Helping Children and Youth with Obsessive-Compulsive Disorder (OCD):
Information for Parents and Caregivers

“He just can’t stop washing…”

William enjoys hanging out with his friends and family, and is a great soccer player. But over the past few months, he’s been much more concerned about being clean. At first, his parents thought it was great, because he began showering more often. But now he needs to shower several times a day and will actually get upset and angry if he can’t have his shower. And in the past few weeks, he’s become so worried about germs that he won’t even touch door handles. And if he does, he has to wash his hands, and so now his hands are chapped, sore and bleeding from all the washing...

What is Obsessive Compulsive Disorder?

Obsessive-compulsive disorder (OCD) is a condition where children or youth have obsessions or compulsions.

Many people are ‘perfectionists’, or a little obsessive about certain things. It can even be helpful when we have ‘just enough’ of these traits.

For example, someone who is obsessive about cleanliness will definitely be better at preventing the spread of germs and infections. But these habits become a disorder when they begin to get in the way of everyday life. With OCD, concerns about cleanliness can get so severe that children or youth may end up:

- Avoiding touching family members because they are afraid of getting contaminated
- Washing their hands so much that hands become chapped and bleeding
- Avoiding going to school due to fears of contamination
- Not being able to turn on the TV because others have touched it
- Spending hours every day consumed with cleanliness related rituals

How common is OCD?

Somewhere between 1 to 5 out of every 100 children and youth have OCD.

Compulsions:
Are behaviours that a child or teen feels forced to do, to relieve distress related to the obsession. For example, some children or youth wash their hands over and over again to feel less anxious about being contaminated.

Obsessions:
Are distressing thoughts or images that won’t go away. For example, a child may worry about being dirty or contaminated.
What causes OCD?

Researchers believe that OCD happens when people don't have enough serotonin (a brain chemical or neurotransmitter) in the brain. Many things can contribute to OCD, like:

- **Family History:** OCD happens more often when children and youth have family members with OCD.
- **Life Events:** OCD is sometimes triggered by stress. For example, hand washing can be triggered by media reports about germs or epidemics.
- **Infection:** In extremely rare cases, OCD may be caused by bacterial infection (streptococcus, or 'strep')

Common types of obsessions and compulsions

<table>
<thead>
<tr>
<th>Type of obsessions</th>
<th>A child or teen’s thoughts, feelings and actions</th>
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<tbody>
<tr>
<td>Cleanliness or contamination</td>
<td>Worries that things are dirty or contaminated. This leads to a compulsion of needing to wash or bathe over and over again, or avoid touching things that might be 'contaminated.'</td>
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<tr>
<td>Symmetry and order</td>
<td>Gets upset or distressed if things aren’t exactly ‘just so’ or in a certain order. May spend a lot of time arranging or re-arranging things in one’s room, workplace or other places.</td>
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<tr>
<td>Numbers and counting</td>
<td>Having to count or repeat things a certain number of times, having &quot;safe&quot; or &quot;bad&quot; numbers.</td>
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<td>Self-Doubt and need for reassurance</td>
<td>Fear of doing wrong or having done wrong, which may lead to repetitively asking others for reassurance, over and over again.</td>
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<td>Guilt/need to confess</td>
<td>Needing to tell others about things that she or he has done.</td>
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<tr>
<td>Checking</td>
<td>Excessive checking things like doors, lights, locks, windows.</td>
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<tr>
<td>Perfectionism</td>
<td>Excessive time doing things over and over again until they are perfect, or ‘just right’.</td>
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OCD symptoms can lead to other problems like:
- Troubles paying attention, because the child or teen is so focused on obsessions or compulsions
- Anxiety and anger if OCD routines get interrupted
- Lateness and fatigue from the time and energy needed for rituals
- Withdrawal from usual activities and friends
- Trying to get friends and family to cooperate with the OCD rituals.

Everyone in a family is usually affected by a child or teen’s OCD, so everyone has a role to play in helping to make things better.

**What should we do if we think our child has OCD?**

If you think that your child has OCD, bring your child or teen to a doctor to make sure there aren’t any medical problems that might be contributing to the problem. Your doctor may then refer you to a psychologist, psychiatrist or children’s mental health centre.
How is OCD Treated?

The good news is that there are many effective treatments and ways to deal with OCD. The two main types of treatments that can help OCD are:

1. **Cognitive behaviour therapy (CBT):** CBT is a type of ‘talk’ therapy that helps children and youth learn new ways to think (“cognitive”) and new ways to do things (“behavioural”) to deal with the OCD. CBT is usually provided by a psychologist or psychiatrist. Many good books on OCD make it easier for children and youth with OCD and their families to learn how to use these approaches on their own (for example, “Talking Back to OCD” by John March).

2. **Medications:** Medicines (like specific serotonin reuptake inhibitors, or SSRIs) can help balance the amount of brain chemicals. Medications can be helpful when other treatments aren’t working. Medication may be needed for a short or long time, depending on your child’s needs.

**Cognitive-Behavioural Strategies for OCD**

Cognitive behavioural therapy (CBT) is one of the most effective treatments for OCD. CBT includes ways to change thoughts and behaviours.

