Pediatric Obsessive-Compulsive Disorder

By Jason L. Steadman, Psy.D.

Most likely, you have already heard of Obsessive-Compulsive Disorder (OCD). It is a somewhat "popular" disorder to portray in the media, and fans of the detective show *Monk* or of the 90s sitcom *Friends* are familiar with some of the telltale signs of OCD. However, as comedic media portrayals tend to do, both of these shows give a somewhat inaccurate depiction of OCD. In the case of *Monk,* his symptoms are far more severe than 99.99% of actual cases of OCD, and his "treatment" is a very, very poor depiction of what treatment for OCD should look like. On *Friends,* Monica Gellar is described by many fans as having OCD, but in reality her character portrays a different disorder with different symptoms, but which has a related name – Obsessive-Compulsive Personality Disorder (OCPD). I'll describe both OCD and OCPD a bit below, but we'll focus mainly on OCD, as this is the far more common condition, especially in children.

OCD: A description of the disorder and its associated symptoms

Up until 2013, OCD used to be categorized as a kind of anxiety disorder. However, as we learned more about OCD over the past 2 decades or so, it became clear that even though a person with OCD often complains of anxious symptoms, the disorder itself is pretty different from other anxiety disorders. That's why, in 2013, with the release of the 5th edition of the primary diagnostic manual used in psychiatry, OCD was split into a whole new chapter in the manual, and grouped with other disorders that seem more closely related to OCD than the anxiety disorders are. We now know, for example, that the brain circuits that contribute to OCD are more similar to other disorders of poorly controlled behaviors, including tic-disorders (i.e. Tourette's), Hoarding, Skin-Picking (Excoriation), and Hair-Pulling (Trichotillomania). There are also similarities with other disorders where the mind distorts perception of reality. More specifically, OCD is in the same category as Body Dysmorphic Disorder, where a person becomes preoccupied with a perceived defect or flaw in their physical appearance that is not observable to others (e.g. someone believes that have excessive body fat, but they do not).

When you think about the symptoms of OCD, these above connections make sense. To be diagnosed with OCD, a person must have obsessions and compulsions.

Obsessions are defined as recurrent and persistent thoughts, urges, or images that are intrusive and cause, in most cases, anxiety or distress. To be a true obsession, the person having them must also attempt to ignore or suppress the thoughts, urges, or images with some thought or action (i.e. by performing a compulsion).

Compulsions are repetitive behaviors or mental actus that someone feels driven to perform in response to an obsession or according to rigid rules. The compulsions must also be aimed at preventing or reducing anxiety or distress, but the behaviors are not connected in a realistic way with what they're designed to avoid/prevent, or they are clearly excessive.

In pediatrics, though, it is common for children, especially younger children, to not be able to articulate/describe their obsessions or to clearly connect compulsive behaviors with intended goals. In other words, in young kids, clinically, we most often diagnose OCD based on the presence of clear compulsions, without relying too heavily on identifying obsessions, because multiple studies have found that young kids just don't describe obsessions in the same way that older kids and adults do.

In OCD, we also look at the level of "insight" a person has into their disorder. We can specify if a person has "good" or "fair" insight, meaning they can recognize that their obsessive-compulsive beliefs are definitely or probably not true. A person can also have "poor" insight, where they state that their beliefs are probably true. Finally, a person can have absent insight/delusional beliefs, where they assert that their beliefs are *definitely* true.

In addition to the above, to qualify for true OCD, the behaviors must be time-consuming, meaning they take up more than 1 hour per day, or they otherwise cause significant distress or impairment.

What types of things do kids tend to obsess about?

Obsessions tend to fall in under several categories. **Contamination obsessions** are relatively common. These may include (but aren't limited to) concern with dirt, germs, or illness; disgust with bodily waste or secretions; concern with environmental contaminants (e.g. asbestos, lead, toxic waste); excessive concern about animals/insects (and that they are "dirty"); concern about illness; and so on. **Aggressive obsessions** may also occur and can include recurring fear that you may harm yourself; fear you may harm others; fear harm will come to you; fear harm will come to others because of something you did; violent or horrific images; fear of blurting out obscenities or insults; fear of doing something embarrassing; fear of stealing things; etc. **Sexual obsessions** can happen too, more often in adolescence than in young childhood. These include recurrent forbidden or perverse sexual thoughts, images, or impulses; content involving homosexuality; content involving gender identity; fear you may act out on sexual urges toward others; etc.

