

The Definitive and Reassuring Guide to Childhood's Most Misunderstood Disorder

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Newsletter May 2006, Vol. 22

May 2006, Vol. 22 Janice Papolos and Demitri Papolos, MD



A Day in the Life

Each week, millions of viewers tune into the hit show, 24. They watch as federal agent Jack Bauer of the Counter Terrorist Unit battles threats to national security, barely escaping with his life. The season unfolds in real time: each show depicts one hour; each season, 24. Every so often, a split-screen panel updates the audience about the parallel adventures of other key characters in the story, and, before commercial breaks, the tension is heightened as a digital clock ticks away the hour, the minutes, and the seconds. It's a pretty electrifying hour of "must-see-TV."

24 hours in the life of many children with bipolar disorder and their families is just as heart pounding: filled with threats, crises, and cliffhangers. But the hours are interminable (no one yells "Cut!"), there are no commercial breaks, and there is never a hiatus when the set shuts down and the cast and crew fly off to exotic locales.

No, this is real time 24/7. And because this intense struggle is so difficult for others to understand, we thought we would condense some of what many children and parents are experiencing, with the hope that one document reveals a day in the life.

6:30

The Day Begins:

Parents typically wake to an alarm and immediately face the day with churning stomachs and dread. Probably due to a phase-delay in the pattern of their children's sleep, their sons and daughters typically have difficulty going to sleep at night, and they cannot be awakened in the morning. Parents have to mount a siege simply to get their children up and out the door. One mother described it like this:

Yesterday morning it took an hour-and-a-half attempting to get him

up. We kept shaking him, beseeching, threatening, beseeching anxiously.... We even called his cell phone thinking he might pick it up for a friend's call. He simply growled, muttered something we would have preferred not to hear, and turned over and went back to sleep.

We finally did see him rise from the bed and we ran the shower thinking that might wake him up. Ten minutes later we found him in the bathroom curled up on the bath mat, sound asleep.

While it may seem as if the child or adolescent is behaving in an oppositional manner, a great many of these youngsters actually suffer from something called *sleep inertia*.

What Is Sleep Inertia?

Sleep inertia is a transitional state of lowered arousal occurring immediately after awakening from sleep and producing a temporary decrement in any subsequent performance. Studies show that sleep inertia can last from a few minutes to four hours. Youngsters with bipolar disorder are far closer to the latter than the former. One 17-year-old girl described her attempts to get up in the morning this way:

I feel as though my *insides* are whining. I will do anything not to get up. Sleep is more important than anything in the world. I could sleep until 4:00 in the afternoon. I never think about it from my mother's point-of-view. I don't think *anything*. When I do get to school (after much yelling by my mother and me back at her), I have my head on the desk until somewhere around 11:00 in the morning. Right before lunch I seem to truly get up.

The "phase delay" of their 24-hour rhythms often makes these youngsters sluggish in the morning; more activated as afternoon gives way to evening; and then the rocket thrusters go off as bedtime approaches. Their energy level can climb so high, their thoughts often race, and they are unable to shut down and get to sleep. The next morning this same pattern begins again.

Several other facts make it difficult for a child to get up. The medications can be sedating; he or she may be depressed and chronically tired; or the thought of facing the school day may produce waves of anxiety or panic and the child may express somatic complaints (stomach aches and headaches). Parents are always forced to make a decision: Are the complaints an emerging "bug," or is the child feeling excessive anxiety and trying to stay home where he or she feels more comfortable.

And this all happens before the orange juice appears on the table.

The bus ride to school can also be fraught with anxiety for the child, as he or

she may feel singled out for teasing or bullying, and the noise level can be extremely irritating. Parents often have to drive their still-soporific children to school, risking being late themselves, and sparking anxiety about their own job security.

8:00

School Begins:

While some children look forward to seeing their friends in the morning and may anticipate certain classes or activities, the student with bipolar disorder is shouldering some serious impediments to any comfort level or availability for education.

In addition to morning sluggishness and the anxiety, many kids with bipolar disorder have difficulty interpreting social cues and may feel that other kids are finding them odd or out of step.

Author Tracy Anglada, in her upcoming book *Intense Minds* writes that:

Few children with bipolar disorder feel that they can relate to the outside world. In many ways they have difficulty relating to themselves. They don't feel like they fit in, even with people who care for them. Especially during depression, the world seems to be passing them by, as if there were a barrier between them and everything else. Even in a room full of people they can feel totally alone.

She goes on to quote a young girl named Lee who says, "I would just stop, wherever I was, and watch the world exist, wondering how they all did it, and wondering why it all came so easily for them."

