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A photograph of a child's hands reaching out to touch a large, iridescent bubble. The child is wearing a light green sweater. The background is a soft-focus outdoor scene with green foliage. The image is framed by a blue diagonal shape on the left and a yellow diagonal shape on the right.

# Sensory Processing in Sotos Syndrome

A Guide for Parents/Caregivers

**The  
Children's  
Hospital  
Charity.**

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# What is sensory processing?

Sensory processing refers to how our brain receives information from the senses.

There are eight key senses. Five of these are our **core senses** and three of these are our **internal senses**. These are:

## Core senses:

- Touch
- Hearing
- Vision
- Taste
- Smell

## Internal senses:

- Proprioception - *lets us know where our limbs are and how they are moving*
- Vestibular - *maintains our balance, posture and eye movement*
- Interoception – *detects information from our internal organs. For example, hunger, tiredness, and headaches*

Our brains often need to interpret and use information from multiple different senses at the same time.



Sensory processing is essential to every experience that we have. Sensory information is sent to our brains via our nerves, our brains register this input and process it in order to organise a response.

*For example, you may stub your toe on the corner of your bed. The nerves in your toe, which detect pain, carry a signal to your brain which processes the experience as painful. This results in you grabbing your toe and avoiding the corner of the bed in the future.*

## What are sensory processing differences?

Some children process sensory information differently. This means they experience the world differently to others. Sensory processing differences can make everyday activities or certain environments challenging for a child. This can result in difficulties with learning, sleeping, eating, or challenging behaviour.

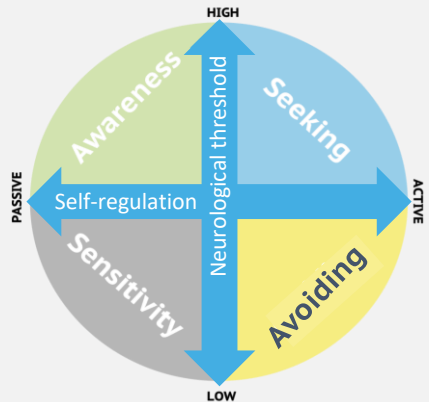
By understanding a child's sensory processing differences, changes can be made to their environment or routines to help reduce the negative impact of sensory processing problems.

*For example, a child may show difficult behaviour that later is found to be caused by an uncomfortable label on their t-shirt or a tight seam on their socks..*

# Sensory Processing Model

Health professionals and researchers use models to explain complex processes that involve the body and/or the brain. In 1997 an Occupational Therapist, Dr. Winnie Dunn, proposed a model to explain children's processing of sensory information.

The model proposes that sensory processing in children can be explained by the relationship between two factors: "neurological threshold" (detection of sensory information) and "self-regulation" (response to sensory information). This interaction results in four categories (or "quadrants") describing different patterns of sensory processing:



**Awareness (Registration)** – children who miss or seem to have low awareness of sensory information.

*Examples:*

- Needs help to find objects obvious to others
- Doesn't notice messy hands or injury
- Gets tired easily or is clumsy
- Is comfortable in different sensory environments

**Seeking** – children who are more interested in sensory information than others.

*Examples:*

- Touches items with interesting textures
- Puts objects in mouth
- Gets excited during movement activities
- Watches people as they move around the room

**Sensitivity** - children who detect more sensory information than others.

*Examples:*

- Is picky about food textures
- Becomes distressed during face washing
- Is easily distracted
- Notices things that other people miss

**Avoiding** - children who actively avoid or become overwhelmed by sensory input.

*Examples:*

- Likes "sameness" or is good at routines (provides predictable sensory experiences)
- Has emotional outburst when being touched
- Puts hands over ears in a noisy environment

Sensory processing differences can be highly individual and varied. A child is unlikely to fall into just one of the sensory quadrants and different patterns can occur across, and within, sensory modalities. Some children may show sensory patterns from all four quadrants.

*For example, a child may be sensitive to sounds but seek out activities involving touch.*

# Sotos Syndrome

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Sotos Syndrome is a rare overgrowth condition which is present from birth.

