

ONE

What You Need

“What’s our motto, Jonah, our motto? Say it with me: ‘You can’t always get what you want,’” Cynthia says. She’s speaking deliberately. Her voice is calm—better yet, neutral. I marvel at its neutrality and always have. *It’s nothing you can’t do, too, sweetheart.* My wife’s words are always in my head. That “sweetheart,” the slightly cloying inflection I give it, is hardly fair to her. It diminishes the soundness of the advice I imagine her giving me, the heartfelt concern I know is real. She’s not being sarcastic when she says it, even in my head; still it’s sarcasm I hear. I guess I never expected marriage to be like this—so intimate, so unnerving. Incidentally, Jonah is having a meltdown in the back of the car. This is not unusual, but that doesn’t mean I’m used to it. We’re twenty minutes from home. Or less, since I’m driving significantly above the speed limit. Even so, it seems as if we’re barely moving, as if we’re stuck in one of those interminable traffic jams that have you craning your neck out the window to see just a little farther ahead. Or if that’s not doing the trick, maybe you put the car in park, step out, and commiserate with your fellow drivers, all the while searching for a better vantage point, as if there really might be some explanation for what caused this mess in the first place.

Jonah’s latest tantrum started when he asked for a chocolate ice cream cone and Cynthia said he’d have to wait until after dinner. It

has escalated from there. Now he's teary-eyed and practically hoarse in the backseat, carrying on an argument we are doing our best to ignore. The crying and the petulance I can just about tune out, but it's the whining that's so unrelenting I catch myself in awe, almost envious, of the sheer force of will required to sustain it. So when Cynthia tries to explain to Jonah that there is such a thing as limits and that a limit is when you can't have what you want at the exact moment you want it, like when you're driving in a car, Jonah is unappeased. "What's a limit?" he keeps asking, getting more and more worked up. He will keep asking the same question or some variation on it—his impatience rising and mine with it—until he will settle for nothing less than our full confession that we are deceiving him. Better still, that we are wrong and that ice cream before dinner will, from hereon in, become a new family policy. I worry, too, that if I were alone with him I would confirm this belief and capitulate. I would head for the nearest Dairy Queen or backtrack to find one, anything to make him stop. Now, I can only daydream about doing that. His mother is more effective at ignoring him at times like this, so his question is invariably directed at me. "Daddy, what's a limit?" "A limit is a bummer," I say and Cynthia gives me a sideways glance.

Jonah is too old to be having this kind of fit, but, still, I try to remind myself that it was worse when he was younger. He used to scream and kick, too, often until he gagged, sometimes threw up. Or he used to say, "I'm mad; I'm not mad. I am; I'm not," launching into what was, at the time, his standard self-contradictory soliloquy. It was the kind of thing that if you weren't stuck in a car with him or at a holiday dinner, if you were in the right mood, could be funny. Like a bit right out of the Marx Brothers or Abbott and Costello. The kid would agree to nothing, not even how he felt.

Jonah was first diagnosed with autism when he was almost four, and back then we were still not sure what we were dealing with. We were on a waiting list at the hospital for a second opinion and there

were days I tried to put anything to do with autism on hold until this appointment. Some days my strategy proved more successful than others. Mostly, we were in a daze. *Speak for yourself, sweetheart, some of us were depressed.* We were never sure, for instance, if his latest tantrum was just one of those times when Jonah was acting like any other kid not getting his way. Back then, it could be difficult to distinguish between autistic behaviour and typical four- or five-year-old behaviour. (I should say neurotypical since that's the politically correct term now. It's used these days to describe, well, everyone who doesn't have autism.) Though, looking back, I suspect we were kidding ourselves. I suspect we understood or were beginning to understand our situation.

When I first learned what was wrong with Jonah I looked up the word *autism* in the dictionary. "A mental disorder characterized by self-absorption," it said, and I remember walking around for days thinking, *That sounds like me.* Then thinking, *That sounds like everyone.*

