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# **RISK** **TALKING**

Are we preparing or scaring  
our food allergic kids?

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# RISK TALKING

The experts say well-meaning parents often say too much, too soon to their children about the risks of food allergies. The result: more and more kids with allergies – and anxiety. In this special report, *Allergic Living* explores the line between caution and fear.

by JANICE PASKEY and GWEN SMITH

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ight-year-old Devon used to love food, but no more. Following some upheaval in her little life – a move last fall from Toronto to scenic Woodstock, New York, and an allergic reaction in a restaurant in the new town – Devon has developed serious food “issues”.

The girl, who’s allergic to peanuts and tree nuts, no longer even trusts her mother’s cooking. Daily, she pulls food packages out of the garbage to triple-check the ingredients for allergens. She’s so fearful about what fellow classmates might eat that her mother, Anna Ross, must physically remove her daughter from the car when taking her to school. “It’s a drama, it’s tears, it’s dragging her up the walkway and handing her off.” Sometimes, the girl will wear her gloves all day to avoid touching *anything* in the classroom.

But Ross doesn’t attribute her daughter’s obsession only to the restaurant reaction, which was moderate (swelling of the throat and lips), or the move. These were contributing factors. Ross suspects it was her own efforts to educate a new school community and classmates about the seriousness of food allergies and the need for vigilance that got the wheels churning in her daughter’s head.

During a quick session in front of Devon’s class, curious kids put up their hands to ask: “Could she *die* if she ate a nut?” While Ross played down the possibility, Devon, at the age of 8, was listening with a new attentiveness. Today, the girl expresses a fear of dying and is seeing a child psychologist, while her mother suffers guilt about whether she said too much in front of her. In an e-mail Ross sent to *Allergic Living* she asked a heart-wrenching question: “should an 8-year-old have to fear her mortality like that?” She is not alone in her worries.

Increasingly, parents are noticing that what they say and do to manage a child’s food allergies, even their very demeanor on the topic, affects the child’s sense of security – or lack of it. Through Anaphylaxis

photography by EDEN ROBBINS

Reprinted from *Allergic Living*, [www.allergicliving.com](http://www.allergicliving.com)

Canada's e-mail registry, *Allergic Living* asked parents how they spoke to their food allergic kids about anaphylaxis, and if they had concerns that they might be scaring them, in addition to teaching them precautions. The topic clearly struck a chord, with over 70 responses arriving in a few days. Many spoke of the tough balancing act of instructing a child to always be vigilant about avoiding allergens, to not eat unknown foods, to have an auto-injector at the ready at all times, to communicate concepts such as cross-contamination in food preparation, but not to tip the child over the edge into fearfulness and take away the joy of being a kid.

Unfortunately, the balance quite frequently does tilt to anxiety: the mother of a girl the same age as Devon referred to her peanut-allergic daughter's "fear and extreme sense of self-protection." Several parents spoke of turning to the "fear factor" about anaphylaxis to drive home to young allergic kids that they have to be careful around food. But conflict about the impact was evident. One Edmonton mother related that her son was so "stressed out" about his peanut allergy that she had him tested for an ulcer at the age of 9 (he didn't have one). Kimberley McNabb of Collingwood, Ontario, spoke of her 10-year-old's refusal to eat even safe foods at friends' homes. While she thinks nothing is more important than being prepared to deal with a serious reaction, she added: "my hope is that I haven't instilled a fear in my son that in future only adds to the stresses of the risk of anaphylaxis."

When it comes to food allergies, "there is so much anxiety," says Dr. Zave Chad, an Ottawa allergist and president of the allergy section of the Canadian Pediatric Society. He notes that there does not appear to be nearly as much stress among children and parents coping with asthma – and yet there are far more deaths caused by that disease than by anaphylactic food reactions. Beth Goldstein, a Toronto social worker in private practice who provides counseling for families with food-allergic children, expresses concern that anxiousness surrounding allergies can affect children's confidence and how they'll live their lives. "If they are afraid, I'm not sure they will reach their potential, they could hold themselves back from opportunities."

