

Learning what happiness is (and isn't) from my daughter with Down syndrome

## **Penny embodies the kind of love that holds onto hope amid suffering, redemption amid pain, and forgiveness amid hurt.**

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Our daughter Penny is 13 years old. She is in seventh grade. She loves Taylor Swift and *Fuller House* and wedding dresses. She says her most embarrassing moment in life was when she found out the boy she has a crush on didn't like her back. The first question she asks every morning when I wake her up is, "Did anyone text me?" She's a middle school girl who applies too much makeup when she wants to look fancy, who begs for a smartphone and the latest copy of *Vogue* when she sees it on the rack at CVS.

Penny also has Down syndrome. When she was an infant, I remember a friend saying (as if it were a consolation), “At least she won’t know if she’s being left out when she gets older.” My friend was assuming that Penny’s intellectual disability would inhibit her understanding of social rejection. Over the years, I’ve heard other versions of the same line: “They are all so happy, so sweet, such angels.”

When Penny is viewed from the outside, those statements might seem to apply. She is ready with a hug for anyone who will receive it. She’s quick to write a note of encouragement, quick to express concern for anyone in pain, and quick to forgive. She still grabs my hand whenever we walk anywhere together, and I am always struck by how small and soft it is. She still has the hand of a child.

And yet, Penny wept over the loss of a friend earlier this year. She wrote about the anger she feels when her younger brother doesn’t listen to her. Fear courses through her body whenever she hears a dog bark. She knows the hurt of adolescence. She reported the sting of overhearing an older kid say, “You’re such a retard”—even though the words weren’t directed at Penny herself. She has felt the ache of loneliness. She tells me how hard the lunch table can be: “I just don’t know when it’s the right time to say what I’m thinking.” She sits in silence most of the time. Penny is rarely, if ever, mocked. Most of her peers are kind to her, if not welcoming. But it hurts to be passed over.

Most people with Down syndrome [report a high level of happiness](#) with their lives. I suspect that their happiness, like Penny’s, doesn’t come from a failure to understand pain or rejection. Penny is happy in the midst of pain and rejection. Her attitude does not arise out of a lack of emotional depth or from an inability to feel rejected, abused, or depressed. Rather, it emerges out of an ability to hold onto hope in the midst of suffering, redemption in the midst of pain, and forgiveness in the midst of hurt. Penny embodies the great poem about love penned so many years ago by Paul in his letter to the Corinthians—that love is patient and kind, always believing, always forgiving.

If this is what love looks like, then I have spent much of my life rejecting love. I have been too busy and too careless to be inconvenienced, challenged, slowed down by it. I have been too ready to grab knowledge rather than receive wisdom. I have been too eager to prove myself, to receive accolades rather than turn my gaze beyond myself to the beauty of my neighbors.

Jean Vanier, founder of the L'Arche communities in which people with and without intellectual disabilities live side by side, has reflected upon the "smallness" of Jesus' love. This kind of love, he says, is often visible in people with intellectual disabilities. In *Signs: Seven Words of Hope*, Vanier writes,

We are discovering that those who are rejected by society on account of their weakness and their apparent uselessness are a presence of God. If we welcome them, they lead us progressively away from an over-competitive world where people need to accomplish great things, toward a world of hearts in communion, a simple and joyful life, where you accomplish little things with love.

In the morning, I hurry Penny to the front door, and I receive a hug. She walks herself to the bus stop, all four foot five inches of her plodding a deliberate rhythm. I know that every moment of the day—the icy sidewalk, the big backpack and the steps onto the bus, the lesson about cell membranes in science class, the rapid-fire conversation in the cafeteria—will be more challenging for her than it ever was for me.

Today is World Down Syndrome Day, a day to celebrate the lives of people with Down syndrome all over the globe. It's a day when I celebrate our daughter in the midst of the hardships and beauty of who she is. I'm confident that she will navigate the challenges, the rejections, and the giddy energy of middle school. She will navigate it all with love. And I will hold onto the promise that love never fails.