I know better now. I know the look in my son's eye, the sound of his voice, when he's gone somewhere else, somewhere deep and nearly impenetrable inside himself. I know why those tantrums were so fierce and unfathomable when he was younger, and why they continue to come and go, fade, return, disappear, mutate. Jonah has gone through a variety of overlapping phases, if you can call them phases. He has lost his temper with us and others, acted aggressively, stared off into space, mumbled, chattered, scripted, perseverated, echoed, and distorted words. Whatever he does, though, he does incessantly. At least, he would if we let him. He would, for instance, read the same books—even at ten, animal alphabet books remain his favourite—over and over again. He is intolerant of change, any change. "An overwhelming preservation of sameness," that's what Leo Kanner identified as the primary marker of the disorder. (Kanner was the Austrian-born American psychologist who first identified infantile autism in 1943; a year later another native Austrian, Hans Asperger, gave his name

to Asperger's syndrome, a milder form of the disorder.) And so we, Jonah's family as well as the people—the experts and educators—working with him, are not only preventing him from retreating to that place where nothing changes, we are *conspiring* to prevent him. Every action we take, every person we hire, every theory or therapy we purchase, everything we do is designed to keep him from doing what he most wants to: to stay just the way he is. *Who are you talking about, sweetheart? Because that sounds like you.*

Autism is a spectrum of disorders (commonly referred to as ASD), and within a broad range of symptoms and deficits, Jonah is generally considered high-functioning. The first psychologist to diagnose him told us this in one session, a not-quite-two-hour introductory class in autism. He will likely have problems with communication and social interaction, she explained. He will be prone to repetitive behaviour, also known as self-stimulatory behaviour, or stims. Take, for instance, the way he lines up his toys, she said, referring to one stim she'd already observed. He will have trouble with empathy, too, with what's called theory of mind. For neurotypical kids, empathy is a natural, progressive part of development—not for Jonah. He will have to be taught that just because he feels something, it doesn't mean other people feel it too and in the same way. Right now, he is inclined to believe that whatever he experiences other people must be experiencing. In individuals with autism, that's called mind-blindness. *That's called yours truly*, I thought. Down deep, I always think everything is happening to me and only me. All *this*, for instance. The psychologist was a chubby, cheerful young woman with a framed bachelor's degree in psychology a little askew on her freshly painted but otherwise unadorned office wall. "Any questions?" she'd repeat every so often. *Were we supposed to raise our hands?* She couldn't have been more than twenty-five and she delivered the news matter-of-factly, as if it couldn't possibly come as a surprise to anyone since it wasn't a surprise to her. She got up from her chair, then smiled and

said, “Have a nice drive home.” *Talk about mind-blindness.* Still, when we didn’t respond or even move, she glanced at Jonah and then at us, at our evident worry and desperation, and summed up her diagnosis with an improvised pronouncement.

“He has a whiff of autism,” she said, nodding her wide face slowly and deliberately. I nearly hugged her; the phrase sounded so quaint. *A whiff? What’s a whiff? Nothing. Hardly noticeable. Like a mole, a lisp. Like being left-handed.*

At first, I assumed Jonah’s development would just be slower than that of other children. He’d be a few years behind; that’s all. For instance, when he was ten, as he is now, he’d be more like an eight- or a six-year-old. He’d be held back a year or two in school. So what? By this same reasoning, I figured that by the time he was twenty-one, well, what would it matter? We were playing catch-up, that’s all. Who cared? Instead, what we’re playing is a whole other game with a whole other set of rules. I find myself dreading Jonah’s birthdays, thinking: *He can’t really be turning eleven this year.* Or dreading another September: *He can’t really be in grade five.*

As it turns out, Jonah’s developmental delay is not just a delay. It’s not just a disability or a disorder or a condition either. It’s something else entirely, something the mental health care profession or the educational system would never dare call it these days. Something I am well aware I shouldn’t be calling it either. But there are moments when I, a reluctant but diligent student of my son’s behaviour, can’t think of any other word to describe him than strange. Sometimes, no P.C., no neutral, no other word will suffice.

I have also learned what any parent of a child with autism eventually learns: there’s no such thing as “a whiff of autism.” It’s true there are kids worse off, and some better off, than Jonah, but that has not made the gulf between my son and the world he has to work so hard to understand and engage with any narrower. It has not prevented me from noticing that it appears to be growing wider every day.

“MOTTO, JONAH?” Cynthia prompts again. She is holding up *Forty Licks*, a compilation of Rolling Stones hits we keep in the car for this kind of occasion. Jonah, who is barely catching his breath, listens and grudgingly says, “Number six: ‘You Can’t Always Get What You Want.’” Jonah is not a child for whom logic will ever be simple, but somehow the simple logic of Mick Jagger’s line appeals to him. That’s why we need to be careful not to overuse it, Cynthia says. It’s a feature of autism that anything that begins as if it’s going to be a good thing—like an interest in classic British rock or knock-knock jokes or animal alphabet books—is bound to turn bad, which is to say turn into a fixation. So Cynthia saves the Rolling Stones lyric for moments of crisis or those moments of crisis we can no longer deal with. Which is another thing you learn when you have a child with autism: everything is a potential crisis.