Children may also have **magical thoughts or superstitious obsessions** (e.g. belief in lucky/unlucky numbers; stepping on cracks; walking under bridges; etc.), **somatic obsessions** (e.g. excessive concern with a body part or aspect of appearance), **religious obsessions** (fear of offending God or another religious object; excessive concern with right/wrong or morality), **hoarding obsessions** (fear of losing things), or **miscellaneous obsessions** (e.g. excessive worry about symmetry; needing to know or remember; fear of saying certain things; fear of not saying just the right thing; intrusive (non-violent) images; intrusive sounds, words, music, or numbers).

What compulsions can happen?

In children, compulsive behaviors can be just about anything, but like obsessions, they tend to fall under categories. It is important to know, though, that some compulsions can be completely internal, meaning they happen in the child's head, without us ever knowing about them. This is especially true of repeating, counting, and magical compulsions, described below.

Washing/cleaning compulsions include excessive or ritualized handwashing, showering, bathing, toothbrushing, grooming, or toilet routine; excessive cleaning of items (e.g. clothes, school desk, other important items); etc. **Checking compulsions** are also very common, and include checking locks, toys, school books/items; making sure everything is exactly where it is "supposed" to be; checking clothes or body for "spots" or other imperfections; checking (often with parents) that did not or will not harm others or did or will not harm the self; checking that nothing terrible did/will happen; seeking constant reassurance from parents that everything is okay; checking homework over and over to ensure that did not make a mistake; checking that things are "still there;" asking parents to perform a "check" of the house, to ensure everything is "safe."

I also commonly see **repeating compulsions** in my practice, which includes re-reading, erasing, or re-writing schoolwork or other assignments/activities; needing to repeat a routine activity (going up and down the stairs 5 times; going in and out a door; spinning in 3 left circles then 3 right circles; and so on). **Counting compulsions** can also occur and may include counting anything – objects, certain numbers, words,

etc. **Magical compulsions** are also common – stepping over certain spots on the floor; touching an object/self a certain number of times; etc. It's important to note that young children often play magical games for fun, and these should not be confused with compulsions. Compulsions are very rarely "fun" for kids (or adults). If they keep playing the game even though they want to stop, that can be a telltale sign that it may be a compulsion.

Ordering/arranging compulsions are another common one in pediatrics. Children may show a need for symmetry or for "evening things up." They may also **hoard,** refusing to throw things away, even relatively meaningless things. **Childhood obsessive rituals also commonly include other people**. Often, this involves asking a parent to repeatedly answer the same questions, making the parent perform a certain meal time ritual, and so on.

The final category includes **Miscellaneous compulsions**, and may include behaviors such as mental rituals (other than counting); needing to tell, ask, or confess; ritualized eating behaviors; excessive list-making; need to touch, tap, or rub; needing to do things until it feels just right; self-damaging or self-mutilating behavior (scratching, pulling hair, poking eyes, etc.).

Other issues that can resemble OCD

PANS/PANDAS

Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) or Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) are two names for the same syndrome. PANDAS is an older name, while PANS has started to replace PANDAS more recently. Both are disorders where a child has an acute onset of OCD symptoms within a few weeks or months of having an infection. Originally, the disorder was associated with strep infections, hence the name PANDAS. But, over time, we've found that the syndrome can occur with other types of infections too, so we've changed the name to PANS. In either case, in children that present with OCD-symptoms, it is important for doctors to ask if there were any infections in the past 6-12 months. Because PANS can have a delayed onset, parents don't always associate the symptoms with the infection. Another thing that separates PANS from classic OCD is that in PANS, the symptoms come up almost overnight, whereas in OCD, parents can usually describe a long history of their child showing anxiety and/or obsessive worries. In PANS/PANDAS, other symptoms can also arise (e.g. the child begins to lose some fine motor coordination or shows regression in developmental skills). The cause of PANS/PANDAS is that the infection is still present and the body has initiated an immune response that began attacking the brain, causing OCD-like symptoms. Treatment is simple in most cases, by giving the child a course of antibiotics. Rarely, some children may not respond to antibiotics and may need more intense medical treatment, such as IVIG or blood plasma exchange. However, IVIG should be reserved for more severely ill patients. Sometimes, the OCD-symptoms can recur even after medical treatment. Cognitive-behavior therapy is also helpful in these cases, to help manage the symptoms with psychotherapy.

