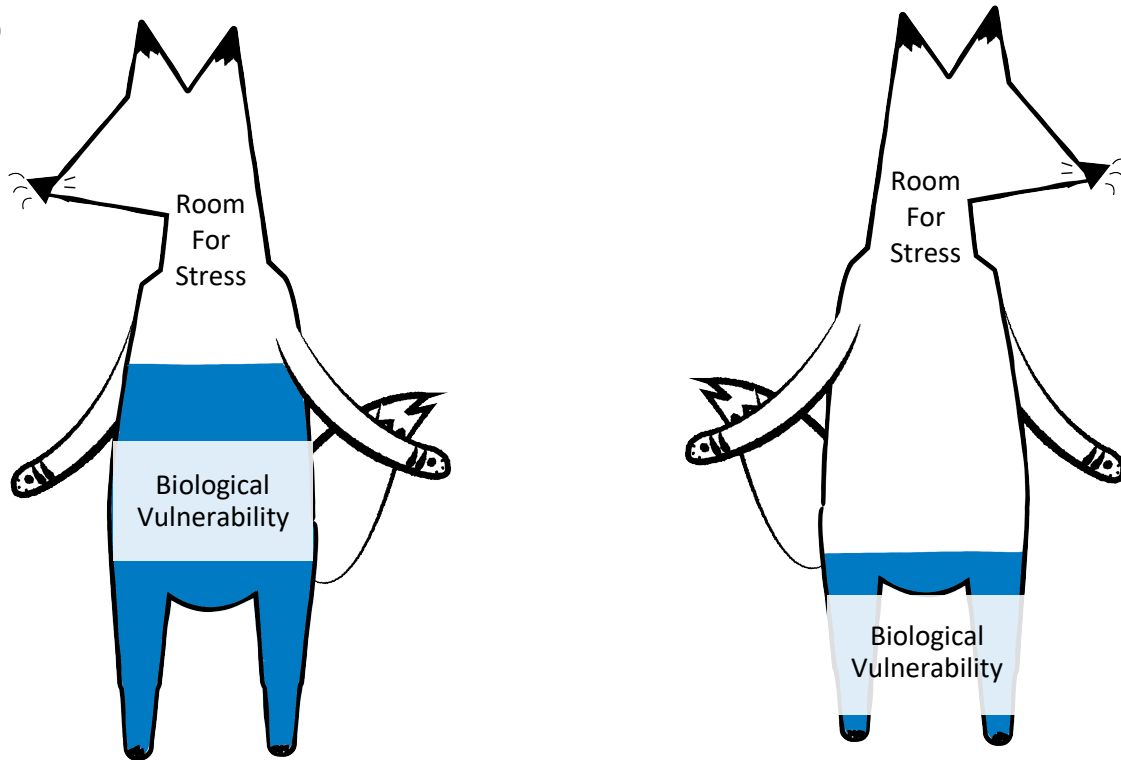
GOALS

To treat any medical condition that is identified.

THE STRESS VULNERABILITY MODEL

Physical symptoms often arise due to the combination of two things:

1. **Biological vulnerability** (like genes, illness, and injury)
2. **Stress** (everyday pressures such as work, school, and performances as well as how we think or feel about them)



- Biological vulnerability and stress interact! People with a history of medical illnesses or injuries have more vulnerability.
- The figure on the left shows someone with a high level of biological vulnerability, and it takes up quite a lot of space inside. This means there is not a lot of room for stress. If there is too much stress, the stress may overflow. For some people, an overflow can be expressed by physical symptoms. For others, depression, anxiety, or angry meltdowns might represent the overflow.
- People might be tempted to compare themselves to others who appear to be coping well with stress. This might not always be a fair comparison, because everyone has different levels of vulnerability. Those with more vulnerability can be helped by learning ways to manage their stress before it overflows.

