

## 28 On Surviving Loneliness and Isolation, and Learning to Live with Loss

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*I understand now that I've lived my life as the person in-between.*

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**I'M WRITING THIS** to my mom and dad, full of hope and dreams and sorrow and grief and appreciation for who I was when I still lived at home, when I was growing up in your house. You must have remembered how lonely and friendless I often felt. How I struggled with bullies at school, with students and teachers both in on it sometimes. I can't remember a time when I felt like I truly belonged anywhere. In years of talking to other autistic people, hundreds of other autistic people, this sense of constant alienation, isolation, separation, and loneliness turns out to be incredibly common.

Most clinicians and so-called autism professionals would say that this is because we as autistic people lack social skills and suffer from impairments in social reciprocity, empathy, and social skills. But you knew me—and you knew how I was terrified of making my friends upset or angry at me, and how I wanted nothing more than to make sure they felt happy.

What you might not have known is that I was terrified of losing all the friends I had. Fifth grade was one of the best years I had had because it was the only year when I felt like I had a group of friends in school who cared about me and were friends with each other. It turned out, of course, that

many of the people in that group weren't actually my friends—or even friends with each other.

And even at a young age, other kids knew: one of the best ways to get me to do something funny for other kids to laugh at was to convince me to do something meant to be socially awkward or wrong or deviant somehow, banking on the combination of my social obliviousness and my desire to please others to see it all through. Like the time other kids told me to tell a girl that I thought she was hot—a word that I thought just meant pretty (but had intuitively sensed that it probably meant something else, too). The joke, of course, was that I liked girls, and since I was supposed to be a girl, that meant I was doing something wrong.

But liking boys didn't work out either. There were the years when I hung out with a boy known to be in special ed classes, the kid that everyone else called a retard. You told me that it would be bad if I let people take pictures of me because someone might make a fake picture showing my face on someone else's body with a boy. Someone did, in fact, do that. And the fact that that boy and I danced together at a class dance made us both fodder for jokes meant to mock the fact that we were both weirdos and retards—bullying that didn't even make much sense, because I was also constantly made fun of for being interested in books and being a nerd.

Since childhood, I've learned that many autistic people form much closer relationships and friendships with people significantly older or younger than we are, which is incredibly noticeable as a child, where spending time with kids two grades older or younger, or with the teachers, is an excellent way to be marked a weirdo right away. As adults, it can take different forms—friendships with people in different stages of life than our own, regardless of exact ages.

For me, the circumstances of my life have undoubtedly shaped the specific type of loneliness and alienation I continue to feel in adulthood. I knew from a young age that I was different from my peers—for better and worse. I always knew. I didn't always use the same words or language to describe myself as I do now, nor did I know all the things I do now. But as a Chinese kid with white parents, and a sister who is also Chinese but clearly of a different ethnicity than me, I already knew that I did not belong. No matter what you wanted for me—to love and be loved, to be raised to be kind and also just, smart and also humble, giving and also careful—there

was no escaping the racial dynamics of the kind of transracial and transnational adoption my sister and I became subjects of.

It's impossible for white adoptive parents of children of color to ever fully understand the political, social, and cultural dynamics surrounding transracial and transnational adoption, including the adoption industry's deep connections to white supremacy, settler colonialism, and family separation. Most adoptive parents—even if we're limiting this to the pool of adoptive parents who actually mean well, and exclude the ones adopting for consciously predatory or exploitative reasons—want the best for the children they choose to bring home. But there are also layers to the ableism we have to deal with when the adopted children turn out disabled.

You remember when the school psychologist decided—in contrast to the neuropsychologist you'd taken me to—that I couldn't possibly be autistic, but instead must have reactive attachment disorder because of the trauma caused by adoption and my early weeks or months (or however long it really was) in a state-operated orphanage? (Ironically, given my current work as a disability rights and disability justice advocate, another kind of institution lesser-named in disability work.) You might not have known that that specific diagnosis is a way to stigmatize people who've survived trauma in early childhood, especially trauma caused by family relations or family separation—and it's often coded by race and class too.

I know that I'm autistic, and I know that like most other autistic people, I've survived trauma after trauma throughout my life. Some of that trauma is what we call ordinary trauma—things that might seem small or minor to people outside our lives, but that nonetheless affects us profoundly. Much of the trauma I've experienced, both in childhood and adulthood, has been connected to isolation and the loss of friends. Social ostracism and shunning are dangerous and deeply violent, whether done within a family unit, in school, in a religious cult, or in an identity-based community.

