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This guideline does not take into account individual patient situations, and does not substitute for clinical judgment

**References:** 



- 1. Waynik, I., Sekaran, P. A path to successful pathway development. Presented at Pediatric Hospital Medicine Annual Conference; July 2016; Chicago, IL.
- 2. Ibeziako, P., Brahmbhatt, K., Chapman, A., et al. (2019). Developing a clinical pathway for somatic symptom and related disorders in pediatric hospital settings. Hospital pediatrics, 9(3), 147-155.
- 3. Sullivan, C., Namerow, L., Giudice, C., Nunes, C. Clinical Pathway: Somatic Symptom and Related Disorders. Presented at Pediatric Hospital Medicine Annual Conference; July 2019; Seattle, WA.

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## Appendix A: Initiating the Discussion

Your child has been admitted with medically unexplained physical symptoms that are significant. We have developed a standard approach to help patients like your son/daughter.

<u>Step 1</u>: We will assemble a team that includes (select all that apply: pediatricians, subspecialists, psychology, physical therapy, occupational therapy, speech therapy, social work, case management, child life, pain team, other subspecialties). The goal of these consultations is to identify what is causing your child's symptoms, and to promote your child's recovery.

<u>Step 2</u>: We will review the medical work up in detail and consider whether any additional evaluations are needed.

<u>Step 3</u>: While the workup is being conducted, we will implement a functional plan to help normalize your child's schedule so that he or she is able to participate in the evaluation and treatments. This may include things like asking him or her to be out of beds for meals, taking walks on the unit, etc. Regardless of the diagnosis, these measures have shown to improve health.

<u>Step 4</u>: Once the work up is complete, we will hold a team meeting with providers and family to discuss our findings and create a treatment plan.

<u>Step 5</u>: We will initiate a plan to support your child's recovery while in the hospital, and we will create a plan with outpatient providers to support your child's continued recovery at discharge.

Our goal, by the end of your child's stay, is for your child to have a complete evaluation, discuss the results, review the diagnosis and create a treatment plan. Your child's symptoms may not be gone when your child is ready to leave the hospital. We will work to establish goals to improve your child's health and help your child return to normal activities. If needed, we can collaborate with your child's school, primary care doctor and other providers in the community to promote your child's functioning and continued improved upon discharge.

## Functional Disability Inventory Child and Adolescent Form

When people are sick or not feeling well it is sometimes difficult for them to do their regular activities. In the past two weeks, would you have had any physical trouble or difficulty doing these activities?

	No Trouble	A Little Trouble	Some Trouble	A Lot of Trouble	Impossible
1. Walking to the bathroom.	0	1	2	3	4
2. Walking up stairs.	•	1	2	3	4
3. Doing something with a friend. (For example, playing a game.)	0	1	2	3	4
4. Doing chores at home.	•	1	2	3	4
5. Eating regular meals.	•	1	2	3	4
<ol><li>Being up all day without a nap or rest.</li></ol>	<b>•</b>	1	2	3	4
7. Riding the school bus or traveling in the car.	0	1	2	3	4

Remember, you are being asked about difficulty due to physical health.

	No Trouble	A Little Trouble	Some Trouble	A Lot of Trouble	Impossible
8. Being at school all day.	•	1	2	3	4
9. Doing the activities in gym class (or playing sports).	•	1	2	3	4
10. Reading or doing homework.	•	1	2	3	4
11. Watching TV.	•	1	2	3	4
12. Walking the length of a football field.	•	1	2	3	4
13. Running the length of a football field.	•	1	2	3	4
14. Going shopping.	•	1	2	3	4
15. Getting to sleep at night and staying asleep.	•	1	2	3	4

## Functional Disability Inventory Parent Form

When people are sick or not feeling well it is sometimes difficult for them to do their regular activities. In the past two weeks, would your child have had any physical trouble or difficulty doing these activities?