1. **Cognitive (thought) Strategies:** OCD makes a child or youth have ‘OCD’ thoughts. Cognitive (thought) strategies help a child or teen to replace OCD thoughts with more helpful ones. For example, a child with cleanliness obsessions touches a school textbook and gets the automatic thought, “Now I’m all dirty and I’m going to get sick! I have to wash my hands!”

   Cognitive techniques help children and youth come up with more helpful coping thoughts, like, “I’m not going to let the OCD push me around! So what if I’ve just touched the book? I’m not going to get sick. And if I do, well, then maybe I can miss school.”

**Event:** Hand touches book

**Without Treatment:**
- Thought: “Oh no! I’m going to get sick!”
- Feeling: Worry and fear
- Outcome: Strong urge to wash hands

**With Treatment:**
- Thought: “I’m not going to get sick. That’s just the OCD trying to boss me around.”
- Feeling: Calmer
- Outcome: Less urge to wash hands
2. Changing behaviours one step at a time...

- OCD Hierarchy:

  A hierarchy is a way of deciding which OCD behaviours to work on first.

  **Most difficult to resist**
  - Checking windows
  - Checking locks
  **Easiest to resist**
  - Hand washing

- Exposure with Response Prevention:

  **Exposure** means exposing your child or teen to the (feared) situation that triggers the OCD.
  
  For example, if you have a child whose hand washing rituals are triggered by touching “contaminated” objects, then you would expose the child to “contaminated” objects. Exposure is always done bit by bit, in a gradual way that the child can tolerate, like going up a flight of stairs.

  **Response prevention** means preventing the ‘response’ (or ritual) that the OCD tries to ‘boss’ your child into doing.
  
  For example, children with hand washing compulsions would feel an urge to wash their hands after touching objects they feel are dirty or “contaminated”. Response prevention happens when children agree ahead of time, that if they touch something, that they will try to avoid the typical response of hand washing. Although this causes anxiety at first, the more often they avoid hand washing, the easier it becomes over time to stop hand washing (or other compulsions). Naturally, it is usually not possible to completely stop the compulsions all at once; it is done gradually, step-by-step... For example, if a child’s compulsion is to wash hands four times, then the next step would be only to wash three times. Once that is successful, then the child goes to the next step of only washing hands two times, and so on....

- Ultimate Goal

  Washing hands just 1 time

  **Step 1**
  - Washing hands 4 times each time

  **Step 2**
  - Washing hands 3 times each time

  **Step 3**
  - Washing hands 2 times each time

  **Step 4**
  - Washing hands just 1 time
Narrative strategies for OCD

Narrative therapy is a powerful way to deal with problems by talking about them in a certain way. Many therapists will use both narrative and cognitive behavioural strategies in treating OCD in children and youth.

1 Make the OCD the problem, not the person with OCD: Although OCD symptoms can be very frustrating and cause conflict with families, remember that it is not your child or teen that is the problem, it is the OCD. A powerful way to do this is to talk about the OCD as a ‘third person’. This helps you to join forces with your child or teen, to work together against the OCD.

Therapist or parent: “You know this thing about needing to wash your hands over and over? That’s not you, that’s OCD. It’s a condition that tricks your brain into making you wash your hands. What would it be like if OCD wasn’t around anymore?”

Child or teen: “A lot better”

Therapist or parent: “And that’s why we’re going to work together, and find ways to keep OCD from bossing you around.”

2 Naming the OCD: Although teenagers are usually happy to call their symptoms ‘OCD’, younger children often like to give it their own name.

Therapist or parent: “Although adults call it OCD, it can help if you give it a name. Is there any name you want to give it?”

Child or Teen: “Germy! Because it makes me think I have germs all the time.”

Children and youth have called OCD “the brain bully”, “Mr. Meany” or “Mr. Nag”.

3 Agree with the child on the goal, like getting rid of the OCD: When faced with OCD symptoms like hand washing, it’s natural for many adults to simply try to stop the child from hand washing. But since children and youth may not have the same insight as adults, they may get upset if adults suddenly try to stop them from their OCD rituals. From the child’s point of view, stopping the rituals is going to make them feel worse in the short-run. Adults must help the child to see that things would be better in the long-run.

Therapist or parent: “Okay, so what would it be like if we could help you get rid of Germy?”

Child or teen: “A lot better!”

Therapist or parent: “Remember what it was like before Germy started bossing you around?”

Child or teen: “Yeah...I didn’t have to wash my hands all the time. And I was able to go to my friend’s houses.”

Therapist or parent: “That’s why we are going to work together, so that we can stop Germy from bossing you around so much. It might be tough at first, but eventually, you’ll feel better, and be able to do more fun things again. And your hands will feel so much better.”
Here is another example of this:

**Therapist or parent:**  
“OCD tries to trick you into thinking your hands are dirty, so that you’ll have to wash them. What do you think?”

**Child or teen:**  
“Yeah... that’s what Germy does. I feel so icky and I just have to wash my hands.”

**Therapist or parent:**  
“And after you wash your hands, how do you feel?”

**Child or teen:**  
“Better!”

**Therapist or parent:**  
“What if we could find another way to help you feel better, without having to wash your hands?”