Adding to their discomfort with classmates, children and adolescents with bipolar disorder often suffer significant weight gain from the medications they take, and-to put it bluntly-fat kids are rarely on the "A List" in terms of popularity. Their self-esteem is extraordinarily low. Their level of irritability is high and can be exacerbated by the chaos and noise of students pushing through hallways. The days are fast-paced with so many transitions and these youngsters lack flexibility and do not transition easily.

And this is the first 90 minutes of the day and academics haven't even entered the picture.

(Split Screen): Meantime, the parents are at home or have reached work and are worried that every time their cell phones ring it will be the child pleading to come home (many of them suffer severe separation anxiety); or it will be the school nurse reporting that their child doesn't feel well; or (the biggest fear), it will be the Vice-Principal in charge of disciplinary issues calling to discuss "an

incident" in which the child lost control, or was irritable and disrespectful to a teacher, or got into a fight with another child.

On the other hand, some parents don't have to worry during the school day, as their children seem to be able to keep things together in the outside world and save all their pent-up frustration and anger for the mother when they get home. (More about this later.)

8:00-2:45

The Longest Day:

If all students with bipolar disorder did well in school and achieved a sense of mastery in their work, they'd have a balancing force that would smooth out some of their anxiety and worry and frustration. But this is rarely the case. Many of these children have co-occurring learning disabilities (difficulties with reading, writing, and mathematics), and most have significant attentional problems. In addition, evidence is rapidly accruing that a majority of these children and adolescents have many deficits in the area known as "executive functions."

What Are Executive Functions?

The frontal lobes of the brain (including the prefrontal cortex, which is a layer of tissue that lies just behind the forehead) are the most forward part of the brain. The frontal lobes coordinate speech, reasoning, problem solving, strategizing, attention, self-control, organization motor sequencing, working memory, and other processes central to higher functioning. Working memory-the ability to hold information in short-term memory while manipulating it toward problem solving or sequencing it in a logical order-allows human beings to tackle and complete tasks. All of these abilities and more are essential for success in the academic environment as well as all other situations in life, particularly as the child reaches middle school and beyond.

Many youngsters with bipolar disorder are severely compromised in these abilities.

These students can be so distracted by external stimuli and it is difficult for them to sustain attention and interest in the material being covered in the classroom. Many seem to get lost in space and time, and easily become bored. (Some kids will attempt to seek stimulation by becoming the class clown or by becoming provocative.)

Time is so indeterminable and fuzzy to some of these students that they can become confused as to when each class ends. Their anxiety increases and makes them irritable and even less available for education. (Educators could help in a major way if they quietly cued the student as to how much longer the class would last and could discretely inform the student as to where his or her next class was.)

And then there are the difficulties with written expression.

The Problem With Writing

There are no statistics, but it is estimated by some psychiatrists and neuropsychologists who treat and test children with bipolar disorder, that at least half of these children have disorders of written expression. The numbers may even be higher.

The problem for some children is language-based (and may co-exist with dyslexia); for others it is a motor outflow difficulty or a problem with fine motor coordination; and for many children with bipolar disorder the problem may be a severe difficulty in organizing thoughts, relinquishing original ideas and reformulating them; and marshaling the energy and attention to complete the task-the executive function deficits we spoke of above.

In addition, some students with bipolar disorder are so perfectionistic that they erase repeatedly and become extremely frustrated as the work proceeds at a snail's pace and most remains unfinished.

Moreover, in a hypomanic state, the thoughts may race and ideas pour out faster than the motor or organizational controls; conversely, in a depressed phase, there may be a slow-down of thought and a paucity of ideas.

Any one of these problems will make writing a demand that will most likely be resisted-very vehemently-and with increasing frustration and anger.

12:30

Lunch:

Unstructured periods of the day such as lunchtime and recess bring a host of other problems. Cliques sequester tables and team games, and the noise levels and chaotic atmosphere are overwhelming to such sensitive children. It might be best if they have a safe place in the school-the office of the guidance counselor, or a place in the library-where they can eat lunch or just relax.

2:30

Completion of the School Day:

As the time comes to pack up homework assignments and the books and papers necessary to complete them, students with bipolar disorder often have difficulty with the organizing and sequencing process that must take place in order to ensure all these materials are present and accounted for and find their way into the backpack. And if anything goes missing, the stage is set not only for failure with that evening's assignments, but for tense times with the mothers

and fathers who are expected to motivate their children and oversee the evening's assignments. (Any IEP that is drafted for a child with these organizational difficulties should plan for a teacher or an aide to help in the packing of the back pack and should teach the student how to break down the required tasks for the evening and double check the materials they will need to complete them. In addition, most children should have a duplicate set of books at home.)

Many children will need a significant reduction in the amount of homework they're expected to complete each night, or should have time scheduled into the school day when they can complete the assignments, as they are dealing with other problems as the afternoon and evening draw closer.