Children with Sotos Syndrome are usually tall for their age and have large heads. Increased height often becomes less apparent after puberty. Individuals with Sotos Syndrome have characteristic facial features which include a prominent forehead, down slanting eyes and a prominent chin. Individuals may also experience sensory processing differences, behavioural challenges and learning difficulties.



Sotos Syndrome is caused by abnormality of a single gene (NSD1) and in most cases, the abnormality occurs spontaneously. The syndrome is not usually inherited from a parent, however, if an individual with Sotos Syndrome has a child, the child will have a 50% chance of inheriting the syndrome

# The Sensory Profiles in Rare Genetic Syndromes Study

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Research has shown many children with rare genetic syndromes (including Sotos Syndrome) experience symptoms associated with autistic traits, which may increase the likelihood of sensory processing differences. So far, there has been no research that has investigated sensory processing in children with Sotos Syndrome.

The aim of this study was to investigate the sensory profile of children aged 3-14 years old with Sotos Syndrome.



A **sensory profile** is a measure of how a child processes sensory information and can help inform understanding of sensory differences

Parents and caregivers were asked to complete questionnaires about their child's sensory processing and other behaviours.

Children's sensory processing was measured according to six sensory modalities (hearing, visual, touch, movement, body position, and oral) and according to the four sensory quadrants (awareness, seeking, sensitivity, avoiding). The findings were compared to a population of typically developing children aged 3-14 years old.

## Who took part?

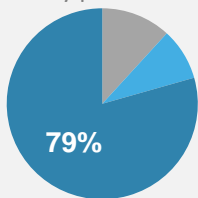
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Thirty-six parents/caregivers of children with Sotos Syndrome aged 3-14 years old took part. There were 18 male and 18 female children. Participants took part from the UK, USA, Australia, New Zealand, and Canada.

# How common are sensory differences in Sotos Syndrome?

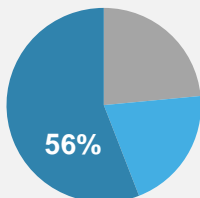
## Research Findings

Body position



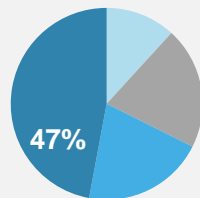
79% of children with Sotos Syndrome were **much more** likely to process **body position** information differently compared to the majority of children of a similar age (e.g., get tired easily or walk as if feet are heavy)

Touch

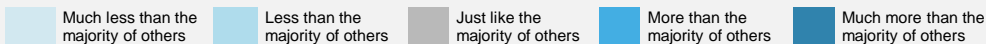


56% were **much more** likely to process **touch** information differently (e.g., more sensitive or less sensitive to touch than others)

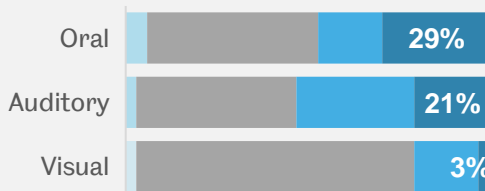
Movement



47% were **much more** likely to process **movement** information differently (e.g., constantly on the go or lose their balance easily)



Differences were also seen in the processing of oral and auditory information.



Low Awareness (Registration)



77% were much more likely to **miss** sensory cues compared to others

Sensitive



44% were much more **sensitive** to sensory cues

Seeking

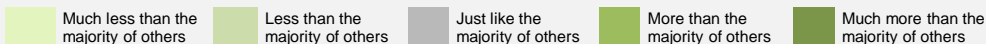


41% were much more **interested** in sensory experiences

Avoiding



38% were much more likely to **avoid** sensory experiences



## Quotes

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*“She loves cuddling her Mum but dislikes touching others or being touched by others....She is very averse to trying on new shoes which is very problematic. She becomes tired easily with physical exertion. She moves stiffly, with poor posture but has a great sense of rhythm and dances gracefully.” - Caregiver of 12-year-old girl with Sotos Syndrome*

*“He talks to himself constantly out loud and paces or jumps on the trampoline while doing so.” - Mother of 14-year-old son with Sotos Syndrome*

*“She is very resistant to hygiene. It is a nightmare getting her to clean her teeth properly”- Caregiver of 12-year-old girl with Sotos Syndrome*

*“He is wary of others and so notices where people are. He struggles to pay attention to things other than his iPad, his favourite picture book, or his light up button toy. Anything other than this he won't give much attention to...he just becomes consumed with wanting his iPad back.” - Mother of 8-year-old son with Sotos Syndrome*

*“She is clumsy and often knocks things over, breaking things as a result of misjudging her strength.” - Caregiver of 12-year-old girl with Sotos Syndrome*



# Useful Strategies

The below tables contain strategies that may support your child’s sensory processing differences. Use of strategies such as these may help to reduce sensory-related behavioural problems.