MAKING A PHYSICAL SYMPTOM MANAGEMENT PLAN

DESCRIPTION

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 providers to learn ways to watch for symptoms, and “catch” them early.
- Talk with your child’s doctor to see if medication can help with your child’s symptoms (e.g., pain, insomnia, etc.).
- Try home remedies, including 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 different ways of coping work differently for each child.
- 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 a safety plan for what your child can do when symptoms get worse or really interfere with activities. It helps to explain how others should respond to your child at these times. These plans can even be used when your child is out in the community, at school or at spare time activities.
- Seek physical and occupational therapy if your child is having difficulties with walking, coordination, and 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.) Another important reason to access physical or occupational therapy is so that your child will not have long-term problems from being inactive.
- Make sure your child’s treatment team knows about any complementary therapies your child is having so the therapy can be coordinated with other parts of the symptom management plan

GOALS

The goal of physical symptom management plans is to:

- 1) Look for ways to relieve some of your child’s symptoms;
- 2) Increase your child’s participation in activities;
- 3) Encourage your child’s sense of control and mastery.



MINDFULNESS

Mindfulness is one thing that can be added to the treatment 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 “multitasking.”

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.

Breathing/Mindfulness

[Keltymentalhealth.ca/breathr](https://keltymentalhealth.ca/breathr)

<https://www.anxietycanada.com/mindshift-cbt>

ENCOURAGING BALANCE AND PACING

DESCRIPTION

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. Sometimes there are unintended advantages to being absent. For example, missing school can mean getting to avoid stressful schoolwork or tests. Because somatization is usually a response to stress, parents might notice a pattern. Parents and/or teachers may see that 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 "go all in" when trying to get back into things, especially if it's an activity 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 both their thinking and plans/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 are feeling worse. 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 special needs designation, if appropriate.

GOALS

To focus on a gradual recovery to help your child achieve success, mastery, and independence as they take part in their everyday activities.



School Template Letter: Ask your team to use the School Template Letter below to write a letter to your child's school team to help with Symptom Management and Balance and Pacing at school.

SCHOOL TEMPLATE LETTER

Dear School Team,

Sam has been diagnosed with a Somatic Symptom Disorder.

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. See <http://keltymentalhealth.ca/Somatization-Disorders> for more details on pediatric 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. "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 mind body connection. Everyone somatises. 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.

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 make the "somatic" more likely. And sometimes a medical illness can 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 Sam's recovery it is essential that he attend school. Although Sam's somatic symptoms are powerful at times, it is possible and important for symptoms to 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 room to room. 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 in successful participation in school and the recovery process. If possible, it would be very helpful for Sam to work with a school counselor to further develop the following skills:

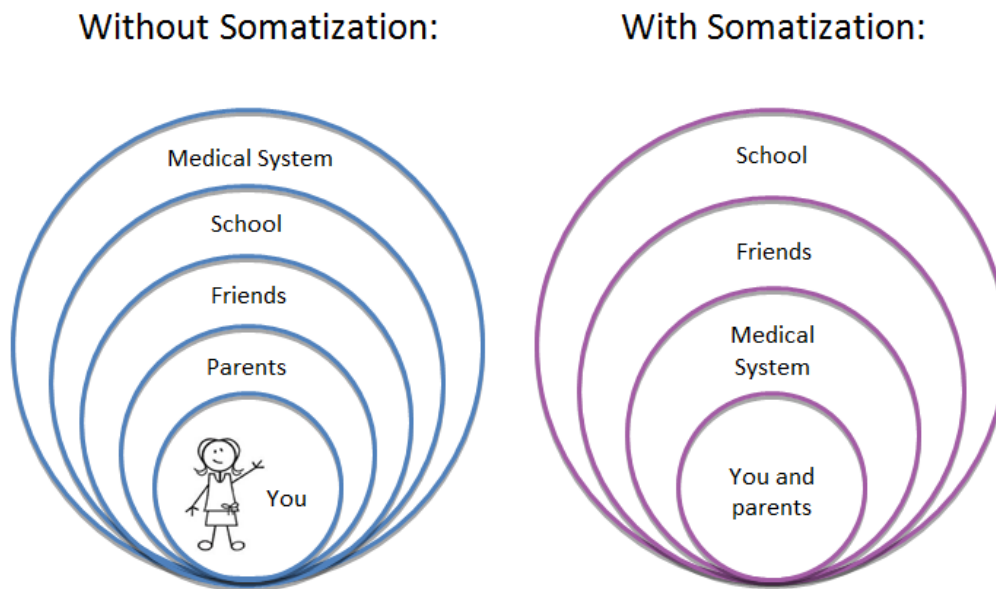
- Being an 'early detector' of stress triggers and physical symptoms
- Proactively pacing activities throughout the day/week.
- Practicing stress and symptom coping skills (e.g., relaxation breathing, taking a break to lie down, going for a short walk)
- Developing emotional awareness and expression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