(Split Screen): Of course none of this takes into account the seasonal changes that occur for people with bipolar disorder. Like adults, many of the children and adolescents suffer seasonal dips or accelerations in mood: they may start the school year off well, but as the days of autumn shorten, the slow-down and lethargy of depression may catch them out, and the concentration that school demands begins to elude them. They may not care what the assignments are and lack the energy to contemplate them. Conversely, the lengthening days of early spring and the increase in intensity of the daylight may promote periods of increased energy. Thoughts may begin to race, the kids have a greater urge to move, and many ideas pour into their minds. Again, concentration becomes a problem and school may feel restrictive and a waste of time, and homework may be viewed as stupid and beneath them.

3:00

Getting Home:

Since the bus ride home can be wild and disturbing, thus making incidents with other children more likely, many parents (in most cases the mothers) pick their children up at school. And now, the child who has somehow managed to keep it together throughout a day that has brought anxiety, frustration, irritation, and a sense of failure and humiliation, is in the private orbit of the mother-away from all onlookers. This simple ride home can devolve into the hell-mobile-on-earth as the child makes unreasonable demands, insists on going here or there, wants this or that kind of food, and begins shouting, kicking the back of the parent's seat, and exploding with a litany of foul language. The parent must attempt to de-escalate the gathering storm and drive at the same time.

Many pull over and try to reason with the child; sometimes this merely inflames the situation and the mother simply puts up with the abusive language and behavior and tries to get home as quickly as possible.

Some gratify the demands of the child to keep the peace (especially if the child

is not yet stable or there are siblings in the car). The fury pouring out of their children at very close range is extraordinarily unnerving.

(Split Screen): If the child is able to take the school bus home, any welcome from the parent to the child may create an opportunity to vent. A simple "How was your day, honey?" may open the flood gates and a mother stands by while her son or daughter turns from the school day's Dr. Jeckyl to the at-home Mr. Hyde. If the word "no" shows up anywhere in the mother's vocabulary, the child may begin to tantrum and rage (and these rages can go on for hours).

Tracy Anglada in *Intense Minds* describes the microscopically-short fuse of youngsters with bipolar disorder. She says: "Anger is an emotion we all experience...if you get fired from a job, you get angry...if a car runs a red light and narrowly escapes slamming into you, you may feel angry. The anger associated with bipolar disorder in children is different. It is an internal state that requires no outside prompting. It has a fuel all its own. This internal anger is so reactive but with higher intensity and less restraint."

One of the children we interviewed for our book gave a fascinating description as to how he feels when a rage gathers. He explained:

It comes out so quickly; faster than a knee-jerk reaction. It's like electricity shoots through me. It's like being struck with lightening. I feel rage and hurt and a need to strike back. I would be raging every day, multiple times a day, verbally abusive, nasty, negative, but very careful not to show it to the outside world.

A teenager described her rages this way:

I used to go to my room and punch the walls and I couldn't stop crying. It was like a dream you couldn't recover in the morning: You know something bad and worrisome has been a concern somewhere in your brain, but you just can't remember it.

Most of the children are so remorseful after these affective storms, that one mother told us that "His remorse is more heartbreaking than his rages."

Certainly there is something poorly regulated in the central nervous system of most children with early-onset bipolar disorder. So many of the children have sensory integration problems, exaggerated stress responses, elation and irritability, depression and low energy states, poor impulse control, and low frustration tolerance, that it is no wonder that the confluence of these states and traits culminate in aggressive rages.

Because these children are so proud and often manage to keep it together in the outside world, people don't believe that this charming child can turn so quickly in the home environment, and they are apt to jump to the conclusion that the child is manipulative, or that the mother is igniting the problem, thus placing a double burden on the already-abused mother.

It is more likely that the emotional ties to the mother are so intense and these children are so uncomfortable in their own minds and bodies that they unreasonably expect her to reestablish a harbor of safety, all the while withstanding their aggression.

One 14-year-old boy told us that the thing that infuriates him more than anything when he's raging at his mother is when she turns away or does not look at him kindly. He cannot see that his actions are the catalyst of the painful encounter. When she turns away, he feels abandoned to his terror and loss of control. His mother should do something to lessen his overwhelming fear and to demonstrate her concern for his safety and protection.

Indeed, a sense of threat seems to pervade the waking and sleeping hours of these children, yet they are too proud to show their fear to the outside world and reserve it for the one person they know will never walk away-their mother.

