

Information about:

Obsessive Compulsive Disorder (OCD)

Revised 2013



Vermont Family Network
600 Blair Park Road, Ste 240
Williston, VT 05495
1-800-800-4005
www.VermontFamilyNetwork.org

Introduction

Information About Obsessive Compulsive Disorder (OCD) is part of a series of information packets developed by the Vermont Family Network (VFN). Designed to provide basic information, the packet includes fact sheets, articles, advocacy tips, and resources for families of children with special needs and for the professionals working with them.

After reading the packet, we hope that you'll have a greater understanding of obsessive compulsive disorder (OCD) and the ways in which parents and professionals can support children at home, in school, and in the community. We've selected information from a variety of sources, and many articles are on the Internet.

Thank you to BEST (Building Effective Strategies for Teaching), Vermont Agency of Education, for making this publication possible. Thanks also to the organizations and authors who gave us permission to use their articles and fact sheets. Use of any specific articles in this packet is meant for information purposes only and doesn't indicate any endorsement on the part of VFN of the views and opinions of the authors.

Contents

| Title | Pages |
|---|---------|
| Obsessive-Compulsive Disorder in Children and Adolescents <i>American Academy of Child and Adolescent Psychiatry</i> | 1 - 2 |
| Introduction: Obsessive-Compulsive Disorder <i>National Institute of Mental Health</i> | 3 - 5 |
| OCD At School <i>Beyond OCD</i> | 6 - 8 |
| Academic Support Strategies <i>OCD Education Station</i> | 9 - 19 |
| Advocating for Your Child: 25 Tips for Parents <i>David Fassler, M.D.</i> | 20 - 26 |

Obsessive-Compulsive Disorder in Children and Adolescents

Obsessive-Compulsive Disorder (OCD), usually begins in adolescence or young adulthood and is seen in as many as 1 in 200 children and adolescents. OCD is characterized by recurrent intense obsessions and/or compulsions that cause severe discomfort and interfere with day-to-day functioning. Obsessions are recurrent and persistent thoughts, impulses, or images that are unwanted and cause marked anxiety or distress. Frequently, they are unrealistic or irrational. They are not simply excessive worries about real-life problems or preoccupations. Compulsions are repetitive behaviors or rituals (like hand washing, hoarding, keeping things in order, checking something over and over) or mental acts (like counting, repeating words silently, avoiding). In OCD, the obsessions or compulsions cause significant anxiety or distress, or they interfere with the child's normal routine, academic functioning, social activities, or relationships.

The obsessive thoughts may vary with the age of the child and may change over time. A younger child with OCD may have persistent thoughts that harm will occur to himself or a family member, for example an intruder entering an unlocked door or window. The child may compulsively check all the doors and windows of his home after his parents are asleep in an attempt to relieve anxiety. The child may then fear that he may have accidentally unlocked a door or window while last checking and locking, and then must compulsively check over and over again.

An older child or a teenager with OCD may fear that he will become ill with germs, AIDS, or contaminated food. To cope with his/her feelings, a child may develop "rituals" (a behavior or activity that gets repeated). Sometimes the obsession and compulsion are linked; "I fear this bad thing will happen if I stop checking or hand washing, so I can't stop even if it doesn't make any sense."

Research shows that OCD is a brain disorder and tends to run in families, although this doesn't mean the child will definitely develop symptoms if a parent has the disorder. Recent studies have also shown that OCD may develop or worsen after a streptococcal bacterial infection. A child may also develop OCD with no previous family history.

Children and adolescents often feel shame and embarrassment about their OCD. Many fear it means they're crazy and are hesitant to talk about their thoughts and behaviors. Good communication between parents and children can increase understanding of the problem and help the parents appropriately support their child.

Obsessive-Compulsive Disorder in Children and Adolescents (continued)

Most children with OCD can be treated effectively with a combination of psychotherapy (especially cognitive and behavioral techniques) and certain medications, for example, serotonin reuptake inhibitors (SSRI's). Family support and education are also central to the success of treatment. Antibiotic therapy may be useful in cases where OCD is linked to streptococcal infection.

Seeking help from a child and adolescent psychiatrist is important both to better understand the complex issues created by OCD as well as to get help.

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American Academy of Child and Adolescent Psychiatry. (December 2011). Facts for Families: Obsessive-Compulsive Disorder in Children and Adolescents (No.60). Retrieved from http://www.aacap.org/cs/root/facts_for_families/obsessivecompulsive_disorder_in_children_and_adolescents

Introduction: Obsessive-Compulsive Disorder

Do you feel the need to check and re-check things over and over? Do you have the same thoughts constantly? Do you feel a very strong need to perform certain rituals repeatedly and feel like you have no control over what you are doing?

If so, you may have a type of anxiety disorder called obsessive-compulsive disorder (OCD).

What is OCD?

Everyone double checks things sometimes. For example, you might double check to make sure the stove or iron is turned off before leaving the house. But people with OCD feel the need to check things repeatedly, or have certain thoughts or perform routines and rituals over and over. The thoughts and rituals associated with OCD cause distress and get in the way of daily life.

The frequent upsetting thoughts are called obsessions. To try to control them, a person will feel an overwhelming urge to repeat certain rituals or behaviors called compulsions. People with OCD can't control these obsessions and compulsions.

For many people, OCD starts during childhood or the teen years. Most people are diagnosed by about age 19. Symptoms of OCD may come and go and be better or worse at different times.

What are the signs and symptoms of OCD?