Not all of these strategies will be useful to your child. When selecting strategies **you should be guided by your child’s individual needs and think carefully about what is right for them** (e.g., your child may have low awareness of body position but is sensitive to touch). All children will be different and it is important not to force activities on your child. Advice and tailored support can be provided by a professional with training in ‘Sensory Integration’.

<b>Seeking</b>	More than others	<ul style="list-style-type: none"> <li>• Incorporate novelty into child's routine</li> <li>• Choose activities that incorporate touch with others (e.g., dancing, massage) or with the environment (e.g., gardening, cooking)</li> <li>• Select clothes, furniture, or utensils with a variety of textures</li> <li>• Help the child engage in physical activity before a task (e.g., handing out books in the classroom, setting the table before dinner)</li> <li>• Introduce new tastes and smells (e.g., scented soaps, spices)</li> <li>• Chew gum, or eat mints when feeling restless</li> <li>• Talk to the child about what they smell or see</li> </ul>
	Less than others	<ul style="list-style-type: none"> <li>• Send the child on errands throughout the home and classroom</li> <li>• Play in parks on different equipment</li> </ul>
<b>Avoiding</b>	More than others	<ul style="list-style-type: none"> <li>• Avoid high traffic areas, crowds, and/or busy times</li> <li>• Establish consistent routines that are comforting and supportive (e.g., a daily walk)</li> <li>• Limit large group exposure; find opportunities for small groups or one-on-one interaction</li> <li>• Provide quiet places for the child to have time alone</li> <li>• Explain personal distance needs to others</li> <li>• When choosing clothing, select fabrics that don’t irritate and styles that are not constricting (e.g., seamless socks)</li> <li>• Warm wipes or towels before using them</li> </ul>
	Less than others	<ul style="list-style-type: none"> <li>• Incorporate breaks when doing tasks</li> <li>• Plan home and school schedules ahead of time and talk about changes in advance</li> <li>• Develop routines for outings to familiar places</li> </ul>

<b>Sensitivity</b>	More than others	<ul style="list-style-type: none"> <li>• Incorporate breaks and time-outs</li> <li>• Help the child break down tasks into smaller parts</li> <li>• Go to places where the sensory environment is known/predictable (e.g., the park, museums)</li> <li>• Use deep pressure touch rather than light touch</li> <li>• Provide a buffer space for the child to play without getting easily bumped</li> <li>• Use lots of blankets or heavy comforters on the bed</li> <li>• Reduce the volume or number of auditory stimuli</li> <li>• Provide written instructions or pictures alongside verbal information</li> <li>• Simplify complex visual information or environments (e.g., organise drawers so the child can find things easily)</li> <li>• Serve foods with spaces between them</li> <li>• Remove all light sources at bedtime</li> <li>• Introduce new foods and smells gradually</li> </ul>
	Less than others	<ul style="list-style-type: none"> <li>• Talk to the child about sensory features in daily activities (e.g., listen to the birds)</li> <li>• Vary routines</li> </ul>
<b>Low Awareness</b>	More than others	<ul style="list-style-type: none"> <li>• Visit places that offer a variety of sensory experiences (e.g., parks, interactive exhibits)</li> <li>• Vary bathing or dressing routines (e.g., try a shower instead of a bath)</li> <li>• Use heavy blankets to sleep</li> <li>• Provide opportunities to carry/ move heavy objects (e.g., carry groceries)</li> <li>• Add texture to objects to help with detection (e.g., writing materials for school, switches on toys)</li> <li>• Teach the child to use visual cues to notice when people or objects touch them (e.g., look to see if hands are messy)</li> <li>• Set water heaters at a lower temperature to prevent burns</li> <li>• Use extra care when drinking hot liquids and eating hot food</li> <li>• Use visual cues (e.g., watch where you are going) to support movement activities</li> <li>• Clear pathways of objects that could be tripped over</li> <li>• Have the child repeat or explain information back to you to make sure they have processed what was said</li> <li>• Make visual cues clearer (e.g., underline, bold, highlight)</li> </ul>
	Less than others	<ul style="list-style-type: none"> <li>• Identify familiar routines to return to when the child seems overwhelmed</li> <li>• Provide familiarity in settings, people, and experiences</li> </ul>

