Language, Please

Word Choice

with Alice Wong
Story synopsis

Alice Wong is a disabled activist, writer, editor, media maker, and consultant who founded and directs the Disability Visibility Project. In 2022, Wong was finishing up her memoir, Year of the Tiger, where she writes vividly about her love of food. Then, she experienced a medical crisis that required a G-J (gastric and jejunostomy) tube, which meant that she could no longer eat by mouth. In her story for Eater, Wong reflects on how she has learned to keep nourishing herself and the people she loves.

Why this story?

Wong’s story is the only first-person piece in our lineup of interviews. One of the reasons we were keen to include it is because of the instructive ways that Wong defies the usual bounds of the personal essay form. Through her prose and editorial process, she connects her story to those of other writers, advocates, activists, and food lovers. Wong is not trying to prove anyone’s humanity. A specific experience of disability — like consuming nourishment through a feeding tube — may be new to her, but for whole communities of people, that same experience is an everyday reality they’ve been living with for years. Grounded in what Wong calls “non-normative ways of being,” her writing unlocks vital understandings of disability, hospitality, and care.
Language, Please: When you were in the ICU, one of the ways that you sustained your connection to food was through television.

The second episode of Iron Chef: Quest for an Iron Legend featuring Esther Choi made me want everything she made, such as her pork rib-stuffed donuts with sesame milkshake and dalgona cookie. A nurse saw me watching the episode and asked if I was torturing myself since I was temporarily on TPN (total parenteral nutrition), a form of intravenous nutrition. Was it torture? I didn’t even consider that, because it was my way of fulfilling my desire visually.

From Constant Cravings

L,P: In this passage, you shift from your own experience of seeing all that incredible food being prepared to a nurse’s impression of what that must have been like for you. Why was it important to reveal that contrast?

Alice Wong: While I was deeply craving food and mourning the loss of my ability to eat by mouth, I still derived pleasure and felt partially satiated by watching the Food Network as a way to pass the time and distract myself. And while many health care providers mean well, they can think about disability as a deficit or loss without accounting for the power of adaptation and the imagination. Many people see me as a collection of diseases, dysfunctions, and difficulties because that’s what is most apparent, but they’re not seeing the real me.
For disabled people, having a non-normative way of being opens us up to ableist abuse, harassment, discrimination, and microaggressions. The other day, I was waiting outside of Rhea’s Deli with my caregiver on Valencia Street in San Francisco as we were waiting for her sandwich order. We were on our way to spend a sunny afternoon at Dolores Park and a random person saw me, pointed at me, and asked my caregiver, “What’s wrong with her?” And he proceeded to touch my hand without my consent. So many nondisabled people believe that death is better than a disabled life, which is such a failure of the imagination and quite tragic, in my opinion. And this is why I write, because I am sharing my lived experiences in a way that’s not trying to prove my humanity to others but to simply illuminate the realities I go through with the insistence that people accept me as I am.

L,P: Your story interlaces evocative language (yolks breaking, butter bubbling) with technical descriptions (how muscular dystrophy affects the body, what TPN means, steps to avoid aspiration). Can you share how you think about balancing narrative and explanation in your writing?

AW: I try not to prove my worth, elicit empathy, or persuade an audience that “I’m just like them” in my writing. Instead, I prefer to not explain too much about the details of my disability. Of course, it is part of who I am, but in much of my writing, there are larger, complex themes I want to express. Many editors I have worked with who are nondisabled (I presume) have asked me to expand more on some aspects of my body and health even though I may find it basic, because the details I share are new to them and therefore probably new to the audience. And I’ve done the same as the editor of the Disability Visibility Project, when I ask writers to provide a little more context or add a hyperlink if the reader wants to learn more.

The narrative aspect is central to me in order to create a world and sense of what I experience and feel. For this essay, I knew I had to include a cursory explanation at the beginning to give some background on the circumstances that led to my new body, which serves a purpose for the reader but is not the heart of my piece.