Cynthia and I both used to avoid the A-word, as we called it, though we did so for different reasons. Cynthia because she believed, down deep, that with hours and hours of ABA or applied behavioural analysis therapy, with luck, with dedication, determination, and a positive, proactive attitude, autism was something we could overcome or at least battle to some kind of uneasy but workable truce. She believed that one day Jonah would be “indistinguishable” from any other neurotypical kid.

“Indistinguishable” was the word she repeated, mantra-like, every chance she got in the first few months after Jonah’s diagnosis. It was the promise implicit in the course of action we were embarking on—ABA therapy. Indistinguishable implied Jonah would not be like everyone else but that he would almost be. At the very least, he would appear to be. We might always know the difference, of course, but there was a chance other people—friends, teachers, store clerks, future girlfriends, and employers—might not. We were determined to fool them all, now and in the future; we were depending on it. There was still no guaranteed treatment for autism, certainly no cure, but there

was reason to be hopeful. Cynthia was reading everything she could about ABA back then and finding examples of kids who were doing fine, all things considered. *All things considered*. What a preposterous phrase to apply to a child, *my* child. It made me want to scream or, better yet, punch a wall or throw something, something heavy. I never needed qualifications for Jonah before. In fact, he was the only thing in my life I never needed them for. Now, I was learning that qualifications were all I had. I would have to take solace in them, but that would take time. *How much time, sweetheart?* Cynthia, meanwhile, met with the mother of another boy, a few years older than Jonah, who was in a private school where no one, not his classmates, not the teachers, not the administrators, knew he had autism. “It’s true,” Cynthia said when she got home, her tone lighter, less ominous than it had been for weeks. “No one can tell.”

During their meeting, the other mother had recommended one of her son’s therapists to Cynthia. This therapist had recently started her own practice and become a consultant. She was a slight, no-nonsense woman in her late-twenties when we first met her. She had long black hair and wore nothing but black; even so, it was hard to tell what look she was going for—Zorro or Morticia. Her job was her life and she undertook it with a zeal and self-assurance that was, for us, irresistible. Autism was and still is a seller’s market and The Consultant, one of the kinder nicknames I would come up with for her, knew it. This was exactly what we wanted: someone who knew everything. We were more than willing, then, to believe in her methods, to believe in her as much as she believed in herself. The Consultant had only a bachelor’s degree in psychology but her credentials were impressive nevertheless. She was only two degrees of separation from the California clinical psychologist O. Ivar Lovaas, an iconic, sometimes controversial figure in the world of autism treatment. What distinguished Lovaas—who began his research in the 1960s when autism was still considered a psychosis, a variation on childhood schizophrenia—was his belief

that children with autism were both treatable and teachable. That was the real breakthrough in the model of behavioural therapy he used: his acknowledgment that children with autism should be treated like human beings and not locked away like animals. (When Cynthia first began reading about Lovaas, she was so grateful to have come across his research she wrote him what can only be described as a fan letter. She thanked him for providing us with something we could do for our son and enclosed a photograph of Jonah. He wrote back to wish us luck and to tell her he had shown her letter and Jonah's photograph to everyone working in his institute. He said he knew it would encourage them. His letter went up on the cork bulletin board in our kitchen and has remained there.)

By 1987, Lovaas had almost two decades of research studies to support his conclusion that in a good percentage of cases the children he and his team of therapists had treated had gone beyond "indistinguishable"—that "recovered" was, in as many as half those cases, a more accurate description of the results achieved.

The Consultant had also met Bridget Taylor; she'd even brought Taylor in as a supervisor once for one of her clients. Taylor had studied under Lovaas and was also legendary, mainly for the role she plays in Catherine Maurice's memoir *Let Me Hear Your Voice: A Family's Triumph over Autism*. Maurice's 1994 chronicle of how her daughter and then her son were "recovered" is an uplifting advertisement for unconditional parental love, but also for the almost miraculous effectiveness of ABA. Maurice's memoir also provides a kind of template for many autism narratives to come. First, it reveals what doesn't work—in Maurice's case, some cockamamie, parent-blaming hug therapy she initially swears by only to repudiate by the end of the story. Then it provides the antidote—namely ABA.