**Child or teen:**  
“That would be better!!”

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**4 Blaming it on the OCD doesn’t take away responsibility:** Some parents get worried that if we blame the symptoms on the OCD that the child might not take responsibility for dealing with the problem. For example, if a child with OCD gets into a fight and hits his sister because she interrupted him during his rituals, he simply says, “Well, it’s not my fault, it’s the OCD!”

To make sure that responsibility still stays with the child, a therapist (or parent) might say something like this:

**Therapist or parent:**  
“You didn’t cause your OCD and it’s not your fault. It’s also not your parent’s fault or anyone else’s fault.”

“But getting over the OCD is still your responsibility. Seeing a counsellor, or taking medications will help. But you’re not alone; we are all going to work together to help you deal with this. How does that sound?”

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**5 Ask your child how you can support her:** You might say things like:

**Therapist or parent:**  
“How can we work together against the OCD?”

“Is there anything I can do to help you control the OCD, and keep it from controlling you?”
Praise your child for ‘bossing back’ the OCD: All children and youth need praise, especially those struggling with OCD. A child struggling with OCD often hears a lot of criticism or negative comments from others. You might start with:

“How did you do today in bossing back the OCD?”

“I’m sure there were times today where the OCD wasn’t as strong, or when you bossed it back. How did you manage to do that? What did you say or do that helped?”

And of course, remember there are many ways to praise a child or teen:

“How did you do today in bossing back the OCD?”

“Good job on bossing back the OCD!”

“Awesome!”

“William is doing much better now…”

William’s parents brought him to see his family doctor, who recommended a psychologist. After seeing the psychologist, William and his parents learned all about cognitive behavioural therapy and ways to ‘boss back’ his OCD. His parents learned strategies too, and how to support William in fighting the OCD. Interestingly, William’s father realized that he had had minor symptoms of OCD all his life too, and he had just as much benefit from learning about OCD as William did. But back to William - with all the help, his showering and hand washing are almost back to normal... How ironic life is, thought his mother -- who would have thought that one day I’d actually be praising my son for NOT showering!

Where to find help in Eastern Ontario

☐ In a crisis? Child, Youth and Family Crisis Line for Eastern Ontario, 613-260-2360 or toll-free, 1-377-877-7775

☐ Looking for mental health help? www.eMentalHealth.ca is a bilingual directory of mental health services and resources for Ottawa, Eastern Ontario and Canada.

Where to Find Help in Ottawa and Eastern Ontario

☐ The Children’s Hospital of Eastern Ontario
   Your doctor can make a referral by calling our mental health intake line at: 613-737-7600, ext. 2496. For more info on our programs, www.cheo.on.ca

☐ To find a psychologist in Ottawa: Call the Ottawa Academy of Psychology referral service (613) 235-2529. Listing of many, but not all, Ottawa psychologists, www.ottawa-psychologists.org/find.htm

☐ To Find a Psychologist anywhere in Ontario
   College of Psychologists of Ontario, 1-800-489-8388 www.cpo.on.ca.
Support Groups

- **Obsessive Compulsive Disorder (OCD) Parent Support Group**, for parents with children who have OCD. Holds monthly support meetings. For more information, please email barbnesallah@rogers.com or call Janet at 613-220-1507.

- **Parent’s Lifelines of Eastern Ontario**, a support group for parents of children and youth with mental health difficulties. Web: [www.pleono.ca](http://www.pleono.ca)

- **Anxiety Disorders Association of Ontario**, 797 Somerset St W, Ottawa, ON, K1R 6R3, Toll-free: (877) 308-3843, 613-729-6761. Web: [www.anxietyontario.com](http://www.anxietyontario.com)

Want more information?

**Useful websites**

- [www.aacap.org/factsfam/ocd.htm](http://www.aacap.org/factsfam/ocd.htm) (American Academy of Child & Adolescent Psychiatry Fact Sheet #60)
- [www.mentalhealth.com/fr20.html](http://www.mentalhealth.com/fr20.html) (Obsessive-Compulsive Disorder - Internet mental Health) Disorders Association of America
- [www.ocfoundation.org](http://www.ocfoundation.org) (Obsessions in Children - The Obsessive-Compulsive Foundation)

**Books for Parents**

- *What to do when your child has Obsessive Compulsive Disorder - Strategies and Solutions* by Aureen Pinto Wagner Ph.D.
- *Obsessive Compulsive Disorder - New Help for the Family* by Herbert L. Gravitz Ph.D.
- *Up and Down the Worry Hill* by Aureen Pinto Wagner Ph.D. (Great for young children)

Authors: Reviewed by the Mental Health Information Committee at the Children’s Hospital of Eastern Ontario (CHEO) and by members of the Child and Youth Mental Health Information Network (www.cymhin.ca). Thanks to Sylvia Naumovski and Sarah Cannon, Parents for Children’s Mental Health, [www.parentsforchildrensmentalhealth.org](http://www.parentsforchildrensmentalhealth.org)

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Disclaimer: Information in this fact sheet may or may not apply to your child. Your health care provider is the best source of information about your child’s health.

References