**S**o how did we reach the point where the manner in which we teach children about one serious condition can lead to a level of anxiety that's not healthy? Experts think it may start with how we explain food allergy to others. "If you listen to the way some parents talk," says Laurie Harada, executive director of Anaphylaxis Canada, "they say, 'this could kill him' or 'bringing a peanut butter sandwich to school is like bringing a



*Devon Ross: her fear of allergens developed at age 8.*

loaded gun.' It has great visual effect, but often the child is within earshot, and is that the image you want your child to have?" Chad agrees that such terms can be harmful. "Back in the early '90s, in the days when people thought food allergies were 'in your head' and people were not buying into the seriousness, discussing the potential for severe reactions was very useful," he says. "It galvanized the community, it got people working on this."

"But I think the pendulum has now swung a little too far the other way." He says emphasis on severe reactions can frighten parents and that affects how they communicate with the community – and their children. "Kids pick up on the anxiety of parents extremely quickly," Chad says. "The parent who is over-anxious is not helpful to their child."

In Trenton, Nova Scotia, Jill Fraser became so stressed about her son's allergies that she lost sleep, felt tension in her shoulders and jaw, and stepped up control over her allergic child, who was not sleeping well either. Fraser's son, Harper, was found to have a milk allergy, then later, at 18 months, a peanut allergy. With the peanut diagnosis, Fraser cried at the pressure she felt to keep her little boy safe. At first, she wouldn't even take Harper down the supermarket aisle where peanut butter was on the shelf. Fraser had more reason than most to worry; a childhood schoolmate had died from an accidental exposure to peanuts. But she even became worried that the boy might react to other major allergens: from shellfish to sulphites to stinging insects. For a time, Harper was afraid of playing in the grass because of bees.

**'I over-controlled regular things to make up for this monster (anaphylaxis) that I could not control,' says Jill Fraser. She was so worried about her son's food allergies that neither of them were getting a proper night's sleep. Today, the family is 'functioning better' and mother and son are both much calmer.**

She was trying to control her son's every movement. "On the swing, I'd say, 'careful Harper' or when he was going down a set of stairs 'careful Harper,' running around the yard 'careful Harper. "I over-controlled regular things to make up for this monster (anaphylaxis) that I could not control."

Talking to a psychologist helped, causing her to realize that she was over-compensating. Fraser is still vigilant about managing her 4-year-old's allergies, but feels a greater sense of calm. Both she and Harper are sleeping better, and she speaks to him in a more relaxed fashion. For the first time, she's even hired a non-family member to care for her two kids while she's at work. Her anxious parenting had caused some tension with her husband (whom she found "too carefree"). But now "we are functioning better. We have more common ground with our strategies for parenting, which we learned from the psychologist."

What causes high anxiety in parents, which gets passed on the kids, is the fear that a child might die from an anaphylactic reaction. Such fear can be so visceral that it puts the primal need to protect into overdrive. But just as physicians are encouraged to "heal thyself," some parents need to learn to "calm thyself" – and look more closely at the allergy facts, which offer some reassurance.

First, despite a doubling of the incidence of food allergies in North America in a decade, deaths from anaphylaxis are still rare. (Thanks in part to preventative measures.) Second, Chad says allergists now have improved knowledge from fatality studies of the profile of the person at a higher risk of

a life-threatening reaction – and it is not every person who tests positive to food allergies. Those with asthma, especially adolescents, fall into a higher risk category, and a previous anaphylactic reaction also increases risk.

The statistics make Chad's point: an Ontario study published in 2001 reviewed deaths from anaphylaxis to food over the previous 14 years. There were 32 deaths, mostly among teens and young adults who also had asthma, and peanuts and tree nuts were the allergens most often implicated. A U.S. study published in the *Journal of Allergy and Clinical Immunology* in April 2007 examined 31 food allergy deaths and found that most who succumbed were again teens or young adults, most of whom were *not* carrying auto-injectors and had eaten away from home. In all the cases for which medical history was available, the person had also been asthmatic.

As a prevention strategy in children who do fit the at-risk profile, Chad opts for "superb asthma control," as well as vigilance about good allergy practice: carrying epinephrine at all times, allergen avoidance, label reading and frequent hand-washing. "If the child does not have asthma, I even bold it on the sheet [given to parents]: 'no asthma equals less chance of having a major reaction'. Not everybody is the same."