"You should read it," Cynthia said. I promised to. But it would take me years to finally get around to *Let Me Hear Your Voice* and my expanding shelf of similar books. You see, back then, I couldn't

bear to read anything about autism, not all the way through anyway. The stories I was coming across tended to be front-loaded with catastrophe: head-banging tantrums, vacant stares, grim prognoses, bogus therapies. Invariably, I couldn't make it past the first twenty-seven pages of *Let Me Hear Your Voice*. It's there that Maurice writes: "We are catapulted into a future that has suddenly become menacing, terrifying." Similarly, on page forty of another classic autism memoir, *The Siege: A Family's Journey into the World of an Autistic Child*, author Clara Claiborne Park writes: "But autism? What was autism? How could we adjust to an unknown? To live with autism would be like living under water. We might never come up, yet we had not the option of drowning." Likewise, the title essay in Oliver Sacks's *An Anthropologist on Mars: Seven Paradoxical Tales* has an early passage that stops me cold: "Most people (and, indeed, most physicians), if asked about autism, summon up a picture of a profoundly disabled child ... almost inaccessible: a creature for whom very little future lies in store." Even if I knew consolation was coming, as dust-jacket blurbs invariably promise, as is the case in *Let Me Hear Your Voice*—both Maurice's children fully recover—or as happens in Sacks's story of Temple Grandin and her remarkable life and achievements, it didn't matter to me. There was no chance I was going to make it that far in either book.

Eventually, we hired The Consultant, though *hired* is not the right word. We pleaded with her to take Jonah on, to take all of us on really. In the beginning, The Consultant was encouraging but made no promises. She also made it clear from the start that she was the boss. It would be her way or the highway. Any suggestions we had would be noted but most likely ignored. From the moment she began, The Consultant was the person who knew what was best for our son. Her first recommendation was that we take Jonah out of daycare immediately. She'd observed him there and told us bluntly that he was lost. He's happy there, we maintained. "No, he's not,"

The Consultant assured us. He has friends there, we insisted. “No, he doesn’t,” she replied. Cynthia made a case for taking him out gradually, for reducing his days per week, then his hours per day. By then, Cynthia had realized herself that Jonah didn’t belong in daycare, that the daycare should have told us as much at least a year earlier. But she also wanted time to accept what this change in Jonah’s life and ours signified. How irrevocable it was. “Once he was out of daycare it meant he was out of the world of ‘normal’ for good,” Cynthia would explain years later. Back then, we also believed we could put quotation marks around “normal,” as if the word itself existed on some kind of sliding scale of behaviour, as if it could be graded from A to F. What you learn when your child has autism is that normal is simply normal, a separate category; pass/fail.

Still, there was no point in appealing to The Consultant on emotional grounds and no point arguing. There wouldn’t be time for daycare in any case. Jonah’s ABA therapy was going to be intensive, as close to forty hours a week as we could manage. Our son, barely four, was going to have a busier schedule than either his mother or I had or, for that matter, ever had. Cynthia worked part-time as an art therapist. I was a freelance literary journalist, reviewing books and writing author profiles. I hadn’t had a raise in thirty years. “ABA will be demanding,” The Consultant said, taking more trouble to warn us than I’m guessing she took with other parents, parents who probably seemed to her to have full-time grownup jobs and responsibilities. Her clients were usually lawyers or doctors, professionals of some kind, or executives, businessmen and women. Therapy like this was costly, after all, and they tended to be the only ones who could afford it. (We obviously couldn’t, but we were lucky in this regard: Cynthia’s parents volunteered to pay for everything related to Jonah’s therapy and did so with no second-guessing, no questions asked, no regrets or recriminations. It was at the time a remarkable act of love and faith. It remains so. An act I know they would probably prefer I didn’t mention here.)

ABA could also be uncompromising, and the decree that we take Jonah out of daycare was our first inkling of that. Was it a test? Even if it wasn't, it was an indication that from here on everything would feel like a test. What would really be required of us with this new therapy, The Consultant pointed out, was consistency—and not just in Jonah's program or the team of therapists The Consultant would eventually train and hire for his program, but in Jonah's everyday life. She was talking about us. *Consistency*. The word sounded, as did so many other words in those days, less like a prescription than a threat. Like something that was beyond my comprehension and capacity.