People with OCD generally:

- Have repeated thoughts or images about many different things, such as fear of germs, dirt, or intruders; acts of violence; hurting loved ones; sexual acts; conflicts with religious beliefs; or being overly tidy
- Do the same rituals over and over such as washing hands, locking and unlocking doors, counting, keeping unneeded items, or repeating the same steps again and again
- Can't control the unwanted thoughts and behaviors
- Don't get pleasure when performing the behaviors or rituals, but get brief relief from the anxiety the thoughts cause
- Spend at least 1 hour a day on the thoughts and rituals, which cause distress and get in the way of daily life.

Introduction: Obsessive-Compulsive Disorder (continued)

What causes OCD?

OCD sometimes runs in families, but no one knows for sure why some people have it, while others don't. Researchers have found that several parts of the brain are involved in fear and anxiety. By learning more about fear and anxiety in the brain, scientists may be able to create better treatments. Researchers are also looking for ways in which stress and environmental factors may play a role.

How is OCD treated?

First, talk to your doctor about your symptoms. Your doctor should do an exam to make sure that another physical problem isn't causing the symptoms. The doctor may refer you to a mental health specialist.

OCD is generally treated with psychotherapy, medication, or both.

Psychotherapy. A type of psychotherapy called cognitive behavior therapy is especially useful for treating OCD. It teaches a person different ways of thinking, behaving, and reacting to situations that help him or her feel less anxious or fearful without having obsessive thoughts or acting compulsively. One type of therapy called *exposure and response prevention* is especially helpful in reducing compulsive behaviors in OCD.

Medication. Doctors also may prescribe medication to help treat OCD. The most commonly prescribed medications for OCD are anti-anxiety medications and antidepressants. Anti-anxiety medications are powerful and there are different types. Many types begin working right away, but they generally should not be taken for long periods.

Antidepressants are used to treat depression, but they are also particularly helpful for OCD, probably more so than anti-anxiety medications. They may take several weeks—10 to 12 weeks for some—to start working. Some of these medications may cause side effects such as headache, nausea, or difficulty sleeping. These side effects are usually not a problem for most people, especially if the dose starts off low and is increased slowly over time. **Talk to your doctor about any side effects you may have.**

Introduction: Obsessive-Compulsive Disorder (continued)

How is OCD treated? - Medication (continued)

It's important to know that although antidepressants can be safe and effective for many people, they may be risky for some, especially children, teens, and young adults. A "black box"—the most serious type of warning that a prescription drug can have—has been added to the labels of antidepressant medications. These labels warn people that antidepressants may cause some people to have suicidal thoughts or make suicide attempts. Anyone taking antidepressants should be monitored closely, especially when they first start treatment with medications.

Some people with OCD do better with cognitive behavior therapy, especially exposure and response prevention. Others do better with medication. Still others do best with a combination of the two. Talk with your doctor about the best treatment for you.

What is it like having OCD?

"I couldn't do anything without rituals. They invaded every aspect of my life. Counting really bogged me down. I would wash my hair three times as opposed to once because three was a good luck number and one wasn't. It took me longer to read because I'd count the lines in a paragraph. When I set my alarm at night, I had to set it to a number that wouldn't add up to a 'bad' number."

"Getting dressed in the morning was tough, because I had a routine, and if I didn't follow the routine, I'd get anxious and would have to get dressed again. I always worried that if I didn't do something, my parents were going to die. I'd have these terrible thoughts of harming my parents. I knew that was completely irrational, but the thoughts triggered more anxiety and more senseless behavior. Because of the time I spent on rituals, I was unable to do a lot of things that were important to me."

"I knew the rituals didn't make sense, and I was deeply ashamed of them, but I couldn't seem to overcome them until I got treatment."

National Institute of Mental Health. (2010). Introduction: Obsessive-Compulsive Disorder. Retrieved from <http://www.nimh.nih.gov/health/publications/obsessive-compulsive-disorder-when-unwanted-thoughts-take-over/index.shtml>

OCD At School

Teachers and other school personnel may be powerful allies in identifying, assessing and treating OCD. Because they interact with students for extended periods of time during the school year, they are uniquely positioned to observe behavior that deviates from the norm. School personnel, therefore, may play a critical role in helping identify behavior that is symptomatic of OCD.

Symptoms of OCD may be apparent during various parts of the school day, including class time, study hall, recess, lunch, or during extracurricular activities. Teachers and other school staff members may notice behavior that signals concern from an academic standpoint (e.g., a drop in grades); socially (student has become isolated and peer relationships have begun to suffer); emotionally (a previously happy student appears to be sad or depressed); or behaviorally (a student starts refusing to do assigned work).

If a student is undergoing a mental health assessment, teachers can also provide important information by completing checklists or providing other pertinent student data (number of absences from school, test scores, grades, etc.). This information can be very helpful in providing mental health providers a more well-rounded picture of a child's overall functioning.

Once a child or adolescent is diagnosed with OCD, school personnel can play an extremely important role in treatment by providing the student any necessary supports for functioning successfully in school. Beyond OCD created a special web site called the OCD Education Station, which has a wealth of information for teachers and other school professionals on this topic.

[Learn more about the OCD Education Station](#)

“Stigma” versus Benefits

When a student's OCD has a negative impact on his or her school functioning, he or she may be eligible for various school-based services. For many students with OCD - frequently those with milder cases - those services may be obtained under Section 504 of the Rehabilitation Act of 1973. Section 504 is a civil rights law that protects individuals with disabilities from discrimination. Therefore, an educational program must be designed for students with disabilities to meet his or her individual needs to the same extent that the needs of students without disabilities are met. In other words, Section 504 essentially levels the playing field for students with OCD. Interventions in the form of accommodations are documented in what commonly is referred to as a “504 plan.” Accommodations include providing extra time to take a test, allowing a student to do a written assignment on the computer instead of writing by hand, and countless others.