More information on PANDAS can be found here
https://www.nimh.nih.gov/health/publications/pandas/index.shtml

Anxiety Disorders

Sometimes, symptoms that feel like OCD are really just "run of the mill" anxiety. Generalized Anxiety Disorder (Overworrying) can classically present with obsessive anxious thoughts. In anxiety disorders, though, there are no compulsions present.

Autism Spectrum Disorders

Children with Autism Spectrum Disorders (ASD) can commonly struggle with rigid thinking, demand for "sameness," and repetitive behaviors. Thus, ASD can often look a lot like OCD. However, the symptoms are different. In ASD, there are other symptoms present that help differentiate from OCD, and an experienced clinician can tell the difference. If you have questions about this, ask your doctor and/or request a consult with Dr. Steadman.

Eating Disorders

The major eating disorders include Anorexia Nervosa, Bulimia Nervosa, and Binge Eating Disorder. Bulimia and Binge Eating Disorder are both characterized by a loss of control over eating. Patients with these disorders tend to eat large amounts of food at a time, and then they feel guilty about it afterward. In Bulimia, this guilt leads to "purging" – usually through vomiting, excessive exercising, or the use of enemas. In both Bulimia and Binge Eating Disorder, though, weight is either within normal limits or overweight. Anorexia, on the other hand, is classified by excessive control over eating and diet, and requires the patient to be underweight (except in Ayptical Anorexia, where weight can be normal). Anorexia tends to have a lot in common with OCD, then, in that patients obsess repeatedly over food, their diet, and the way their body looks. These obsessions lead to compulsive behaviors, including weighing the self repeatedly, counting calories, refusing to eat even when hungry, and other, related behaviors. I consider Anorexia, then, to be a special type of OCD related to the body and diet. Anorexia, though, is a dangerous disorder (until recently, it was the most deadly psychiatric disorder, only recently surpassed by opioid use disorder), and so it should be treated with extra caution and ideally by a specialized medical team with expertise in Eating Disorders.

Tic disorders and stereotyped movements

Tics are short, involuntary motor movements or vocalizations that can occur in children. Tic disorders are neurological illnesses often treated medically by neurologists. However, psychologists can also offer behavioral treatments for tics, which works quite well to reduce tics. Sometimes, parents can describe compulsive behaviors as tics and can describe tics as compulsive behaviors, because they can look similar, especially if you aren't a doctor with a lot of experience telling the difference. One reliable way to differentiate is that tics come in short bursts and are involuntary. Compulsions, on the other hand, might be described as "involuntary" ("I just have to do it – I can't help it"), but they are still planned, controlled behaviors. Tics are not planned – they are like reflexes.

Stereotyped movements are more complex than tics. They do not tend to come in short bursts, and typically involved different muscle groups than tics. They are similar to compulsions in that they are repetitive, recurrent, and bothersome, but stereotyped movements are not preceded by obsessions, and they are typically still less complex than true compulsions. Common stereotyped movements include head banging, body rocking, and self-biting. They are most common in children with developmental or intellectual delays, but can occur in any child.

Psychotic Disorders

True psychosis in children is extremely rare. So, based only on statistics, it is very unlikely for your child to have a true psychotic disorder. However, in psychosis, it is possible to have delusional beliefs and odd behaviors, similar to those seen in OCD. But in psychosis, there is an array of other symptoms, including hallucinations, thought disorder, and what we call "negative" symptoms.

Depressive Disorders

Children with depression can often "ruminate" on things – that is, they review things in their mind over and over again, which can have an "obsessive" feel. However, this is pretty much the only feature of depression that is similar to OCD. If a child is obsessive ruminating over things, and that leads them to feel depressed, then it is sufficient to just diagnose depression. It is possible to have both depression and OCD, though, if the symptoms of both are truly present.