(Split Screen): Not all children tantrum and rage, but whether they do or not, most are prone to boredom. They can't seem to get invested in anything and whine and complain constantly about being bored. Because the children feel helpless and so often out-of-control, they desperately need to reconnect and escape from the intolerable feelings inside. Often they become provocative-they shake things up with other people to add that much needed spark that makes them feel involved and in control. They may tease and annoy a sister, or cause a brother to lose at Nintendo. They leave chaos in their wake. Meantime the mother gets to play bad cop and camp counselor all at the same time to redirect her very bored, disaffected youngster. (Video games and television may be the only activities that bring some peace into the household as someone has to prepare dinner or at least set the table for take-out food and oversee the homework and activities of the other siblings.)

6:00

Dinner:

This can be dicey as the youngster may be involved watching television, playing Nintendo, and not be easily disengaged or transitioned to the dinner table. Parents have a choice: they can demand the child's presence, thus risking a full-scale blow-up; or decide that they have to pick their battles and it's more important to have a pleasant dinner with their other children.

Some evenings all will flow smoothly; others will quickly disintegrate. Parents have to learn to live with the extraordinary unpredictability of their children's behaviors. One father explained: "Things can be going along smoothly and then something would anger him and an attack would start for hours on end. We tried never to let our guard down, but he was often so charming and sweet that we would constantly express surprise when it happened. We are always

walking on eggshells."

7:00

Homework:

The time to sit down and organize and concentrate in order to do homework often coincides with periods of rapid cycling that can begin in the afternoon and early evening hours. The moods of the children cycle upwards: they become silly and giddy, their thoughts race, and it's nearly impossible to get them to concentrate on homework assignments. And, as we saw earlier, any demand to return to an arena that is difficult and frustrating is bound to raise resistance and opposition.

Parents become extremely anxious about the work that will go unfinished and the children will score badly on tests (thus reinforcing their already-low self-esteem and demoralizing them even more). They also fear that the teachers will frown on their parenting skills. (Note: We have found that once teachers understand what is happening for the child and family, they do everything to help out. However, the teachers cannot be left in the dark as to what is happening to the child in the after-school and evening hours.)

9:00

Time For Bed:

Despite the parents' best efforts to establish a slow-down of the day and to help settle the child for sleep, two factors will work against this happening: As we mentioned above, the minds and bodies of these youngsters are more active in the evening hours; and many of them are absolutely terrified of going to sleep.

They are prone to night terrors where predators stalk them, chase them, and kill them or their families in particularly violent and horrific ways. "I was being chased by a masked shadowy man and I got to the stoop of my house, and he kept stabbing me in the back-over and over," said one boy "Or, I am being chased by headless men who are going to eat me."

Blood and death and dismemberment appear often in the dreams. One little girl told her mother that she dreamed that something very scary was pulling her under her kindergarten room, as blood began to flood the floor of the classroom. Many of the pictures these children draw in the daytime reflect themes of pursuit, weapons, and blood dripping from severed limbs and lopped off heads.

With such emotionally-charged imagery attaching to the dream state throughout the night, is it any wonder that these children are so often in combative and irritable modes during the day, and that they are absolutely

terrified of bedtime?

Parents spend hours at their children's bedsides at night trying to reassure them and make them feel safe and protected. Most of the younger children eventually sneak or force themselves into their parents' bedrooms as they are too afraid to stay in their rooms alone.

Meantime, marriages are placed under heavy strain. The sheer exhaustion of having to deal with all of this (and the doctors' appointments, the trips to the pharmacy, the huge expenses, the guilt about the other siblings, and the fears of what the outside world is thinking of them) leaves the parents with little time or energy to develop plans for their own needs and pleasures in life.

6:30 AM

A New Day Dawns

We hope that this snapshot of "a day in the life" generates understanding and compassion for the child who must tolerate this emotional turmoil and its consequences, and for the parents who are trying desperately to help their children and keep their families together.

Unquestionably, proper medications smooth out the cycling patterns, inhibit the rage reactions that seem so out of proportion to their triggers, and help dampen the period of activation that so often occurs in the late afternoon and evening hours. Therapists can help the children with many of their anxieties and fears and often-ill-fated social interactions, as well as help them scale back their extreme responses to people and events. Understanding educators can "take the hand of the child" and help relieve the worries of their days.

With everyone's help, the ice upon which these children and their families skate will not be so extremely thin.

We'll write again soon, but before we sign off, we'd like to tell you how pleased we are that the third edition of *The Bipolar Child* will be published this August by Broadway Books. This new edition is significantly expanded and covers the many changes that have taken place in the field of pediatric bipolar disorder in the past few years.

It is our hope *The Bipolar Child, Third Edition* will be extremely helpful to you and your children, and to their educators and treatment teams.

To view some highlights of the additions to the book, <u>click here</u> to visit www.bipolarchild.com/thirdedition.

As always, we look forward to hearing from you.

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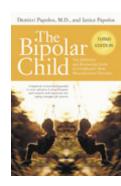
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