Which is the reason I avoided the A-word back then; because I believed, down deep, that words like *indistinguishable*, like *recovery*, like *consistency*, like *autism* were beyond all of us. What was being asked of me simply felt like too much to ask. I was also afraid that whatever progress Jonah made was not going to be enough. By which I mean—and was as deeply ashamed to admit this seven years ago as I am now—enough for me. When Jonah was diagnosed, Cynthia dealt with the devastating news by springing into action, developing a game plan, researching, networking, badgering government agencies and, later, school boards, doing battle with teachers and principals, researching ABA, finding The Consultant, hiring her, hiring therapists in consultation with her, talking to strangers, other families in similar circumstances, joining online listservs and chat rooms, borrowing and begging money, holding out hope, reading books, magazine articles, blogs, whatever she could. To-do lists and memo sheets littered the house back then; you'd come across book titles and strange phone numbers on Post-it notes, calendars, and pads by the telephone.

My primary game plan was to sulk. And sigh or mutter to myself every so often, not loudly, just loud enough for Cynthia to hear and, on occasion, come running. Mostly, though, she tried to ignore my bad behaviour the way you would ignore the behaviour of a disobedient household pet. In other words, she tried not to take my sulking

and muttering personally. She tried to tell herself that I couldn't help myself. You wouldn't get into an argument with a cat, for example, for clawing up the sofa, or a dog for peeing on the carpet. As a result of this kind of thinking on her part, we didn't get into nearly as many fights back then as we might have. Cynthia also knew, thanks to her early training in ABA, that ignoring bad behaviour was the most effective way to deal with it, to deal, that is, with Jonah *and* me. We were both seeking attention, after all, and she had already learned, from a behavioural point of view, that the worst thing she could do was provide it.

CYNTHIA NEVER DOES complete the chorus to "You Can't Always Get What You Want" for Jonah. She never goes on to the lyric about how if you try you can, at least occasionally, get what you need. She knows Jonah won't understand. Come to think of it, who would? Who ever does?

Want is easy, after all. Want is unambiguous. It knows no reason, accepts no excuse. It wants what it wants. Want is chocolate ice cream before dinner. Want is everything the way you expected it. It's your son typical, intact, yes, normal. As it turns out, our family motto doesn't suit my son or me. Both of us want precisely what we are not permitted to have.

As for need, that's something else entirely. The song gets it wrong, as it happens. It makes need sound uncomplicated when, in fact, it's trickier. It's about striking a bargain. What can you make do with? Minimum: you better grow up. Absolute minimum: you better figure out how to accept what's happened so you can be the father your child is going to need.

"Please, Daddy, number three?" Jonah says, holding up *Forty Licks*, making his spluttering request from the back of the car. I turn to glance at him and Cynthia frowns and points ahead, at the road. This is a significant difference between us. She recognizes there are worse

things than autism—not taking notice of an oncoming truck, for instance—while I have a hard time imagining anything worse. So as she turns to pat Jonah’s leg, I lower my rear-view mirror just enough to see his bottom lip quivering, his eyes welling up. I also see the strain in Cynthia’s profile, the effort she’s making at staying neutral and comforting our son, the effort that is always there whether I acknowledge it or not. When she turns back to look at me her expression is no longer neutral. She is silently communicating what I should already know. I should see the problem is not that Jonah is asking for a song—that’s good, that’s him problem-solving—it’s the way he’s asking. We can’t give in to that. We can’t reward his continued fussing. *Not now, sweetheart. We’re almost home. Be consistent. Stick to the plan. Breathe.* But Jonah is fussing and pleading, headed for another tantrum, when I accidentally run a stop sign. That’s when I see my wife relent. She can’t ignore me any longer. I have made it dangerous to do so. She is also tired, finally, of being the only adult in the car. She exhales and nods. The third track on *Forty Licks* is “Satisfaction”: more tantrum than tune, Jagger in a rawer mood, less philosophical, more animalistic, less mature, more demanding. I glance at Jonah’s suddenly beaming face in the rear-view mirror. He is giggling, out of the blue. It must be an inside joke. He has this capacity, my son, to turn on a dime, not only to forget the past, but to act as if it never existed. It is a strange gift but a gift nevertheless. One he clearly doesn’t get from me. “Shmatisfaction,” he says, giggling. Cynthia places her hand on the back of my neck. “We’ll be home soon,” she says, whispering under the clamour of Keith Richards’s unrelenting guitar riff.

I sigh and mutter what I know she’s heard me mutter countless times before: “Then what?”