OCD At School (continued)

“Stigma” versus Benefits (continued)

Many students with OCD, particularly those with more severe cases, may receive services under the Individuals with Disabilities Education Act of 2004 (IDEA), the federal law governing special education and related services. To be eligible for special education services under IDEA, a student must be between the ages of 3 and 21 (or as defined by state law) and meet the definition of either a preschool child with a disability or one or more of 13 disability categories listed in IDEA (experts in the field strongly recommend that students with OCD be identified under the IDEA category “Other Health Impaired”). Moreover, the disability(ies) must have an adverse effect on the student’s learning, social and emotional functioning. A comprehensive evaluation is required to determine if a student has a disability that negatively affects his or her school functioning.

If a student does meet eligibility criteria under IDEA, an individualized education program, or IEP, must be written. The IEP is an extremely detailed written document outlining all special education and related services the student should receive. It essentially serves as a blueprint for how the child is to be educated.

As a parent, trying to determine if your child is eligible for services and if so, whether to seek them under Section 504 or IDEA, can be confusing. A brief comparison of these two laws may be helpful.

In many cases, Section 504 is the appropriate vehicle for providing needed accommodations and interventions for students with OCD. Section 504 provides a quicker and more flexible means for supporting these students in the school setting. Section 504 may also be preferred over IDEA by parents and students who fear potential stigma associated with special education and related services. However, the requirements for a free, appropriate, public education are more detailed under IDEA than in Section 504. IDEA also includes more rights and safeguards for students with OCD and their parents than Section 504. Therefore, if a student with OCD is struggling with academic, social, and/or behavioral problems, it may be preferable to seek special education and related services under IDEA.

OCD At School (continued)

“Stigma” versus Benefits (continued)

If OCD is negatively affecting your child’s school performance, there are a number of steps you can take to help you find the support he or she needs:

- Go to our additional special web site, the [OCD Education Station](#). It provides a wealth of information regarding students with OCD, school-based difficulties they may experience, and strategies to help them better function in the school setting.
- Talk with other parents whose children have already experienced problems with OCD in school and ask them what approach they took as well as the type of services their child received.
- Attend a local support group for parents of children with OCD. It is likely that some or even many of these parents will have worked with school personnel to obtain supports and accommodations for their children. They may be able to provide invaluable suggestions about how to approach schools as well as how NOT to approach schools.
- Learn more about the Individuals with Disabilities Act and Section 504 of the Rehabilitation Act of 1973 (web sites containing more information are listed in the More Resources section of this web site).
- If you are encountering great difficulty with the school in your attempts to get services for your child, you may want to consider contacting an expert in special education or an attorney who specializes in disability law. He or she will be able to provide important information about your child’s rights to a free, appropriate education.

[Learn more about OCD and education](#)

Academic Support Strategies

In order to help students who have OCD get the most out of the classroom learning experience, academic support strategies are frequently necessary. These supports and accommodations will need to be based on the OCD symptoms the student is experiencing.

Some medical and education professionals are concerned that providing accommodations and other educational supports for individuals with OCD doesn't help them overcome their obsessions and compulsions. And it is true that working around a child's OCD symptoms (e.g., allowing a student to do a test orally instead of in writing, reducing the amount of work a student is required to complete), rather than working through the symptoms, does not ultimately help to "fix" the OCD. But wheelchairs don't "fix" physical disabilities, nor do hearing aids "fix" deafness. Yet students with these disabilities -- outwardly visible disabilities -- would be unable to function in the school setting or access the general education curriculum without them. And it would be difficult to imagine that anyone would question or deny a student the use of a wheelchair or hearing aid. But because their disability is hidden, young people with OCD do not look "different." Yet their need for educational supports is no less real than that of students with observable disabilities. Providing temporary accommodations and support strategies can make the difference between a student's keeping up with the class or getting hopelessly behind.

With successful treatment, a child's school-based OCD symptoms may be reduced to the point that educational supports will no longer be necessary. Cognitive Behavior Therapy, for example, involves having the student work through his or her OCD symptoms to overcome difficulties related to writing and rewriting, checking and rechecking, etc. Until the child reaches that point, however, accommodations and supports may be necessary to help the child function in school. For example, within the context of Cognitive Behavior Therapy, a student may have a goal of being able to read a simple paragraph without counting every period at the end of each sentence. Until he or she is able to achieve this goal, it may be necessary for the student to have the text read to him or her by another individual or to listen to a pre-recorded CD of the material.

In addition, students with OCD, like all other students with disabilities, have a legal right to accommodations and support strategies under Section 504 of the Rehabilitation Act of 1973 or IDEA. More information about laws and how they pertain to students who have OCD can be found in [Understanding the Law as it Relates to Students with OCD](#) section of this web site.

Academic Support Strategies (continued)

A number of different sources can be tapped to determine the specific kinds of academic strategies to use with students who have OCD. It may be helpful, for example, for school personnel to confer with one another to share ideas and resources that have been used successfully with these students. It is also essential to speak directly with the student about strategies that have helped him or her succeed academically. In many cases, the student has devised a way to accommodate the difficulty he or she is having. Students -- especially older students -- can be surprisingly inventive, and they may have developed strategies that can be implemented easily in the classroom. Information from the student's parents and, whenever possible, the student's therapist can also be critical in developing academic support strategies. Collaboration among the parents, outside mental health providers, school personnel, and the student will lead to the most effective interventions possible for students with OCD. Other ideas can be found in some of the books and web sites listed in the [Tools and Resources](#) section of this web site.