Dr. Timothy Vander Leek, an Edmonton allergist and assistant clinical professor in the University of Alberta's division of clinical immunology and allergy, says children also need to hear that just being in the same room with an allergen won't hurt them, and that the smell of an allergen such as peanut butter will not trigger a

## THE FREEDOM TO SOAR ABOVE YOUR ALLERGY SYMPTOMS!

*Jill Fraser:  
used to try  
to control  
son Harper's  
every move.*



## What causes high anxiety in parents, which gets passed on the kids, is the fear that a child might die from an anaphylactic reaction. Such fear can be so visceral that it puts the primal need to protect into overdrive.

reaction. “What parents can say is, “If a child is sitting right next to you eating a food you’re allergic to, as long as you don’t eat it, you will be fine.” (He notes exceptions such as the risk of airborne proteins from cooking fish or from opening peanut packages on an airplane.) Vander Leek, too, sees many worried food allergic patients. “It’s extremely common to see kids who have an unhealthy level of concern in a way that becomes a burden on their lives.”

**H**ow can parents avoid this undue anxiety and instill caution without fear? “We have to acknowledge that there are no easy answers,” says Dr. Jane Garland, a child psychiatrist and professor at the University of British Columbia in Vancouver, who heads the B.C. Children’s Hospital’s Mood and Anxiety Disorders Clinic. But she says food allergic kids will take comfort if they know that the adults around them – parents, daycare workers, teachers or coaches – are well-informed about managing their condition. “That’s their safety net. Then they feel that the burden is not all on them,” she says. “That really reduces children’s anxiety – ‘somebody’s in charge here and knows what to do if there’s a problem.’”

Garland thinks getting a realistic estimate of the level of risk

# PARENT TO PARENT

From **Tracey Lee** of Newmarket, Ont. – Find an activity that doesn’t involve food – a sport or hobby – that the child can enjoy. For her daughter, “speed skating has been a huge confidence builder.” Through it, she’s also met other kids with food allergies.

**Heather Lowthian** of Ottawa – With kids aged 3 and 5, she uses some levity. “My daughter grew up with the saying, ‘no peanuts, tree nuts or donuts!’ We have our appointments with the ‘prickly doctor.’ We let them know that sometimes things are not fair but being safe is the most important. It is OK not to *want* to wear your EpiPen with a pretty outfit, but you have to. We give lots of hugs.”

**Frances Ling** of Florham, N.J. – She suggests looking for good support group materials. She likes the Food Allergy & Anaphylaxis Network’s newsletter for kids, which she uses to open the allergy conversation with her daughter.

**Susan Clemens** of Ottawa – She told her 3-year-old that “her EpiPen was like a fire hydrant. I have never had a need to use one, but I am glad they are always nearby to help protect me.” **Tanis Mack** of Nepean, Ont. also finds analogies useful. For her allergic son, she compared the auto-injector to a seatbelt. “We know the dangers of driving in a vehicle, but if we wear our seatbelt every time, we’re doing all we can to keep ourselves safe.”

**Kerri Dobszewicz** of Keswick, Ont. – To help the comfort level of her nut allergic 8-year-old, there’s a rule that if daughter can’t eat it, Mom doesn’t either. “This helps her to not feel isolated in a food situation that is unsafe.”

**Patrice Lindsay** of Toronto – She arranged with a health teacher to have her son’s Grade 6 class learn about food allergies. Classmates got to try out EpiPen trainers, and really liked the session. “This increased our son’s confidence and reduced his worry about being different.” –G.S.

from an allergist is also a good idea. If the child does not fit the profile of those at greatest risk of an anaphylactic reaction, let him know, as that should offer comfort. If the risk is high, let the child know it's still very manageable, and that the "safety net" is in place. She says a big part of child anxiety management, in any circumstance, is knowing the likelihood, and having the skills to deal with it.

Anxiety, unfortunately, is common in our modern world, even before food allergies are taken into consideration. Fifteen per cent of children are anxious just by temperament. "Since allergies are common and anxieties are common, there are going to be lots of kids who have both," Garland says. Yet anxiety does have its place.

Lynn Miller, a psychologist and assistant professor at UBC, notes that it can make us aware of a danger or threat: "historically it alerted us to predators in our environment, such as wild animals."