OCPD

As mentioned above, OCPD is quite different from OCD, although they are often confused with each other. Most of us probably know someone with OC personality traits. If someone has enough of these traits (4 or more), and these traits cause clinically significant impairment, OCPD can be diagnosed. The traits of OCPD include the following:

1. Preoccupation with details, rules, lists, order, organization, or schedules to the extent that the major point of the activity is lost
2. Shows perfectionism that interferes with task completion
3. Is excessively devoted to work and productivity to the exclusion of leisure activities and friendships
4. Is overconscientious, scrupulous, and inflexible about matters of morality, ethics, or values.
5. Is unable to discard worn-out or worthless objects even when they have no sentimental value
6. Is reluctant to delegate tasks or to work with others unless they submit to exactly his or her way of doing things
7. Adopts a tight spending style toward both self and others; money is viewed as something to be hoarded for future emergencies
8. Shows rigidity and stubbornness

As you can see, these traits are different from the definition of obsessions and compulsions used in OCD. People with OCPD do not have compulsions as defined in OCD. Instead, OCPD is a term used to describe a person with extremely rigid beliefs about how things should be done and a high demand that things be done to their particular standard.

How do you treat OCD?

Cognitive behavioral therapy (CBT) has the best evidence for treating OCD. In fact, there is a special type of CBT designed just for OCD, called Exposure and Response Prevention (ERP or EXRP). ERP works by exposing your child to the things that normally trigger compulsions and teaching them skills to help manage anxiety while also preventing the compulsion. So, for a child who obsesses about germs on doorknobs, for example, the therapist may have them touch a doorknob without being allowed to wash their hands afterward. This step would not necessarily be done right away in therapy. An experienced therapist will know how to prepare you and your child for this intervention and will be gentle in deciding when and how to introduce the intervention without overwhelming you child. A typical course of CBT of OCD includes 8-16 sessions over 3-4 months. However, there are forms of intensive treatment that may include receiving treatment every day for 1 week. These intensive treatments work well, but are usually expensive, as they are rarely covered in full by insurance. CBT has no real side effects, but patients do sometimes complain of mild to moderate discomfort with facing anxieties during treatment. Frequency of appointments can also be a burden, as appointments are usually scheduled once per week for 45-90

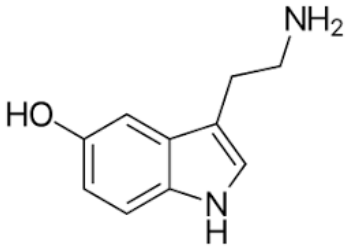
minutes, continuing for 8-16 weeks. Most clinicians will work with you to reduce these burdens as much as possible though.

Treatment for OCD can sometimes include medication as well. Specifically SSRIs (Selective Serotonin Reuptake Inhibitors) have been shown to be quite effective. SSRIs are the same medication used as antidepressants and to treat anxiety. Common types of SSRIs include Zoloft (sertraline) and Prozac (fluoexetine), though there are many types. These are prescribed by an MD, either your child's pediatrician or a psychiatrist. On average, these medications take 3-6 weeks to take effect, so you should not expect an immediate response in your child. Patients are also usually advised to continue taking them 6-12 months *after remission* (after symptoms have gone away or improved enough to no longer be significant). It should also be noted that medications do not cure OCD and some symptoms may return if you stop medication. SSRIs also come with several potential side effects, and so it is important that you review these with your prescriber before you start taking the medication.

How do medications work?

SSRIs work by blocking the reuptake of serotonin in your brain. Serotonin is an important chemical in your brain that allows brain cells to talk to each other. When serotonin isn't being used well, people tend to get depressed or anxious. Low serotonin can also cause sleep and stomach problems.

A picture of serotonin is included below. Another name for serotonin is its chemical name 5-hyrdoxytrytophan (5-HT). So, sometimes you may read papers that use 5-HT as an abbreviation for serotonin. Serotonin is made from another chemical called tryptophan, which we can only get in our bodies from food. However, there isn't a way currently to increase brain serotonin by increasing tryptophan (see below), so there are no medications that do that.



We have two genes that make a protein that converts tryptophan into serotonin – *Tph1 and Tph2. Tph1* is responsible for creating serotonin in the gut, and we call this "gut derived serotonin." *Tph2* is responsible for creating serotonin in the brain, called "brain derived serotonin." It's important to know, though, that these two sources of serotonin never cross over. More than 98% of the body's serotonin is made outside the brain, but none of that serotonin ever goes into the brain. Only serotonin made in the brain can be used in the brain. So, while changing your diet can do a lot of good for you in other ways, it does not have a therapeutic effect on brain serotonin.