Flexibility is important, too. OCD symptoms can wax and wane in young people. Academic accommodations and supports may be needed when symptoms worsen (wax), but can be set aside when the symptoms subside (wane). School personnel should also be prepared to change the type of accommodations used based on the specific difficulty the student may be having at the time.

Following are some examples of academic accommodations and support strategies that have been found to be successful with students who have OCD. Of note is that many of these strategies can be helpful to students who exhibit difficulties similar to the student with OCD (e.g., problems with writing, reading, organization, etc.). Included is a section on assistive technology (AT) that may be beneficial for students who have OCD. This section has been excerpted from *Students with OCD: A Handbook for School Personnel* by Dr. Gail Adams (see [Tools and Resources](#) section of this web site).

Academic Support Strategies (continued)

| What the Student with OCD May Be Experiencing | Example of Academic Accommodation or Support Strategy |
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| <p>Difficulty with fears of contamination related to normal classroom activities that involve sharing objects, passing items from student to student, and touching surfaces; may involve washing or other contamination rituals</p> | <p>Allow the student to be first to get any handouts; he or she can hand the stack to another student, thus avoiding papers that were touched by others.</p> <p>Provide a separate set of classroom materials for the student, so he or she does not have to share them with others (book, jar of paste, paints, markers, crayons, etc.). During group activities, allow the student to use this set of materials. Provide a separate set of books for the student to use at home (child may fear bringing “contaminated” materials into the home).</p> <p>Allow the child to avoid being first in line to leave the room -- this keeps the student from having to touch the door knob or handle.</p> <p>Allow the student to leave class a few minutes before passing time to avoid crowded hallways.</p> <p>Allow the student to use hand sanitizer in lieu of going to the bathroom constantly to wash.</p> <p>Work with the student to reduce his or her trips to the bathroom, if they are frequent. You will need to determine the current number of times he or she goes to the bathroom in order to set a reasonable limit, <i>gradually</i> reducing the number of bathroom trips; e.g., it would be inappropriate to try to reduce the number of bathroom visits from 10 (current number) to only 1 all at once.**</p> <p>(**Note: It would be most advantageous if the teacher, a school mental health professional such as the school psychologist or social worker, the parents, and the student collaborated to design and implement an intervention of this nature.)</p> |
| <p>Difficulty with concentrating or focusing on what is being said</p> | <p>Ask the student if he or she would find it helpful if a signal, such as a code word, was used to redirect his or her attention. If so, be sure to involve the student in the choice of signal.</p> <p>Seat the student closer to the teacher to redirect the student's attention, as appropriate.</p> <p>Provide the student with notes or an outline of what is covered in class.</p> |

| What the Student with OCD May Be Experiencing | Example of Academic Accommodation or Support Strategy |
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| <p>Difficulty with concentrating or focusing on what is being said (continued)</p> | <p>Allow the student with OCD to choose (or teacher can assign) another student to share notes or go over class work in preparation for homework or as part of homework. (Be certain both students are comfortable with this arrangement.)</p> <p>Give directions that are clear and short and use visuals to accompany verbal directions (e.g., have directions written on a chart). Also, capture students' attention prior to giving directions, e.g., tell students they need to listen carefully; modulate voice; provide a signal such as a hand clap.</p> |
| <p>Difficulty or slowness with writing, because student must write letters, numbers, words, or sentences over and over; everything has to be "just right" or "just so" (perfectionistic tendencies); revising work multiple times. Extreme fatigue may result from staying up late repeatedly writing and rewriting assignments</p> | <p>Reduce the amount of written homework assigned.</p> <p>Refrain from sending class work home that the student has been unable to complete in school due to writing difficulties. This can create additional stress for the student who is already distressed by OCD symptoms.</p> <p>Allow the student to use a word processor to type assignments.</p> <p>Allow the student to use a tape recorder to record a class assignment (such as a book report).</p> <p>Provide a written outline of the lecture for the student (student may write additional notes on the outline).</p> <p>Allow the student to use a preferred handwriting method (e.g., permit the student to print if cursive writing is problematic).</p> <p>Allow the student to dictate answers, a report, etc. to someone who will write the information.</p> <p>Grade a student's work on content rather than neatness.</p> <p>Allow the student with OCD to choose (or teacher can assign) another student to share written notes. (Be certain both students are comfortable with this arrangement.)</p> <p>Provide the student with alternatives to written assignments, e.g., permit him or her to demonstrate his or her knowledge by drawing a picture, mural, etc. in lieu of writing an essay.</p> |

| What the Student with OCD May Be Experiencing | Example of Academic Accommodation or Support Strategy |
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| <p>Difficulty with reading (e.g., student may need to reread a sentence until it feels "just right"; may need to count how many lowercase "a's" are in a sentence, etc.)</p> | <p>Allow another individual to read to the student (peer, paraprofessional, other) unless the student with OCD (or peer) is uncomfortable with this arrangement.</p> <p>Reduce the amount of material to be read: assign a shorter reading assignment or photocopy the reading assignment and highlight the sections of the text that must be read.</p> <p>Divide reading assignments into shorter segments and allow breaks in between.</p> |
| <p>Difficulty with organization (e.g., organizing materials, time)</p> | <p>Provide the student direct instruction in organizational skills.</p> <p>Have the student use an assignment book that parents and teachers check daily. Allow space for teachers and parents to make written comments, thereby promoting communication.</p> <p>Use visual organizing systems such as color-coded folders (e.g., math folder is red; reading is blue).</p> |
| <p>Difficulty with longer assignments/long term projects (student may procrastinate because work has to be done "perfectly"); student has difficulty making decisions (e.g., fears making "wrong" decision)</p> | <p>Model how to break longer assignments into smaller sections that are easier to handle. For a science project, the sections might include: topic selection; explanation of the approach they will take; researching the topic; writing up an outline of what the display will cover; making the display, etc. For a book report, sections could be: reading the book (divided into several chapters at a time); outline of important points to cover in the report; first draft; final draft. Use charts, outlines, other graphic organizers to provide cues for completing the assignment.</p> <p>Contract - with the student - deadlines for each section. Smaller deliverables with jointly determined due dates can make a seemingly overwhelming project easier to manage.</p> <p>Establish limits on how much time should be spent on any part of a project. Communicate with parents to enlist their help in limiting the time spent.</p> <p>Have the student set up a notebook or other system for organizing his or her work. Use this notebook or "log" to send notes home to parents concerning the student's progress or indicate where extra attention may be needed to finish or understand an assignment. Parents can also</p> |