But what it won't help is the child trying to manage food allergies. "The problem is when you're afraid, you have less ability to think straight," says Miller, who specializes in childhood anxiety. This is because the physiological reaction to fear is to prepare for

**At certain ages kids' brains are growing rapidly, increasing their capacity for anxiety. Around 7 or 8, 'many kids develop worry about germs, disasters and things going wrong,' says Dr. Jane Garland.**

flight: blood drains from the brain to the muscles, the stomach fills with acid. This state doesn't allow a child to size up the risks accurately in a new environment, such as on a field trip or at a new friend's home. What the parent wants, she says, "is a child who's calmly assessing the situation rather than one who's frightened and unable to assess properly." Nor will such a condition help in dealing with an emergency, asking for help or administering an auto-injector.

# talking the talk

Advice from experts on how to speak to food allergic children about the risks.

## TODDLERS AND PRESCHOOLERS

**Start the awareness** – You'll need to inform a young child that an allergen can make him or her sick. Show what that food looks like, perhaps using a photo, and stress that it must be avoided. Begin to introduce the allergy rules (e.g. no sharing, hand washing, and never eating a food unless your parents approve it.)

"As with any difficult topic, keep it simple," says Lynn Miller, an assistant professor of psychology at UBC. "You can have the child restate what they think they have understood." Above all, talk in positive terms. "You can tell your child they are raised with something special, and that everybody has to learn to manage something in their lives." If you are going to be



*Lynn Miller: Speak in positive terms.*

present at birthday party, she suggests saying you're coming as a "special helper" – then you're not the food vigilante.

**Don't say 'you could die'** – Dr. Zave Chad suggests instead, "It's serious, you could get hurt," while other experts opt for "you could get really sick." He says

"young children understand 'you could get hurt' a lot better than 'you could die.'" Child psychiatrist Dr. Jane Garland notes that most kids don't fully grasp the concept and permanence of death until the age of 8 or 9.

## ELEMENTARY SCHOOL

**Recognize anxiety spikes** – There are three big "cognitive bumps" of brain changes within these years: ages 5 to 6; between ages 7 and 8; and just before adolescence, at 10 or 11 (older in some boys). After the second "bump", kids understand more about their allergies, and are more inclined to become anxious in trying to manage them. The brighter your child, the more they can contemplate abstract concepts, and the more anxious they may become.

**Talk about fears** – It will depend on maturity, but by about 9, Miller thinks parents need to start addressing (calmly) that it is possible to die of anaphylactic reactions – since an allergic child will hear this from other kids. "But you can discuss: 'what's the likelihood?' and 'everybody can die of something.'" For instance, you might say that if a person was so frightened he never left home, that wouldn't be a normal life, and that "there is a balance and risk we all take."

She says to mention how few deaths

Miller says “cautiousness” is the place where kids can best deal with their allergies. The parent who stays attuned should be able to spot the difference between caution and excessive anxiety. Children with the latter are likely to have physical symptoms: stomach aches are the leading indicator, followed by headaches, and clinging or not wanting to go to events. Anxiety disorder associations caution to watch for daily and uncontrollable worrying over several months. Miller says learning some responsibility to manage allergies independently can help kids to arrive at caution over fear. Once they’re old enough, she suggests that participating in sleepovers (at homes with fully informed parents) is a good way to boost their confidence.

It’s useful for parents to know that there are certain ages at which kids’ brains are growing rapidly, giving them an increased capacity both to think – and to get anxious. “One of those times is between 7 and 8, when many kids develop a lot of worry about germs, disasters and things going wrong,” says Garland. She sees Anna Ross’s daughter Devon as a good example. “In her case, it has more to do with food, but at that age, she might have devel-

oped the same thing around something else.” A later brain growth spurt comes just before adolescence (which Miller notes can vary from age 10 in girls to age 14 in boys).

Many parents told *Allergic Living* that they impress upon young children the risk of dying from an anaphylactic reaction. The intent is to get the child to pay attention and manage the allergies, but several experts cautioned against such language. “I don’t think it’s that helpful,” says Garland. “I can think of very few situations where such kids need to be told – ‘you could die from this.’ It’s one of those phrases that is terrifying for anyone at any age.”

Instead, she suggests saying, “You have to be careful because if you have a reaction to this food, you might not be able to breathe. That’s different language.” A young child can’t grasp the concept of death, she notes, but “not being able to breathe is more meaningful because people need to be able to breathe to live. It’s put in the positive framework.” Or, she would say: “you would feel really, really sick. They don’t want to feel really sick.”