	No Trouble	A Little Trouble	Some Trouble	A Lot of Trouble	Impossible
1. Walking to the bathroom.	0	1	2	3	4
2. Walking up stairs.	•	1	2	3	4
3. Doing something with a friend. (For example, playing a game.)	0	1	2	3	4
4. Doing chores at home.	•	1	2	3	4
5. Eating regular meals.	0	1	2	3	4
6. Being up all day without a nap or rest.	0	1	2	3	4
7. Riding the school bus or traveling in the car.	0	1	2	3	4

Remember, you are being asked about difficulty due to physical health.

	No Trouble	A Little Trouble	Some Trouble	A Lot of Trouble	Impossible
8. Being at school all day.	•	1	2	3	4
9. Doing the activities in gym class (or playing sports).	<b>•</b>	1	2	3	4
10. Reading or doing homework.	•	1	2	3	4
11. Watching TV.	•	1	2	3	4
12. Walking the length of a football field.	•	1	2	3	4
13. Running the length of a football field.	•	1	2	3	4
14. Going shopping.	•	1	2	3	4
15. Getting to sleep at night and staying asleep.	•	1	2	3	4

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# Appendix C: Functional Plan

The primary provider should place eStar order set with applicable interventions to communicate with nursing and therapists.

• Pain assessment using FLACC scale vs comfort scale (assessed with vital signs, likely every 8 hours unless clinically requires this more frequently)

- Establish sleep-wake cycle (example lights on at 8 am, lights off at 9 pm)
- Out of bed for every meal
- Promote activities of daily living (hygiene, wearing own clothes)
- Walks on unit per ambulation order (if appropriate)
- Homework ad lib
- Consults:
- Physical therapy- to complete FDI
- Occupational therapy
- Psychology (if admitted to hospital medicine)- to complete mental health assessment

• Child and Adolescent Psychiatry (if admitted to subspecialty or the weekend) – to complete mental health assessment

- Child life to provide patient with age appropriate activities and facilitate visual daily schedule
- Social Work
- Case Management
- Consider the following subspecialty consults:
- Child and Adolescent Psychiatry (if admitted to hospital medicine and patient requires initiation of medication)
- Pain Team

# Appendix D: Informing Meeting Script

It is key to have representation from every subspecialty participate in the informing meeting, including primary team, psychology and each subspecialty service consulted on the case or saw the patient as an outpatient in the context of the patient's presenting symptoms. It is helpful to review or bring records of completed and pending diagnostic studies completed inpatient/outpatient/outpatient/outpaties, including lab studies and imaging.

As we said at the beginning of your son/daughter's admission, after all of the specialists have consulted and completed your child's medical workup, we come together as a multidisciplinary team to discuss what we have found to be contributing to your child's symptoms and what the evidence-based treatment is for the condition. We want to give you a chance to ask questions and to be sure that you feel comfortable about our assessment and treatment plan.

We want to share with you a summary of your child's symptoms, why we consulted with these specialists, what diagnoses we are considering and what our findings did or did not support. Please tell us along the way if we have any part of the history wrong, or if there is anything you do not understand. Please let us know if there is any medical condition or diagnosis that you feel we have not adequately addressed.

## **Primary Team Review:**

\*Your child presented with: \_\_\_\_\_

### Prior work up included: \_\_\_\_\_ Each Subspecialist Review:

The differential diagnoses that are consistent with your child's symptoms include: \_\_\_\_\_

The work up that we performed included \_\_\_\_\_, and revealed \_\_\_\_\_.

Therefore, the following diagnoses were ruled in/out: \_\_\_\_\_.

Given these findings and with the input from our specialists, we think your child's symptoms are best understood as \_\_\_\_\_. In our experience, symptoms due to \_\_\_\_\_ respond best to the following treatment approach: (specify as applicable)

- Cognitive behavioral therapy
- Medical management: \_\_\_\_\_
- Behavioral management: \_\_\_\_\_
- Outpatient support (PT, OT, psychiatry)
- Close follow up with your pediatrician to continue following your symptoms
- Continued follow up with relevant subspecialists

\*Include positive signs, such as Hoover sign to help illustrate diagnosis as well

Note: If a somatic symptom disorder is being considered, the attending leading the meeting should use the actual term (functional neurologic disorder rather than "stress") and ask psychology to give a formulation of potential contributors (which are not always known at the time of admission).