| What the Student with OCD May Be Experiencing | Example of Academic Accommodation or Support Strategy |
|---|--|
| <p>Difficulty with longer assignments/long term projects (student may procrastinate because work has to be done "perfectly"); student has difficulty making decisions (e.g., fears making "wrong" decision) (continued)</p> | <p>write notes for the teacher in the notebook, and the teacher should check the notebook daily to foster communication between the school and parents.</p> |
| <p>Difficulty with note-taking</p> | <p>Provide the student direct instruction in note-taking strategies, e.g., Cornell System for taking notes.</p> <p>Provide student partial notes that contain the main ideas of the lecture; leave space for student to write additional notes.</p> <p>Allow student to review positive examples of notes (e.g., examples of good notes taken by other students).</p> |
| <p>Difficulty with studying (including studying for tests)</p> | <p>Suggest that the student study with a partner or in groups.</p> <p>Encourage the student to spread studying out over a period of time (e.g., each night before a test) rather than cram (e.g., trying to complete all the necessary studying the night before an exam).</p> <p>Teach students strategies for aiding memorization (mnemonic devices) such as acronyms (e.g., HOMES to remember all the great lakes) or acrostics -- taking the first letter of each word in the sentence "All cows eat grass" to remember the spaces in the bass clef: A, C, E, G.</p> |
| <p>Difficulty with checking and rechecking due to obsessive doubting; repetitive checking to see that all assignments have been completed correctly or "just right"; checking to be certain that all the necessary books and school materials (pens, pencils, assignment sheets, etc.) are in the book bag, desk, or locker and/or organized properly</p> | <p>Allow the student to use the spelling checker on the computer to limit worry over spelling errors (limit number of times spelling words are checked).</p> <p>Allow the student to use a calculator to check math answers <i>one time</i> after he or she has completed the assignment or test by hand.</p> <p>Work with parents to provide the student with two sets of materials and books -- one for school and one for home -- to alleviate stress over whether the student has the right materials to work with in each location. Make duplicate</p> |

| What the Student with OCD May Be Experiencing | Example of Academic Accommodation or Support Strategy |
|---|---|
| <p>Difficulty with checking and rechecking due to obsessive doubting; repetitive checking to see that all assignments have been completed correctly or "just right"; checking to be certain that all the necessary books and school materials (pens, pencils, assignment sheets, etc.) are in the book bag, desk, or locker and/or organized properly (continued)</p> | <p>assignment sheets -- one to keep at school and one to take home.</p> <p>Allow the student some time during the day to organize his or her materials. By providing a set time to do this, some of the anxiety over whether all materials are properly organized is reduced.</p> <p>Check the student's book bag or have a paraprofessional do so, to make sure the correct assignment sheets are going home with the student. If the student is supposed to leave certain supplies at school because he or she has a duplicate set at home, make sure the school set of materials stays at school. A simple form could be devised that lists materials that need to go home/stay at school each day.</p> |
| <p>Difficulty with reassurance-seeking; asking questions repeatedly; asking the teacher to confirm that the student understands the assignment or has completed an assignment correctly</p> | <p>Answer questions, but avoid answering the same question over and over. It can be helpful to limit the number of questions that the student can ask, per class period, per assignment, or per day. You will need to determine the current number of questions he or she asks in order to set a reasonable limit, <i>gradually</i> reducing the number of questions asked.**</p> <p>(**Note: It would be most advantageous if the teacher, a school mental health professional such as the school psychologist or social worker, the parents, and the student collaborated to design an intervention of this nature.)</p> <p>After a question has been asked and answered, confirm to the student that he or she knows the answer now, and move on. Be careful to differentiate between legitimate questions concerning points in an assignment or chapter and questions asked for the purpose of continually seeking reassurance.</p> |
| <p>Difficulty with test taking</p> | <p>Encourage the student to skip around on the test and answer the easiest questions first.</p> <p>Give the student untimed tests, extra time to complete the test, or require the student to answer only certain questions (identified with an asterisk, or every other question, etc.) if time limits are a trigger for anxiety.</p> <p>Place the student in a different (quiet) location to take the test if distraction is a problem.</p> |

| What the Student with OCD May Be Experiencing | Example of Academic Accommodation or Support Strategy |
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| Difficulty with test taking (continued) | <p>Provide breaks during testing.</p> <p>Allow the student an alternative method for producing test answers if writing is problematic; record answers on tape recorder; produce answers orally; produce answers in an alternate test format (e.g., multiple choice, short answer, fill-in-the-blanks) in lieu of essay tests. These options will allow the student to demonstrate his or her knowledge of the material without having to labor over how the words or letters look on the test answers.</p> <p>Assign fewer questions on a test or allow the student to write the answers to every other question.</p> <p>Allow the student to write answers directly on test sheet/booklet if filling in circles is a problem. Teacher may transfer student responses to answer sheet (e.g., teacher may use student's responses to fill in circles on computerized answer sheet).</p> |
| Difficulty making decisions | <p>Assign a book, topic, etc., instead of asking the student to select it.</p> <p>Give the student a choice of two topics, items, etc. to choose from.</p> |

