



# Ellen Notbohm's Newsletter

*Award-winning author and columnist*

EllenNotbohm.com

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*“One of the principal goals in my life has been to avoid embarrassing my children.”*

~ Hugh Laurie

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## Ten Things Your Child with Autism Wishes You Wouldn't Share

Like any warm-blooded parent, my friend flushed with delight when her daughter handed her a lovely crayon-inscribed homemade card. On the front, it read

*“Happy Mother’s Day, Mommy! Even though . . .”*

But my friend’s warm-blooded glow cooled to mortification when she opened the card:

*“. . . your breath smells really bad in the morning!”*

Then there’s the child whose science worksheet instructed him to illustrate his understanding of solids, liquids and gasses. For the latter, he drew a grimacing fellow in a baseball cap labeled “Dad,” with wavy lines emanating from “Dad’s” hindquarters.

Knee-slappers, right? But would either of these parents been amused if the child shared his/her artwork on the Internet?

I’m writing and posting less than I used to because I’ve become acutely aware of the unforgiving permanence of the Internet. Am I willing to forever stand by what I say today in a fit of snark, ire, or the misguided belief that every thought that passes through my head is irresistibly witty, profound or original, demanding of publication? Boring my readers and embarrassing myself are the lesser of my concerns. My primary consideration runs deeper: how will my children perceive me? How will what I post about them affect our permanent, forever relationship?

Parental oversharing on the Internet has become an epidemic right along with autism. Why? Some will say they do it seek support from others in similar circumstances, or to raise autism awareness. One parent blew off my concerns about oversharing, saying “I don’t mind putting myself out there.” But he’s also

putting his child out there, without the child's permission. I wanted to ask, is this the same child whose lack of social thinking skills you bemoan? A mother railed back, "Parents who share intimate details about their kids online are probably the same parents who speak about their child in his or her presence, as if the child isn't there. One day they will wonder why their child lacks empathy!"

Can we *not* talk?

Here are ten things your child with autism wishes you wouldn't share on social media:

1. Poop stories, and their subsets. Your child isn't the first nor last to smear feces, fail to make it to the toilet, produce eye-watering smells or The Big One that cost \$230 for Roto Rooter. Ditto for discovering the elastic properties of snot, producing a trendy new shade of barf, fan-drying his private parts.
2. "Please shut up!" What creatures of short memory we parents can be! Our hearts break, even as our tempers fray when we endure our child's meltdowns, wishing with all our being that s/he could find the words to tell us what's wrong. We yearn for our child to speak, s/he struggles heroically to acquire language, then wants to talk ceaselessly, but only about one thing, be it trains, butterflies, watches, or Pokémon. Yes, it can drive us to distraction, if we let it. But if I were a kid who ever read a parent's post declaring to the world how bored to madness s/he was with my conversation, you can bet that "shut up" is exactly what I'd do. So much for keeping the lines of communication open. And I have to wonder: how often do our kids think the same of adults: "WHEN are they going to shut up and give me some peace???"
3. "My Mother/Father/In-law/Sister/Brother/Ex-partner the Monster." People change, grow, mature, evolve. I get so many "seen the light" letters from anguished relatives of our autism kiddos who say they can't forgive themselves for what they didn't know or realize, and now, armed with information and understanding of autism, are intent on reshaping their relationship with the child. Is your anger or contempt of the moment worth damaging possible future relationships with people who can play meaningful, lifelong roles in your child's life?
4. You wonder who your child would be if s/he didn't have autism.
5. Anything that begins with "At least . . ." At least it's not cancer. At least he doesn't look autistic. At least he has a normal brother. At least he doesn't eat dirt. At least he talks, sort of. At least your mom will watch him once in a blue moon so you can get the heck out of the house.
6. Suggesting that you have a favorite child, whether it's the one with autism or that other one.
7. One-upping other parents about how hard your kid—or spouse or mother-in-law—is to manage.
8. "My child's sleep problems have wrecked my sex life." Beware, beware. When kids get the opportunity, they turn this one on its ear, along the lines of "My

parents' sex life has wrecked my sleep and they don't even know it." Unforgettable, true story from pre-Internet days: a little girl asks her mother a rather involved question at bedtime. When Mom says they can talk about it in the morning, the girl replies that she wants to talk about it now because Mom and Dad are often having "those dumb conversations" behind their closed bedroom door on Saturday mornings. Mom says, "What conversations?" a split second before realizing she shouldn't have asked. "The ones where Daddy gru-u-u-nts like a big pig," mimics the girl, "and you say, 'Ohhhhhhh, Ed!'"