Since I do not breathe through my nose and mouth, I can no longer smell, which obviously affects taste. I didn’t have enough space to include this in the essay, but as I was recovering, my dad was stir-frying something with a ton of garlic and I actually got a small whiff of it, and it was such a joyous moment. The other day I was at Philz Coffee, and I could actually smell the roasted coffee beans! These moments are rare and fleeting and I was so excited to be able to savor that moment, as both garlic and coffee are some of my favorite things. And I am grateful to have a library of food memories that I can access and relive at any time. Last week, I dreamed that I sank my teeth into a huge piece of pork belly and I could actually feel and taste it. Dreams are awfully powerful, and I am thankful for them.
Life without flavor and scents can be difficult, but this is the reality of millions of chronically ill and disabled people. Our lives are not merely ones of deprivation, tragedy, or sadness.

From *Constant Cravings*
What are some of the challenges (and opportunities) related to language when you imagine readers who will have a broad range of their own experiences with disability?

I try to be succinct and not write in defense of myself but rather to challenge a reader to reimagine and expand the possibilities of what a person’s relationship to food can look like. I am still exploring and growing myself and hope to share what I’ve learned with others.

A dream of mine is to write a cookbook/memoir about disabled hospitality. Two recent publications are examples of food writing by disabled people, which has been largely absent and not highlighted by the food industry: Jules Sherred’s Crip Up the Kitchen and Sonali Menezes’s zine Depression Cooking, which is part of s.e. smith’s profile of Menezes in my Low and Slow series for Eater. Part of my work as an editor, writer, and media maker is to amplify and support disabled creatives because we’re out there doing radical and innovative things.

After two months without tasting anything, you decided to start trying bites of food and spitting them out — first peaches that your dad mashed in a blender, then broths, ice cream, and finally, during a meal with friends to celebrate being alive: french fries.
While I enjoyed selecting the multicourse meal for them — which was an act of pleasure and care — I intended to take a small taste of fries. Abby, my friend who sat next to me, fed me by dunking one fry with aioli at a time while I held my spit cup. The hot, crispy, and soft potato! The cool, creamy, and garlicky aioli! My eyes rolled [to] the back of my head as Abby continued to send fry after fry in my mouth. In the midst of that blissful moment I let my guard down and almost choked when a bit of potato went to the back of my mouth. I tried to produce more saliva and coughed as best as I could with tears streaming down my face from the effort. Food has become dangerous and thrilling at the same time. I refuse to let my fear steal my joy and am determined to have a maximalist life. Viva noncompliance!

From Constant Cravings

L,P: There is so much richness in this passage — so much to unpack! You share the loving ways that your community shows up in your life. You describe picking out dishes for your friends as “an act of pleasure and care.” And then you close the paragraph with the phrase “Viva noncompliance!” — a sentiment that echoes through your writing. Is there more to say on these themes?
AW: Going out socially, especially at a restaurant during the pandemic (which we are still in now), was a big step for me a few months after I left the hospital. I was pretty self-conscious about how I would communicate with my new text-to-speech app, and worried if I could keep up in overlapping conversations with my friends and whether I could still fully express my sparkling personality. And I wanted to test my boundaries despite advice from my doctors. Those fries and aioli (aioli over ketchup, always) at the Morris became a new food memory and served as a reminder of the risks involved in trying to regain a semblance of eating. Dignity of a risk is a concept in the disability community that all people have the right to make their own decisions, even unwise ones. I took a pause trying to chew and taste something solid, but small bits still ended up in the back of my throat despite spitting it out as soon as possible, causing me to choke. Disabled people have been told what we should and shouldn’t do by professionals forever, without the space to make mistakes, take risks, and live autonomously. In my desire for these hot, delicious fries I gave in and do not regret it for a second, even though it came at a cost. About a year later, I took a small bite of herbed kennebec fries with horseradish aioli from grace restaurant at the San Francisco Museum of Modern Art, and the exact same thing happened again, no matter how careful I was. Unfortunately, this confirmed to me that I really shouldn’t do this anymore and stick to tasting liquids only. I actually got a little sad this time because this meant it might be my last time tasting a french fry ever, which is something to be mourned (prayer hands emoji).