Assistive Technology

One of the requirements of IDEA 1997 and the Individuals with Disabilities Education Act of 2004 is that students with disabilities have access to assistive technology (AT) devices and/or services. These laws also state that AT must be considered for all students eligible for special education services. Assistive technology devices are items, pieces of equipment or product systems (acquired commercially or off the shelf, modified, or customized) that are used to improve or maintain the functional capabilities of children with disabilities. Assistive technology services refer to any services that directly help a child with a disability select, acquire, or use an assistive technology device. Assistive technology is used by individuals with disabilities to allow them to perform tasks that otherwise might be difficult if not impossible. AT can create new opportunities, break down barriers, and level the playing field for students with OCD and other disabilities.

Academic Support Strategies (continued)

Assistive Technology (continued)

Currently, there is no scientific evidence related specifically to the use of assistive technology with students who have OCD. Because these students frequently experience difficulty in the areas of reading, writing, and organization, however, a list of various assistive technologies addressing problems in these areas is provided below. As is the case with any accommodation or support strategy for students with OCD, one type of assistive technology may be extremely effective for one student but ineffective with another. The word processor, for instance, has been a tremendous assist for many students who experience writing rituals. Other students with paper-and-pencil writing rituals, however, have been known to get "stuck" on the computer, as well.

The following sections contain pieces of information from three articles on assistive technology by Kristin Stanberry and Marshall Raskind: (1) Assistive Technology for Kids with Learning Disabilities: An Overview (2009); (2) Assistive Technology Tools: Writing (2009); and (3) Assistive Technology: Reading (2009). All three articles appear on the web site for [LD Online](#). Inclusion of a specific AT in the following list does not suggest an endorsement, and the list is not exhaustive.

Difficulties with reading

- Audio books and electronic publications: user listens to recorded books/other text materials via audiocassettes, CDs, Daisy readers, computers, and MP3 players. Available through the National Library Service for the Blind and Physically Handicapped, Recording for the Blind and Dyslexic, Audible.com, Project Gutenberg, Kindle, Bookshare;
- Optical character recognition: user scans printed material into a computer/handheld unit; text is read aloud by means of a speech synthesis/screen reading system. Examples: Kirzweil 3000, Read and Write Gold, Wynn software, Quicktionary 2 (a pen-like, hand-held scanner that can scan a word or line of text; immediate word-by-word translation is provided);
- Paper-based computer pen: user takes notes while recording a speaker (e.g., teacher). User later can listen to any part of the recording by touching the pen to the corresponding section of notes. Has many other features, as well. Example: Pulse Smartpen by Livescribe;
- Speech synthesizers/screen readers: display and read aloud text (typed, scanned, Internet print) on a computer screen. Examples: AspireReader, Read:Outloud, Write:OutLoud, Kurzweil 3000, Read and Write Gold, Wynn Software; and

Academic Support Strategies (continued)

Difficulties with reading (continued)

- Variable speed control (VSC) tape recorders: user may listen to prerecorded text or tape a speaker (e.g., teacher) and listen to it later. Playback rate may be sped up or slowed down without a voice distortion. Available through MaxiAids.com, Independentliving.com.

Difficulties with writing/expressive writing

- Text expanders: in conjunction with a word processor, user develops, stores, and reuses abbreviations for commonly-used words and phrases. Saves the writer keystrokes and promotes correct spelling of words and phrases that have been coded. Examples: Typelt4Me (available through Shareware), ActiveWords;
- Alternative keyboards: standard keyboard customized by adding graphics to keys, grouping keys by color/location, etc. Examples: Intellikeys, Big Keys;
- Portable word processors; keyboard devices that are lightweight and easy to transport. Examples: AlphaSmart, Neo, Fusion, Quickpad, Netbook;
- Graphic organizers and outlining programs: user organizes unstructured information into appropriate categories and order. Examples: Inspiration, Kidspiration, Draft:Builder;
- Paper-based computer pen: user takes notes while recording a speaker (e.g., teacher). User later can listen to any part of the recording by touching the pen to the corresponding section of notes. Has many other features, as well. Example: Pulse Smartpen by Livescribe;
- Speech recognition software programs: in conjunction with word processor, user speaks into a microphone and spoken words appear on computer screen as text. Examples: Dragon Naturally Speaking, Microsoft Windows (XP, Vista, Windows 7), Speech Recognition, SpeakQ, Macspeech Dictate, Voxforge;
- Talking spell-checkers/Electronic dictionaries: talking devices display chosen words on the computer screen as they are "read aloud." Assists user with correct spelling while writing and proofreading. Examples: Franklin Electronic Dictionaries/Spell correctors, WordWeb Pro; and
- Word prediction software programs: help with word processing by predicting the word the user intends to type; user selects appropriate word. Assists with correct spelling, grammar, and word choices with fewer keystrokes. Examples: Co:Writer, WordQ, IntelliTalk, Read and Write Gold, Kurzweil 3000, Wynn Software.