# Getting Support

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## Where to seek support for sensory processing in Sotos Syndrome:

- Sotos Syndrome social media groups (e.g., Facebook support groups)
- The Child Growth Foundation [www.childgrowthfoundation.org](http://www.childgrowthfoundation.org)
- The Sotos Syndrome Support Association <https://sotosyndrome.org>
- Visit your child's GP
- Discuss your child's sensory processing differences with other professionals (e.g., Occupational Therapist with postgraduate training in Sensory Processing)

## Further Reading

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### Books

- Can I Tell You about Sensory Processing Difficulties? A Guide for Friends, Family and Professionals – by Sue Allen
- The Out-of-Sync Child – by Carol Stock Kranowitz
- Living Sentionally – by Winnie Dunn

### Sotos Syndrome; An Educational Guide

<https://childgrowthfoundation.org/wp-content/uploads/2018/07/Sotos-Syndrome-Educational-Guide.pdf>

Tatton-Brown K, Cole TRP, Rahman N. "Sotos Syndrome" 2004  
<https://www.ncbi.nlm.nih.gov/books/NBK1479/>

National Autistic Society. "Sensory Differences - a Guide for All Audiences."  
*Autism.org.uk*, 2021, <https://www.autism.org.uk/advice-and-guidance/topics/sensory-differences/sensory-differences/all-audiences>

Lane, C., Milne, E. & Freeth, M. "Characteristics of Autism Spectrum Disorder in Sotos Syndrome." *J Autism Dev Disord* 47, 135–143 (2017).  
<https://doi.org/10.1007/s10803-016-2941-z>

Dunn, W. "Supporting Children to Participate Successfully in Everyday Life by Using Sensory Processing Knowledge," *Infants & Young Children* 20(2) 84-101 (2007).  
<https://doi.org/10.1097/01.IYC.0000264477.05076.5d>

# At Home Sensory Diary

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Use this page to note down your child's sensory behaviours.

Sensations your child...	
<b>Tends to avoid or is overwhelmed by</b>	
<b>Is interested in</b>	
<b>Tends to notice easily or is sensitive to</b>	
<b>Tends to miss or is unaware of</b>	

# About The Authors

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## Poppy Webb

*Poppy is a Student Researcher at the University of Sheffield working in collaboration with Harriet Smith and Dr Megan Freeth. Poppy created this booklet as part of a funded research placement provided by the University. Poppy has an aspiration to become a Clinical Psychologist in the future and is beginning to gain experience in specific interests she is passionate about; one being rare genetic syndromes.*

## Harriet Smith

*Harriet Smith is a Research Associate at the University of Sheffield and member of the Sheffield Autism Research Lab. She is lead researcher on the "Sensory Profiles in Rare Genetic Syndromes" project. Her research experience includes projects in genetic syndromes, autism spectrum conditions, tinnitus, and hearing health. Harriet is also in the final stages of her PhD at the University of Nottingham which investigated the impact of tinnitus in children and has developed a child-specific questionnaire measure of tinnitus.*

## Dr Megan Freeth

*Dr Megan Freeth is Principal Investigator on the project "Sensory profiles in genetic syndromes". She is Senior Lecturer in Psychology at the University of Sheffield and Director of the Sheffield Autism Research Lab (ShARL). The goal of ShARL is to have a positive impact on the lives of individuals diagnosed with autism spectrum conditions (ASC) and genetic syndromes via advancements in research. The scope of ShARL's research is broad and includes neuroimaging studies aimed at gaining insight into neural and cognitive divergence and applied studies aimed at improving understanding of the lived experience of ASC and genetic syndromes*

# Acknowledgments

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