SUPPORTING HEALTHY DEVELOPMENT

DESCRIPTION

As part of growing up, children are expected to become more independent in many areas. 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 as 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.

Interacting with people is part of life. There are some we see every day, and others once a week or once a year. And, we can feel closer to certain people than others. Usually, the people that are closest to us are the people who have the most influence in our lives as we get older. Somatization can affect how we interact with people over time.



With somatization, people in some context can become more important than others. For example, you might become more reliant on parents or medical professionals for help. This can get in the way of building friendships, going to school, and other things.

This can be stressful for youth, because they're not doing all the things they want to do (or see their friends doing). This can be hard for parents, because they can feel like they need to overextend themselves to help their kids.

We have learned that it's really important for your child to regain or build aspects of “healthy development” that somatization has interfered with. For example, find ways your child can:

- Attend school in spite of the physical symptom(s),
- Spend time with family doing family activities (e.g., participating in family meals),
- Spend time with friends even when they have physical symptoms.

We expect physical symptoms will greatly improve over time with treatment, but we don't want your child to wait for them to be gone before taking steps towards healthy development. It can be hard to expect our child to take part in normal daily life when they are suffering from a strong physical symptom, but having some plans for a more normal day is helpful in the long run.

ACTIONS

- Learn more about the stages all children must go through on their way to adulthood, including 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.
- Watch out for 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. Other areas might include social relationships, hobbies and interests, and academic education.
- Consider how your child's somatization has affected your life (work, family relationships, social activities). Think about how these areas of life might change again when your child's somatization lessens.
- Consider involving psychologists or counselors to support your family during the recovery process.

GOALS

Focus on ways to help your child take part in the everyday activities and tasks that other children their age do. In this way they will develop an identity that is not defined by physical symptoms.

DEVELOPMENTAL PATHWAYS

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.

PROMOTING EMOTIONAL AWARENESS

DESCRIPTION

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 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 take some time 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:

- 1) Noticing emotional cues that seem to relate to physical symptoms or what is happening in your child's body. For example, 'it looks like you are feeling sad today and your stomach is hurting'. AND:
- 2) Giving your child a comforting response that shows them you understand their emotions. Reflective listening and validation of your child's emotions helps them understand their own emotions better, and also helps them learn to manage their emotions over time.

Over time, by supporting your child in these ways, you can help them become more aware of their emotions and recognize how their mind and body work together.

ACTIONS

- Arrange for counselling/psychological support to help your child learn about emotional awareness and expression.
- Model to your child how to recognize and express different emotions by sharing 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.

GOALS

By increasing emotional awareness, physical symptoms may become less confusing and easier to manage. Your child may feel they can listen to and trust their emotions. The goal is for your child to become more at ease with managing the emotional ups and downs of life.



Suggested Responses (most helpful for physical and emotional distress)

- Being With:** Quietly just being with the person as they express their negative emotion, not trying to change anything. Just giving nonverbal gestures to show you are listening and can see it the way they are seeing it (e.g., nodding along, matching their facial expression, maybe holding a hand or giving a hug, etc.).
- Reflective Responding:** Empathically showing you get what the person is going through, by verbally reflecting it back to them (e.g., "You are really frustrated that I couldn't be there").
- Validation:** Letting the person know that the negative emotion is a legitimate way of reacting in that moment.