Some parents said they use the “you could die” approach with young kids as a type of pre-emptive parenting: trying to instill a



**Dr. Jane Garland:** kids want a ‘safety net’.

there have been from anaphylaxis, and that most happened when the person didn’t have their auto-injector. “This is an opportunity to discuss, ‘what are you going to do [to stay safe],’ and evaluate his or her problem-solving skills.”

**Self-Protection** – By the second or third grade, children need to be able to recognize and know how to avoid their allergens. You’ll need to explain: what an allergic reaction looks and feels like (you could feel really bad, get hives, have a stomach ache or have trouble breathing), and how to handle an emergency. Stress the importance of always carrying an auto-injector, and wearing MedicAlert ID.

**Managing allergies, and anxiety** – It is a lot on little shoulders. A stomach ache is the leading indicator of anxiety, and a sign that all may not be well with a child.

**Sleepovers:** Miller says research shows kids who take part in sleepovers at friends’ houses do a better job of managing their lives as adults. So ensuring your child participates in normal kid activities allows you to talk with him about managing allergies away from home, and provides practice. Miller says the child should think: “I feel confident away from my parents and can manage my own feelings of distress.”

Let your child know the allergies are serious but manageable if they follow rules of awareness, avoidance, and are ready for an emergency.

## TEEN YEARS

**Tougher love** – Kissing, drinking and perhaps even drugs. Add allergies to this mix and it can be a volatile combination. Experts suggest kids in their teens often fall into one of two camps: those mindful and even over-cautious about allergies, and those who display the adolescent penchant for risk-taking. The trick in either case is to keep the dialogue open.

Social worker Beth Goldstein finds that allergies present an opportunity to talk to teens about issues such as smoking marijuana and drinking. She told her



**Dr. Zave Chad:** teens can need tough talk

son, “You can’t share bottles, you can’t share joints.” They also discussed kissing, and the need to ask a girl what she had eaten that day, and then decide if it was safe to kiss.

Chad avoids “death talk” with little kids, but with teenagers who stop taking food allergies seriously, it’s another story. He speaks of a 13-year-old, with asthma, who he saw recently and “who is taking chances. I told him, ‘If you don’t follow these rules, you could have a severe reaction, and you could die from this.’” To teens who say aren’t carrying an auto-injector because they’re sure they can avoid allergens, he’ll say: “that’s called famous last words.” – *J.P., G.S.*



fear of anaphylaxis early to keep a child vigilant during the rebellious teen years. Garland says that strategy can backfire, since kids re-evaluate “almost everything” as teenagers. She cautions that if a teenager decides you’ve been too dramatic in your portrayal of the risks, “the parent’s credibility goes down.” Better to update the information you’re giving to a child according to the age, stage of development and level of understanding.

To speak to Garland, the co-author of a book called *Taming Worry Dragons*, is to appreciate the information overload in some young brains. “We see kids who are terrified about global warming. They say, ‘the icecaps are going to melt, we’re going to be flooded.’ They’re worried about ‘we shouldn’t be driving in the car – because we’re poisoning the atmosphere.’ Earthquake drills in school make them afraid of earthquakes. Children hear these things and it’s up to the adults to really put it into context with ‘the likelihood.’ That’s a big part of anxiety management: ‘how likely is it to happen?’ And if it could happen, do you have the skills to deal with it.”

Kids who get so stressed about allergies that it interferes with their ability to sleep or eat or socialize can learn skills for anxiety management. With those, Garland says, “if they start to worry they know how to calm themselves down physically or to distract themselves.” (These skills include breathing exercises, and someone to talk to who is reassuring.)

She notes the positive as well: a great number of children do a wonderful job of managing their food allergies. She thinks we should also listen and learn from them. Matthew Lindsay, an 11-

**We can also learn from kids with food allergies who’ve been there. Matthew Lindsay, age 11, offers this advice: ‘Don’t freak out. Don’t make this a matter of ‘you make one mistake and you’re dead’. Make your children understand, but don’t scare them.’**

year-old from Toronto, is such a kid. He has asthma and allergies to peanuts, tree nuts and scallops, and has been through his own bad bouts with fear.