Currently, I am channeling my lust/love for food into my relationships with my friends, family, and community. I moved into my own place with a gorgeous kitchen a few months ago, and I’ve been having the most fun baking and cooking for my friends. My parents miss me terribly despite only living 10 minutes away, and I began to cook meals for them once a week when they visit me. They were surprised I could cook (by directing my caregivers) such healthy and tasty Chinese meals. When I recently made a red bean tapioca soup with soy milk instead of coconut, my mom’s favorite dessert, she said, “Not too sweet!” For any person with Asian parents, this is extraordinarily high praise. I felt very proud of myself and hope they realize it’s my way of taking care of them even though I can’t help them in the typical ways. Feeding others, watching them eat with gusto, and using my creativity in menu planning has been my new way to expand what hospitality and care mean to me. Desire and longing are intertwined with bittersweetness, and maybe that’s what I can taste now.
Let’s expand our conversation beyond this story to the Low and Slow series you launched with Eater. Tell us how the idea came about, and what readers can find in the series.

I’ve been a longtime reader of Eater and fortunate to work with executive editor Erin DeJesus on two pieces about plastic straw bans in 2018 and the one we are discussing in this interview. One of the goals of the Disability Visibility Project is to amplify the work of disabled people. While I publish essays by guest contributors from my website, I know it does not have the same reach as Eater or other established online publications. It is a privilege to be a published writer, and I know how hard it is for freelancers to pitch pieces and get constantly rejected, especially if you are disabled or a person living at multiple margins.
After Constant Cravings came out last year, I thought about all the amazing and fascinating food stories by disabled people that are not being told in “mainstream” media and dreamed up a collaboration with Eater for this series. Braising is one of my favorite cooking techniques because it makes any protein tender and you really can’t mess it up. I thought it was the perfect name for this series as a metaphor of the lived disabled experience. I developed a proposal and reached out to Erin and was connected to Monica Burton, who co-edited this series with me. As with my other previous collaborations, The Access Series for Bitch Media and Break the Story for the Pop Culture Collaborative, I featured disabled people of color as much as possible and paid contributors rates that were above the industry norm. The delightful Cheryl Green narrated audio versions for Low and Slow, and Ananaya Rao-Middleton created such gorgeous drawings for the Bitch Media series and this one. Eater commissioned a total of six interviews, essays, and reported issues that began in June with a piece on the joy of gardening by Brandy Schillace, one by Dr. Sami Schalk in conversation with Clarkisha Kent about fatphobia and ableism, and the final two in November. All of the contributors are amazing, and I hope the Eater audience enjoys them as much as I do.

In my introductory piece for Low and Slow, I wrote, “Disabled people are masters of innovation, creativity, and adaptation. We learn how to work with our bodies, sustain ourselves and our communities, and navigate through inaccessible and ableist environments. This series provides merely a sample of this brilliance through the prism of food.” Leveraging my existing relationships with editors to expand opportunities to disabled writers and artists gives me such joy because it’s not just about sharing my story with the world – it’s about centering disabled people in publishing as much as possible. Speaking of my dreams, one of my ambitions is to be an editor-in-chief of an imprint that publishes books exclusively by disabled writers and edited by disabled editors at one of the big five publishers. If journalism and publishing is serious about their commitment to diversity, equity, and inclusion, they could easily fund initiatives like this, which are long overdue and much needed.
L,P: How do you apply lessons from your first-person essays to the process of editing other people’s writing? Any tips for other editors?

AW: Establishing trust with a writer, taking care with your edits and comments, and editing with the intent to make the writer’s story shine are my goals as an editor. I try to explain my choices and be as gentle yet firm as possible. **Having perspectives as both a writer and an editor is useful** because this relationship doesn’t necessarily have to be an antagonistic one but rather a collaboration that will bring forth a story that is ready to rock the world. Since I am not beholden to the pressure to constantly publish, I have the freedom to publish work when they are ready, and with some contributors, they may need several extensions because disabled life and other circumstances get in the way. Most editors are hamstrung by limited budgets, capacity, and time, which I understand, but it would be helpful if editors can be patient with writers, give them time to develop their drafts, and respond to their queries in a timely manner. Perhaps the main tip to editors is to **extend grace and be as flexible and accommodating as possible**, especially working with disabled writers and writers of color.

**Editor’s Note:** Alice Wong’s new book, *Disability Intimacy: Essays on Love, Care, and Desire*, is out in February 2024.