Other Common Responses (less useful for Physical and Emotional Distress)

- Reassurance:** Calming the person down by telling them everything is going to be ok.
- Downplaying:** Helping the person see the problem is not that big of a deal.
- Problem Solving:** Giving the person advice or suggestions about what they could do.
- Distraction:** Changing the situation so you are doing something less stressful or talking about something else.
- Cheerleading:** Helping the person focus on all of their wonderful qualities instead.
- Avoidance:** Protecting the person from having to talk about their problems, especially if they haven't even verbally shared anything yet.
- One-upping:** Helping the person feel like they are not alone by telling them about similar or worse things that have happened to you.
- Questioning:** Especially when you don't agree with how the person is feeling about something, you might ask them why they feel the way they do, or try to get more details so you can understand the situation.



HELP DEVELOP YOUR CHILD'S EMOTIONAL EXPRESSION and AWARENESS

Identify how your family attends to and expresses emotions: The experience of emotion is an internal activity that can happen with or without us being aware of it. Some emotions are easier to pay attention to and others are more difficult.

- What emotions people find easy or difficult to experience is different for different people.
- Difficult experiences are usually those that are unpleasant or even confusing.
- If we find certain emotions difficult, we can sometimes become so good at ignoring them that *we don't even notice we felt them*.
- This can be a helpful strategy in the short-term because it allows us to cope with that difficult moment.
- But this strategy can be problematic if it prevents us from solving an ongoing problem or dealing with a situation that has bothered us for a while.

The good news is that we can learn to develop an awareness of these difficult emotions. By finding the links between our emotions and body sensations, we can start to uncover what our bodies are telling us. We can start to feel more capable, effective, and resilient in the long-term.

Families can be similar in their emotional awareness. For example,

- In some families, sadness or tenderness is more difficult to experience because they 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 they feel guilty for their success.

In all of these examples, holding back certain emotions can help people feel more connected to others, yet at the same time, become disconnected from themselves.

“Being with” your child’s emotions: Parents play a big role in helping their child attend to, identify, label, accept, and express their emotions. One way to “be with” your child’s emotions 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 listening.”** When kids are experiencing intense emotions, reflective listening seems hard to do.

Parents sometimes worry that by showing they understand, they must also agree with the child, or come up with ways of protecting the child from a difficult emotion and/or try and ‘fix’ the situation that caused the emotion. However, reflective listening simply involves being able to see something through the child 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 become responsible for deciding what to do with that emotion. If an emotion is expressed and goes unrecognized, a child may think that their expression is not acceptable. When this happens regularly, children re start to ignore emotions that come up for them. This is often when we see their body ‘talking’ for them.

TREATING MENTAL HEALTH CONDITIONS

DESCRIPTION

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. If your child has a mental health condition it should be treated appropriately (education, therapy and, sometimes, psychiatric medications).

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 with symptoms of depression, as well as non-epileptic seizures.

Emerging Mental Health Disorder: Children can have somatic symptoms without any specific mental health disorder that has been identified. Over time, as somatization is treated, the mental health symptoms can become more obvious. For example, at first a child has a somatic symptom such as pain in the abdomen. Then, as the child learns to identify their feelings, the somatic symptom (the pain) decreases and the mood symptoms become more obvious. When body symptoms decrease and anxiety or sadness increases, parents may feel quite scared and discouraged. In most cases, this is normal. The body no longer has to “talk” for your child’s emotions as they learn the skills to understand and communicate their feelings.

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” symptom such as a visual hallucination without other symptoms of psychosis. In this case the hallucinations may be a Conversion Disorder symptom.

High Risk Symptoms: Somatic symptoms that last a long time 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, treat 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.

GOALS

Support your child’s healthy recovery by being aware of and treating mental health conditions, if needed.