With his mom’s help, Matthew says he’s learning to not be fearful, and offers this wise counsel for parents: “Don’t freak out. Don’t make this a matter of ‘you make one mistake, and you’re dead’. Make your children understand, but don’t scare them. Just explain to them that they are allergic and it can be dangerous but if you’re careful, read ingredients and have your EpiPen, you should be fine.” Matthew used to get nervous just at the sight of a nut and would ask for Benadryl. Patrice Lindsay, his mother, says she would reply, “you haven’t had any direct contact, so let’s give it a few minutes. Tell me if your throat is closing, I don’t see a rash.”

The experts like that kind of calm approach; it helps the child learn to think, not panic. And if some parents have inadvertently fomented fears, others have been excellent at setting the example. When Daniel Burrow, who lives in Ottawa, read about teenager Sabrina Shannon's tragic death from anaphylaxis, he became frightened. Daniel, who was 10 at the time, began having imagined reactions. His mother, management consultant Helen Handfield-Jones, recalls that she and her husband would speak calmly to the boy, who is allergic to peanuts, tree nuts and lactaid pills, asking whether he had eaten anything suspicious and assessing the risk. "We would say, "You say your lips feel funny, but do you have any other symptoms? Does your stomach hurt?" If there were no other symptoms, they would tell Daniel it was likely a false reaction arising from fear. They assured him that they would watch closely for other symptoms. Right in line with the "safety net" approach, his mother would say, "let's also check to confirm all our backup protection is in place: we have two EpiPens, we can get to a hospital if we need to." The anxious phase lasted about eight months. Today, Daniel is 13, doing much better and feeling more confidence. "I'm in a good place," he says.



From left: Daniel Burrow, now in a 'good place' at 13, and Matthew Lindsay.

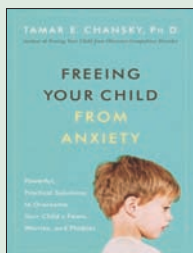
That good place is where allergic kids want to be. Should a

child have to fear his or her own mortality? No, they shouldn't. The road to reducing fear and anxiety may be winding, but the experts say to stay with the journey and most families will get past the bumps and detours. Still, if you and your child are finding your lives too affected by allergy stress, don't be shy about seeking the help of an anxiety expert. Garland reminds that some kids will have the temperament that's predisposed to worrying, "and if we can give them some coping skills as a child, they can cope with anxiety better throughout life."

Websites of Interest: <http://www.anxietybc.com/parent>  
 We welcome your comments, write to: [editor@allergicliving.com](mailto:editor@allergicliving.com)

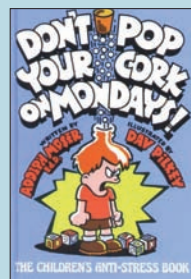
## READING ROOM

Pamela Lee is a Vancouver teaching assistant with an interest in anaphylaxis and anxiety. She recommends the following books:



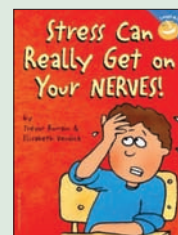
**Freeing Your Child From Anxiety** by Tamar E. Chanskey. This is a good overall resource. It has a section dealing with anxiety arising from trauma (useful since an anaphylactic reaction can be traumatizing). Publisher: Random House \$16.95

**Taming Worry Dragons:** A manual for children, parents, and other coaches by E. Jane Garland & Sandra L. Clark. This manual teaches coping skills to deal with anxiety. Support materials include workbooks for kids and teens; DVDs are available. Publisher: B.C. Children's Hospital. Available online at: <http://www.bcchildrens.ca> \$16



**Don't Pop Your Cork on Mondays** by Adolph J. Moser and Dav Pilkey. One of a series of books dealing with emotional issues for elementary school kids. Pilkey (of Captain Underpants fame) illustrates this book, a personal favourite. Publisher: Landmark Editions. \$16.95

**Stress Really Gets on Your Nerves** by Trevor Romain & Elizabeth Verdick. My son read this book about 1,000 times when he was 7. Humorous, with solid stress control advice. Highly recommended. Publisher: Free Spirit Publishing Inc. \$9.95



Recommended bookstore for kids and anxiety, trauma, ADHD, autism: **Odin Books** <http://www.odinbooks.ca>