I don't think you could have predicted that. But I wish you had known just how much it hurt to be told that I had friends and people who loved me, because in moments when I was grieving the loss of friends, or the realization that people I'd thought were friends were actually bullies or abusers, what I actually needed to hear was simply an affirmation that what I was experiencing was awful. That sometimes people are terrible. That sometimes it's not meant to work out. That sometimes life brings awful bitterness and sorrow, and the only correct reactions are grief and rage.

Even today, I still gravitate toward other loners. Anywhere I go, I have an intuitive sense for the weird and lonely people, often other disabled, sick, mad, neurodivergent, queer, and trans people. We witness each other. We know each other. We can recognize other people who share this pain. The pain of constant rejection and fear of rejection. The pain of trying our damndest to be kind and decent people only to be exploited and betrayed over and over again, often with little or no explanation. This happens to autistic people on such a stunning scale that there probably should be specific research done on it, though I suspect that some of the reason this is so common for us is that many of us can be overly trusting and wish the best for others, even if we are at the same time deeply distrustful and wary of them because of the trauma we've survived. We are often deeply principled and wedded to the values we grow up with and the values we adopt later in life, and as a result, many of us are deeply concerned with a sense of fairness or justice. That instinct means that we're often well-placed to support others like us—and in exactly the right position to be ridiculed by peers, isolated within our social networks, or targeted for manipulation by people seeking to exploit us.

I wish you'd taught me better how to set and enforce boundaries for myself—for my time, my energy, my space, my life, and my love. You wanted me to be safe—most parents who are at least even halfway decent want this for their children. I would give anything for my younger self to have been able to feel both safe and free at the same time.

I understand now that I've always lived my life as the person in-between. I've struggled for years to make sense of my queer and trans identity and experiences, as an asexual person often assumed (incorrectly) to be a woman, who's been at times femme and at times masculine of center, and who's been in heterosexual as well as queer relationships. I've spent years developing a clear and specific understanding of my own positionality as an East Asian person of color and what that means in both how I experience privilege in society and specific racist oppression. In disability advocacy, we're often stuck between being called not disabled enough to have a say on disability or too disabled to be able to have a say on anything at all. That kind of in-betweenness for me has never been limited only to my social and political identities, though, and marks every aspect of my life.

You remember how I usually had friends outside school but not as much in school? How my friends were often in different grades? How I left your church's youth group because of the extreme alienation I felt from the other youth and the pastor alike? How I decided to leave activity after activity? I don't remember what I had said at the time as to why, but I remember now that I never felt like I belonged, was good enough to stay, or would be able to stay for too long before others would decide that I didn't belong. I was always the odd one out—and never able to feel comfortable for long. Even in my fiction and roleplay writing, I'm struck by the shared loneliness among my characters.

Research and personal accounts have documented that autistic people are significantly more likely to be victimized by bullying and abuse of all types throughout our lives. You once told me how hurt you felt whenever you learned that someone had been mean to me. As an adult, I understand and appreciate this sentiment—a type of offering of compassion or empathy. As a child, what I needed to hear, what I wish other autistic, neurodivergent, mad, sick, and disabled children could know, is how much our parents cared that we were hurting.

I've thrived as an adult in many ways. I have friends and a partner, and in many ways, fulfilling passions and work (to the extent that we can be happy about the work we do). But the persistent sense of alienation and loneliness has never left. Nor has the fear of losing friends. More than anything else, I wish that parents of autistic children would understand that we don't need people to speak *for* us, or even to keep us safe in a world that is fundamentally unsafe, so much as we need our parents to demonstrate what it's like to develop healthy friendships. Positive family relationships, romantic relationships, and collegial relationships all have in common the basic tenets of a good friendship: trust, care, respect, and mutuality. I don't miss the complex drama of the middle school years, and I certainly don't want to re-experience the traumas that have shaped my life since then. But I do remember well the ways in which you showed me that love across identities and experiences is possible—in making sure I could take Chinese language classes at a Chinese cultural center, in writing notes back and forth while in-character as part of my imaginary world, in encouraging me to explore all the things I loved to do, on my terms, in my way.

You were not perfect, and neither was I.

I have become a person that I hope my younger self would be proud to know and perhaps look up to. And I have brought the full weight of my grief, my losses, my traumas, and my hard-fought, hard-won growth with me into a world where I know I may never belong by others' standards, but where I'll make damn sure I never stop fighting until we can all experience love and rest and community and care, past isolation, past survival.