9. How you hate your job but need the money because autism treatments are so expensive, or how you hate being at home but can't find decent care because your kid is so hard to deal with.

10. Anything you think is funny but wouldn't if it was directed at you. Would you be willing to be on the receiving end of your oversharing? Apply this acid test liberally. Children grow up—and get on the Internet. What might your child's payback look like? While parental overshares are often about things beyond the child's control (bodily functions, lack of social-emotional skills we haven't yet taught them), most child overshares would be about choices their parents make—getting knee-walking drunk, blowing money, doing stupid stuff behind the wheel of a car, saying cruel things then trying to retract with ten-cent apology, dressing carelessly/tastelessly.

Three little words: ponder before posting.

The irony about oversharing is that it negates the very things we try so hard to teach our children with autism. We want them to develop empathy and respect for others, to learn self-regulation and control of their impulses and emotions, to come out of their self-focused shell and find that the world is not all about me, me, me.

In her book, *Daring Greatly*, educator and researcher Brene Brown writes "Oversharing . . . often results in disconnection, distrust and disengagement." Before hitting that Post button, ask yourself if you'd be willing to share your post aloud to your child now, and willing for him to see it ten years from now. What do you hope to get out of sharing your bit, and is it worth the possible long-term repercussions? Are the emotions of the moment ones you'll stand by tomorrow, next year and forever? Does your motivation for sharing align with the values and skills you're trying to teach your child?

'Nuff said.

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## Gold, bronze awards for Ten Things

**[Ten Things Every Child with Autism Wishes You Knew](#)** won two awards over the summer.

**Bronze medal in Psychology** in the prestigious



**ForeWord Book of the Year Awards.** My fourth time as a finalist, and my first medal win!



**Mom's Choice Gold Award**, globally recognized as a benchmark of excellence in family-friendly media, products and services. This award joins last year's Gold Award for [1001 Great Ideas for Teaching and Raising Children with Autism or Asperger's](#).

Read excerpts from all my books on my website, including full chapters "Help me with Social Interactions" from *Ten Things Every Child with Autism Wishes You Knew* and "I Think Differently" from *Ten Things Your Student with Autism Wishes You Knew*. [www.ellennotbohm.com](http://www.ellennotbohm.com)

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## This month's reads



### Autism Asperger's Digest

#### ["Why Johnny Can't Be Good"](#)

"I know he can't be good all the time," the exhausted mom of an eight-year-old with autism told me, with tears in her eyes. "But why can't he do it for just a day? A morning? An hour?" As we talked, many reasons emerged. But the starting point was this: how is a concrete-thinking child to infer what we mean by "good" when it may be the most subjective word in the English language? Dictionary.com cites 64 definitions! How is our child to know which one we mean? Let's look at our own behavior when questioning why children don't meet our expectations. . .

### Children's Voice

#### ["Awareness is Not Enough"](#)

Autism awareness was an ambitious goal ten years ago, but it is no longer enough. A society can be as aware of autism as they are of the weather--but if, like the old weather cliché, everyone grumbles but nobody does anything about it, awareness may then turn divisive, driving our children farther to the edges of community. . . I dream bigger than





just awareness. I dream of an Autism Action agenda, rooted in my belief that we raise adults, not children, and that the journey to independence begins in earliest childhood.

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## Your questions answered on my blog

### Recent popular topics:

- Autism: one word, many truths. What's yours?
- Grief after diagnosis: common but conquerable
- "He gives up so easily"
- Autism sensory, social issues can be related
- Thwarting a thrower
- My spin on spinning: rock on!
- Loaded question, nuanced answer: Public, private or home school for child with autism?

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Downloadable PDF summaries of [\*\*Ten Things Every Child with Autism Wishes You Knew\*\*](#) and [\*\*Ten Things Your Student with Autism Wishes You Knew\*\*](#) now available on my website.

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Did you miss my [\*\*last newsletter\*\*](#)? ***Holding Up the Mirror of Accountability*** answers a question with a question. When an adult asks how accountable we should hold children with autism for their behavior, I ask how accountable we hold ourselves.

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**Writing a book?** Contact me about affordable rates for developmental editing and writer coaching at [\*\*emailme@ellennotbohm.com\*\*](mailto:emailme@ellennotbohm.com)

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Excerpts from all my books are on [\*\*my website\*\*](#), including full chapters from *Ten Things Every Child with Autism Wishes You Knew* and *Ten Things Your Student with Autism Wishes You Knew*. [\*\*www.ellennotbohm.com\*\*](http://www.ellennotbohm.com)

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