Academic Support Strategies (continued)

Difficulties with organization/memory

- Free-form Database software: in conjunction with word processor, helps user develop and store electronic notes by writing down information on any topic quickly. User later can retrieve information by typing any part of the original note. Examples: AskSam, Microsoft Office OneNote (Kurzweil also has sticky notes feature);
- Information/Data Managers: help user plan, organize, store and retrieve information (e.g., calendar, contact data) in electronic form. Examples: Franklin (hand-held organizers), Palm, Pocket PC, iPod/iPhone, Droid;
- Alarm Reminders: user can program alarms built within cell phones, handheld devices, or specialized watches to remind them of important appointments or assignments. Examples: cell phones with alarm features, productivity apps for iPhone/iPod Touch/iPad/Droid, alarm watches with or without vibration; and
- Paper-based computer pen: user takes notes while recording a speaker (e.g., teacher). User later can listen to any part of the recording by touching the pen to the corresponding section of notes. Has many other features, as well. Example: Pulse Smartpen by Livescribe.

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Advocating for Your Child: 25 Tips for Parents

By David Fassler, M.D.

According to the Surgeon General, 1 child in 5 will experience significant problems due to a psychiatric disorder. The good news is that we can help many, if not most, of these youngsters. The real tragedy is that so few, less than 1 in 3, are receiving the comprehensive treatment they really need.

Children and adolescents with emotional and behavioral problems deserve access to the best possible mental health care. Unfortunately, such services are often difficult to obtain. Parents can help by being informed, involved and persistent advocates on behalf of their children.

The following outline offers specific tips and suggestions which parents may find useful in such advocacy efforts.

Individual advocacy for your own child:

1. **Get a comprehensive evaluation.** Child psychiatric disorders are complex and confusing. A full assessment will often involve several visits. Effective treatment depends on a careful and accurate diagnosis.
2. **Insist on the best.** Talk to physicians, therapists, guidance counselors and other parents. Find out who in your community has the most experience and expertise in evaluating and treating your child's particular condition. Check the clinician's credentials carefully. Are they appropriately licensed or certified in your state? If he or she is a physician, are they "Board Certified"? Push schools, insurance companies and state agencies to provide the most appropriate and best possible services, not merely services which are deemed sufficient or adequate.
3. **Ask lots of questions about any diagnosis or proposed treatment.** Encourage your child to ask any questions he or she may have, as well. Remember that no one has all the answers, and that there are few simple solutions for complex child psychiatric disorders. In addition, all treatments have both risks and benefits. Make sure you and your child understand the full range of treatment options available so you can make a truly informed decision.
4. **Insist on care which is "family centered" and which builds on your child's strengths.** Ask about specific goals and objectives. How will you know if treatment is helping? If your child's problems persist or worsen, what options and alternatives are available?

Advocating for Your Child: 25 Tips for Parents (continued)

- 5. Ask about comprehensive “wrap around” or individualized services, geared specifically to the needs of your child and family.** Are such services available in your state or community? If not, why not?
- 6. Be prepared.** One of the most important things you can do to help your child is to keep all information, including past consultation and treatment reports, in an organized place. Insist on receiving your own copies of all evaluations. Records can easily be misplaced, delayed or even destroyed. Maintaining your own file with all relevant information can help avoid unnecessary duplication of previous treatment efforts.
- 7. Feel free to seek a second opinion.** Any responsible mental health professional will be glad to help with referrals or by sharing information. If you have any questions at all about your child’s diagnosis or the proposed course of treatment, by all means, arrange an independent consultation with another clinician.
- 8. Help your child learn about their condition.** Use books, pamphlets and the Internet. Make sure the information is age-appropriate. Answer questions with honest, accurate and consistent information, but don’t overload children with more detail than they need or want.
- 9. Learn the details of your insurance policy, and learn about the laws governing insurance in your state.** For example, in some states, insurance companies must provide access to a specialist, such as a child and adolescent psychiatrist, within a certain distance from your home. If no such specialist is available as part of the company’s “network”, you may be able to receive treatment from a provider of your choice, with the insurance company responsible for full payment.
- 10. Work with the schools.** Insist on access to appropriate mental health consultation services. Suggest in-service training programs to enhance awareness about child psychiatric disorders. Request copies of your child’s educational records, including the results of any formal testing or other evaluations. Ask to be included in any and all school meetings held to discuss your child.
- 11. Learn about the reimbursement and funding systems in your state.** The more you know, the better you can advocate on behalf of your child. How does Medicaid work? Which services are covered and which are excluded? Is there a “waiver program” which allows increased flexibility based on the specific needs of children and families? Is your child eligible? If not, why not? What other sources of funding are potentially available?

Advocating for Your Child: 25 Tips for Parents (continued)

- 12. Get to know the state insurance commissioner and healthcare “ombudsperson” or consumer representative.** Ask them to attend regular meetings with parent groups. Let them know about your experiences.
- 13. Use a lawyer, if necessary.** Learn about the local legal resources. Find out which lawyers in your community are familiar with educational and mental health issues. Talk to your local Protection and Advocacy agency or American Civil Liberties Union for suggestions. Call the State Bar Association. Talk to other parents who are lawyers or who have used lawyers. Consider a legal consultation to make sure you are pursuing all appropriate avenues and options regarding services for your child.