RECOVERY

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, or eat meals with the family.

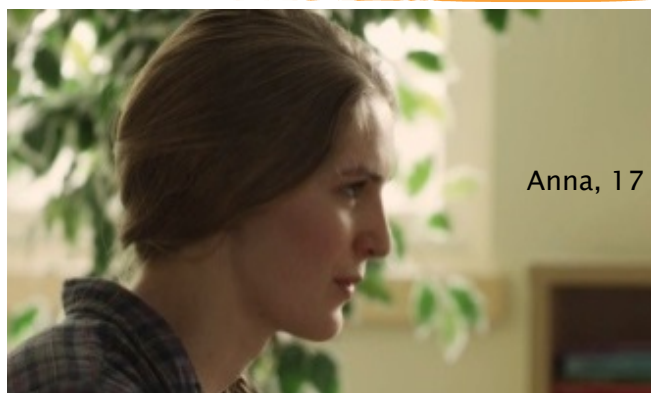
The symptoms are likely to flare-up even if things have been going well. When this happens it’s normal to feel worried as a parent. Know that you aren’t back where you started. A flare-up gives you and your child a chance to practice the skills you have learned. At this stage it is helpful to:

- review the mind-body connection
- explore feelings and stressors
- use coping skills
- see a health care team member for encouragement and support

The journey through the stages of somatization is usually very meaningful for the child and family.

- from **Confusion** to
 - making **Connections** to
 - taking part in **Integrated Treatment** to
 - entering and staying in the **Recovery** stage

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



Anna, 17

‘Body Talk: Stories of Somatization’ part #4 (Recovery) can be found here:

<https://www.youtube.com/watch?v=fL0JsgMFee4&t=3s>

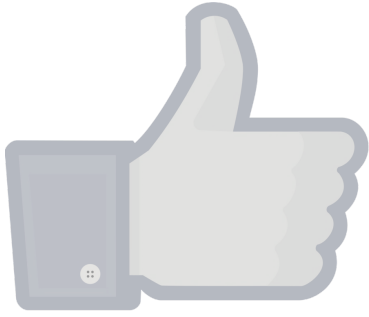
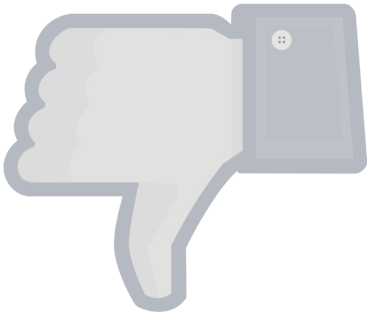
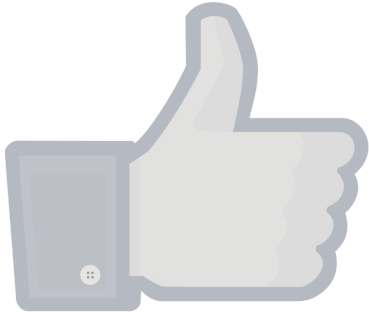
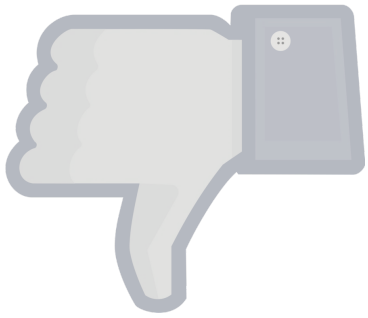


Matthew, 11



PROS AND CONS OF RECOVERY

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.