So, medications have to work a different way, by helping the brain make better use of the serotonin that's already there. The way brain cells work is they don't actually plug into each other like electrical cords. Instead, they place their ends really close to each other, and there is a small space in between. This is good because it allows each brain cell to be more flexible. Each cell then sort of sprays chemicals into the space in between, which is then "sucked up" by the other brain cell that's next to it. But, each chemical works like keys in a lock, and each chemical can only open certain locks. The locks are called receptors. There are 4 different types of serotonin receptors that scientists have identified, each with different functions and in different locations. A serotonin molecule can open any of those 4 locks. Once those locks are open, the

receiving cell can then go about it's business of doing what it needs to do. If the locks are not opened, nothing happens.

When a neuron (brain cell) "sprays" serotonin into that space in between, some of the serotonin connects to receptors/locks, but the rest of it stays in the space. Your body is not wasteful though, and it came up with ways to recycle that extra serotonin. There are two ways. In method 1, your body uses an enzyme to "eat" the extra serotonin (think of this like a tiny, hungry, but friendly monster) and turn it into something else that your body can use. In method 2, your body uses a "transport protein" (think of this like a truck), which packages the serotonin and takes it back into the original cell, to be reused. The downside to this efficiency though is that sometimes the brain works so hard at recycling that it steals serotonin from being attached to receptors.

SSRIs work, then, by blocking off those transport proteins (the trucks), so they can't steal the extra serotonin, which allows it to stay in the space for longer, and then to connect to the receptors. SSRIs do this ONLY with serotonin transporters. They don't block other neurotransmitters, giving us better control over what neurotransmitters we're changing.

Another class of medications, an older class, are called MAOIs (Monamine Oxidase Inhibitors). Monoamine Oxidase is the name of the enzyme that "eats" the extra serotonin. But MAO is a very hungry monster, and it doesn't only eat serotonin. It eats other neurotransmitters too. That's why doctors don't like to use MAOIs for depression or anxiety unless we have to, because when we block MAO, we cause the brain to have several extra neurotransmitters, not just serotonin. MAOIs work really well to improve symptoms, but they have a lot more side effects than SSRIs. Nowadays, we prefer SSRIs because they give us better control, and are generally safer than MAOIs.

At the same time SSRIs are not perfect. We don't always know what the perfect balance of serotonin is for a person to function optimally, and sometimes it takes time to get it right. Each different type of SSRI also works a bit differently, and so sometimes it takes time to find the right medication. So, if you're considering medication for OCD, it's important to understand that 1) symptoms will not go away immediately, because the mechanism by which they work is complicated, 2) there are side effects with medications, especially as we work to find the right balance for your body, and 3) there are multiple options for medications, with some being safer than others.

A final thing to know is that there is such a thing as serotonin toxicity, which occurs when serotonin levels get too high for your body. The most severe problem is called serotonin syndrome, which is rare, but is a medical emergency, as it can be fatal. If you're taking a medication that increases serotonin and you experience any of the following symptoms, you should go to the ER immediately: 1) Shivering/Tremors, 2) Fever, 3) Confusion, 4) Excessive sweating, 5) Loss of muscle coordination or twitching muscles, 6) Muscle rigidity, 7) Agitation/Restlessness. Because of the risk of serotonin syndrome, it is important that you only take the recommended dosage of your medication, to keep your serotonin from getting too high. It's also important that you don't take multiple serotonergic medications at the same time. This includes OTC supplements like St. John's Wort.

You should also not abruptly stop medications that increase serotonin (unless instructed to do so by a doctor), as you can have what is called a "serotonin discontinuation syndrome." This is less severe than serotonin toxicity, but can include symptoms that feel like the flu as well as possible insomnia, nausea, and dizziness. Usually these are mild and last 1-2 weeks. This syndrome is more likely if you've been taking serotonergic medications for a long time, but there are some types of SSRIs (i.e. Prozac/fluoxetine) where the risk for a discontinuation syndrome is minimal. If you or your child is someone who has a hard time taking medication regularly and is likely to miss doses, it may be better to take Prozac compared to other

medications. At the same time, Prozac stays in your body for a lot longer than other types of SSRIs, which means if you have negative side effects, it will take longer for those side effects to go away. For this reason, a lot of doctors may decide not to try Prozac as a first option, until we know how SSRIs affect you.