Statewide advocacy for all children, including your own:

- 14. Become politically active.** Meet with state senators and representatives. Question candidates about their positions on access to necessary and appropriate mental health services for children and families. Testify at hearings on state legislation and budgets. Legislators are more likely to be influenced and persuaded by personal stories than by data, statistics or the opinions of professionals.
- 15. Build coalitions and work with local advocacy and parent organizations** such as NAMI, NMHA and the Federation of Families. Develop and publicize a common “Agenda for Children’s Mental Health”.
- 16. Teach children about advocacy.** Invite them to become involved in advocacy activities, where appropriate, but don’t force them to participate.
- 17. Develop a legislative strategy.** If your state does not yet have parity legislation, put this at the top of the agenda. Other “family protection” initiatives include:
 - access to an independent panel to review and potentially reverse insurance company denials
 - consumer representation on community mental health center boards
 - adequate network provisions, which mandate timely and appropriate access to specialists
 - adequate funding for school and community based mental health services.

Advocating for Your Child: 25 Tips for Parents (continued)

- 18. Seek bipartisan support.** Mental illness affects families of all political persuasions. Building a broad base of support has been a key to successful legislative initiatives, both at the State and Federal levels.
- 19. Fight stigma.** Develop an ongoing local education campaign that reiterates the key messages:
 - child psychiatric disorders are very real illnesses
 - they effect lots of kids and adolescents
 - fortunately, they are also quite treatable, especially if treatment begins early and is individualized to the needs of each child and family.
- 20. Become involved with medical education.** Meet with local medical students and residents. Sensitize them to the issues and challenges families face when caring for a child with emotional and behavioral problems.
- 21. Use the media.** Write letters to the editor and/or op-ed pieces on child mental health issues. Meet with local reporters covering health care topics. Suggest story ideas to local TV stations.
- 22. Work with local professional organizations.** Psychiatrists, psychologists, social workers, psychiatric nurses, and mental health counselors are natural allies with a common advocacy agenda. Coordinate efforts on issues such as parity, funding for mental health services, managed care oversight, etc. Professional organizations may also have access to resources, including funds for lobbying and/or public education initiatives, from their national associations.
- 23. Talk to other parents.** Seek out and join local parent support groups. If none exist, consider starting one. Develop an email “listserv” to facilitate communication. Circulate articles, information and suggestions about local resources.
- 24. Attend regional and national conferences** of parent and advocacy organizations. Such meetings provide information, ideas, camaraderie and support. Sharing experiences with other parents is both helpful and empowering.
- 25. Don’t give up.** Aim for and celebrate incremental victories and accomplishments. Remember, advocacy is an ongoing process!

Advocating for Your Child: 25 Tips for Parents (continued)

There's no right or wrong way to be an advocate for your child. Advocacy efforts and initiatives should be individualized to your state, community and the particular issues, circumstances and needs within your family. Advocacy is also hard work. Even when people want to help, and are willing to listen, it takes lots of time and energy to change the system. But when it works, and it often does, the outcome is clearly worthwhile. You really can make a difference, both for your own child, and ultimately for all children who need and deserve access to appropriate and effective mental health treatment services.

Resources

The following organizations are excellent resources regarding advocacy on behalf of children's mental health:

American Academy of Child and Adolescent Psychiatry
3615 Wisconsin Avenue, NW
Washington, DC 20016
(202) 966-7300
www.aacap.org

American Psychiatric Association
Division of Public Affairs
1400 K Street, NW
Washington, DC 20005
(202) 682-6140
www.psych.org

Federation of Families for Children's Mental Health
1101 King Street, Suite 420
Alexandria, VA 22314
(703) 684-7710
www.ffcmh.org

National Alliance on Mental Illness
3803 N. Fairfax Dr. Suite 100
Arlington, VA 22203
(703) 524-7600
www.nami.org

Advocating for Your Child: 25 Tips for Parents (continued)

Resources (continued)

National Disability Rights Network (NDRN)
900 Second St. NE, Suite 211
Washington, DC 20002
(202) 408-9514
www.ndrn.org

National Mental Health Association
1021 Prince Street
Alexandria, VA 22314-2971
1-800-969-6642
www.nmha.org

The Children's Defense Fund
25 E Street NW
Washington, DC 20001
(202) 628-8787
www.childrensdefense.org

Bazelon Center for Mental Health Law
1101 15th Street NW, Suite 1212
Washington, DC 20005-5002
(202) 467-5730
www.bazelon.org

The Balanced Mind Foundation
1187 Wilmette Avenue
P.M.B. #331
Wilmette, IL 60091
(847) 256-8525

Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)
8181 Professional Place, Suite 201,
Landover, MD 20785 CHADD
1-800-233-4050
(301) 306-7070
www.chadd.org

Advocating for Your Child: 25 Tips for Parents (continued)

Resources (continued)

Juvenile Bipolar Research Foundation
49 S. Quaker Road
Pawling, NY 12564
(203) 226-2216
www.bpchildresearch.org

Depression and Bipolar Support Alliance (DBSA)
730 N. Franklin Street, Suite 501
Chicago, IL 60610
1-800-826-3632
(312) 642-0049
www.ndmda.org

Depression and Related Affective Disorders Association (DRADA)
Meyer 3-181, 600 North Wolfe Street
Baltimore, MD 21287-7381
(410) 955-4647
www.drada.org

Dr. Fassler is a Board Certified Child and Adolescent Psychiatrist practicing in Burlington, Vermont. He is a Clinical Associate Professor in the Department of Psychiatry at the University of Vermont College of Medicine. Dr. Fassler is also a Trustee of the American Psychiatric Association (www.psych.org), a Fellow of the American Academy of Child and Adolescent Psychiatry (www.aacap.org), and a member of the Board of the Federation of Families for Children's Mental Health (www.ffcmh.org).

Fassler, D. (2003). Advocating for Your Child: 25 Tips for Parents. Retrieved from
http://www.nami.org/Content/ContentGroups/CAAC/How_To_Advocate_For_Your_Child.htm