# Appendix E: Facts for Families

## What are Somatic Symptoms?

Physical complaints are common in children. As many as 1 in 10 children will complain of an ache, pain or worry about their body on any given day. Sometimes when there is no medical illness that fully explains the complaint, it may be that emotions are being felt as physical symptoms. Physical symptoms of emotional distress are called **somatic symptoms**.

**Somatization** is the name used when emotional distress is expressed by physical symptoms. Everyone experiences somatization at times. Examples include your heart beating fast or butterflies in your stomach when you feel nervous or muscles becoming tense and sore when you feel angry or under stress. These symptoms are very real to your child; they are not "faking it."

#### What are Somatic Symptoms and Related Disorders?

A Somatic Symptom and Related Disorder (SSRD) is diagnosed when your child has physical symptoms that are not explained by a medical illness or when symptoms of a known illness affect your child much more than expected and these symptoms interfere with daily life such as missing school, not wanting to play with friends or avoiding fun activities.

SSRD symptoms may include:

- Body pains including headaches, joint pains
- Stomach aches, nausea, vomiting, trouble swallowing
- Fatigue, dizziness, memory problems
- Weakness, numbness, trouble walking
- Trouble breathing, shortness of breath
- Changes in vision or hearing including sudden blindness
- A "stuck" feeling or a "lump" in the throat
- Seizure-like episodes, fainting, abnormal movements

There are different types of SSRDs. Your child may be diagnosed with: Psychological Factors Affecting a Medical Condition, Somatic Symptom Disorder or Functional Neurological Disorder (also known as Conversion Disorder). Terms like "functional," "nonorganic," "psychogenic," "psychosomatic," "pseudo seizure," "aphysiological," "amplified," and "medically unexplained" are also sometimes used.

#### Why does my child have an SSRD?

A child may have an SSRD for many reasons. Sometimes it starts with an illness, injury or infection, but the other symptoms do not go away after the illness or injury has been treated. Other times, somatic symptoms start without any prior illness or injury. Somatic symptoms may also be strong feelings or struggles that a child has not been able to share in words. When a child's feelings and/or stress builds up inside, their body may express those feelings physically.

#### How are SSRD diagnoses made?

Varied professionals including your child's primary care provider, pediatric subspecialists (for example, neurologist or gastroenterologists), child and adolescent psychiatrists and pediatric psychologists may be involved in the assessment, diagnosis and treatment. The evaluation typically involves:

- An evaluation of physical, emotional and behavioral symptoms and daily functioning
- A physical exam
- Reviewing the results of medical tests (lab work, imaging or procedures)

## How are SSRDs treated?

**SSRDs are treatable**. Sometimes symptoms are short-lived and disappear quickly with minimal treatment. Other times, a child needs a more lengthy course of treatment or a more intensive treatment setting. There are certain types of therapy/counseling that focus on helping a child learn skills to better communicate about their feelings and manage life stressors. The main goal of treatment is to help a child return to normal levels of functioning, even with symptoms present. Treatment will be based on the needs of your individual child and may include:

• Therapy/counseling for the child and family to help understand the connection between feelings and physical symptoms and to teach skills like breathing exercises, relaxation and biofeedback

- Physical therapy and occupational therapy to help muscle strength and movement
- Actions to relieve physical discomfort such as massage, ice or heat
- Small, gradual steps to improve function
- Return to school with the help of school accommodations and support from teachers, nurses and school counselors
- Return to after school activities as soon as possible (spending time with friends, sports, clubs)
- Regular check-ins with your health care team to check for improvements and any new treatment changes

## What can I do to help my child?

As a family member, you are a vital member of the treatment team; you know your child best and can help others understand your child. Ways you can help include:

• Ask for medical and behavioral health providers who understand the mind body connection

• Encourage new ways for your child to talk about uncomfortable feelings, and let them know it is okay to have these feelings

- Help your child practice coping and relaxation strategies
- Support your child's efforts to focus on healthy function, and less on physical symptoms
- Work with school and other programs to help your child return to usual activities as soon as possible

• Learn ways to cope with your own stress and other understandable emotions that may develop, as a concerned parent or other family member