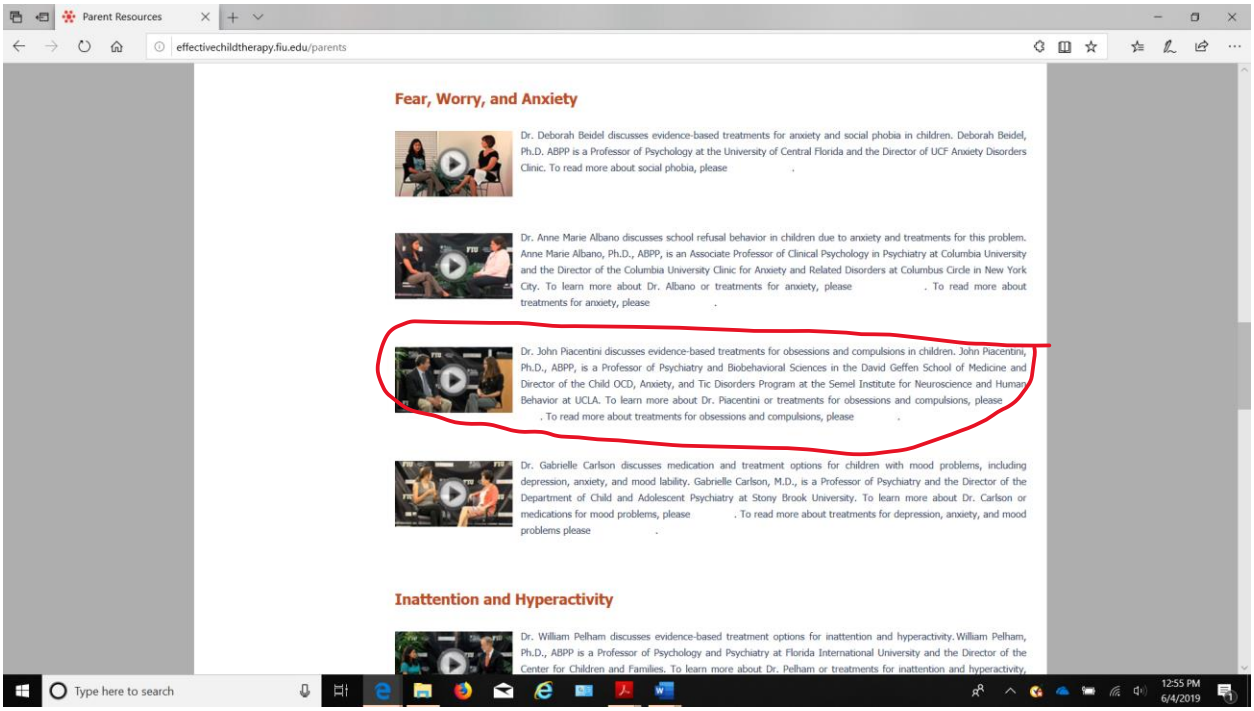
What can I do to help at home?

If your child is having clinically significant symptoms warranting a diagnosis of OCD, in most cases it's best to seek treatment from a professional. However, sometimes children may have milder symptoms that can be managed at home, if parents have the right tools for doing so. **In most cases, combining professionally guided therapy sessions with at home resources is the most effective treatment approach.**

There are TONS of resources available that you can use at home to help your child's OCD symptoms. https://www.ocdkidsmovie.com/ocdresources contains links to numerous resources. A great book for parents (and for kids) is *Talking Back to OCD,* by John March, MD. I have had a number of patients who have used this book successfully, but there are other books available as well that are well-reviewed.

There are also several great online resources for pediatric OCD. The link below contains videos made specifically for parents on a number of childhood psychological concerns. I have circled in the screenshot below the video specific to OCD.

http://effectivechildtherapy.fiu.edu/parents



Here is another good resource providing general information about pediatric OCD, from the American Academy of Child & Adolescent Psychiatry. https://www.aacap.org/AACAP/Families_and_Youth/Resource_Centers/Obsessive_Compulsive_Disorder_Resource_Center/OCD_Resource_Center.aspx

One more link: https://adaa.org/sites/default/files/How-to-Help-Your-Child-A-Parents-Guide-to-OCD.pdf