<p>Good Things About Recovering</p> 	<p>Not-So-Good Things About Recovering</p> 
<p>Good Things About Staying the Same</p> 	<p>Not-So-Good Things About Staying the Same</p> 

PART III

INTEGRATED TREATMENTS FAMILY WORKSHEET

BCCH Pediatric Mind Body Connection

Integrated Treatments

Family Worksheet

Date _____

Treatment Component	Treatment Strategy	N/A	Done	Work On	Notes
Treat the Medical Condition	<input type="checkbox"/> Plan for medical condition treatment, if appropriate <input type="checkbox"/> Arrange for medical follow up _____ _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	_____ _____ _____ _____ _____
Make a Symptom Management Plan	<input type="checkbox"/> Create a list of helpful tools (e.g. ice-packs, stretching) <input type="checkbox"/> Create a list of coping strategies (e.g. breathing, visualization) <input type="checkbox"/> Develop a plan for managing symptoms at school and in public <input type="checkbox"/> Attend physiotherapy therapy, if appropriate <input type="checkbox"/> Consider other therapies (e.g. massage, complementary) _____ _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	_____ _____ _____ _____ _____ _____ _____
Encourage Balance and Pacing	<input type="checkbox"/> Limit stressful activities, temporarily if appropriate (e.g. reduced course load, take a break from competitive sport) <input type="checkbox"/> Take small steps to be active and involved, and keep going once you have started _____ _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	_____ _____ _____ _____ _____

	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Support Healthy Development	<input type="checkbox"/>	Be social (e.g. spend time with friends, family)		<input type="checkbox"/>		
	<input type="checkbox"/>	Be involved in some extra-curricular activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/>	Participate in an academic program (e.g. school, distance education)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/>	Work on healthy child developmental tasks (e.g. independence, identity)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Encourage Emotional Awareness	<input type="checkbox"/>	Notice, label, express, and manage difficult emotions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/>	Develop confidence in responding to the difficult emotions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/>	Develop family skills in communicating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Treat Mental Health Conditions	<input type="checkbox"/>	Assess for mental health conditions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/>	Identify any self-harm risk factors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/>	Plan treatment of mental health treatment, if appropriate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Notes:

PART IV

RESOURCE LIBRARY

RESOURCE LIBRARY

We have developed some on-line resources to help you in this journey. Many youth and families, volunteers and staff at BCCH have helped to make the following list. Please go to keltymentalhealth.somatization.ca to check them out for yourself.

1. Somatization Brochure: This two page brochure gives an overview of what somatization and somatic symptoms are, and why we all somatize.
2. 'Body Talk: Stories of Somatization': 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.
3. Mind Body Connection Explained: This 5 minute animated video uses a story to explain the science behind the mind body connection.
4. Pinwheel Series: This one hour talk involves a discussion with two youth and their parents describing their somatization experience and the journey to getting better.

Other resources

1. AACAP Facts for Families
https://www.aacap.org/aacap/families_and_youth/facts_for_families/FFF-Guide/Physical_Symptoms_of_Emotional_Distress-Somatic_Symptoms_and_Related_Disorders.aspx

PART V FREQUENTLY ASKED QUESTIONS



FREQUENTLY ASKED QUESTIONS

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 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 mind-body 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 move forward with 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 being able to learn coping strategies and emotional skills. And then, 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 check 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?

This is very common. It takes time for children to understand and learn the skills to manage stress, especially if they are sensitive and 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 come up 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 they may seem to 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 will help a child get some control. At the beginning of treatment 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 take a "rehabilitative" approach and 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, illness or death in the family, etc.

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. Often a single situation that triggers the physical somatic symptoms is the more recent stressor in 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, or youth who start out doing well at a spare time activity like hockey or chess, but struggle when it gets harder or becomes more complex. Children can suffer if something they believe they are particularly good at doing now feels more challenging (e.g., “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 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 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:

1. 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 cause their child to 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.
2. Give support as needed and help the child use their symptom management plan (example: for example, after recognizing the physical symptom, encourage coping by setting up a distracting activity for your child to do until the symptom passes, see example below).

3. 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 the school that helps the child to cope and be safe during and after a 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. Never push 'talk therapy' if the child is not keen to work with a counsellor as this can increase the stress that is causing the somatization.

After diagnosis and starting new supports (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 scary. 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 and 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. And it is a chance to show they can identify stresses in their life and practice successful coping skills.

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