

From Hospital Rooms to

Hashtags:

Reimagining Caregiver Advocacy
through Social Media

Presented by Alyssa Nutile & Erica Stearns



Who we are...

Alyssa is a disabled adult, caregiver, advocate, and digital content and social media strategist.

Erica is a disabled adult, caregiver, researcher, advocate, and caregiver peer support specialist.



Caffeinated Caregivers

Caffeinated Caregivers Advocacy Network is a 501(c)3 nonprofit community and advocacy network built ***by caregivers, for caregivers.***

The work we do includes:

- creating and fostering a virtual community of caregivers
- creating and sharing resources and frameworks
- fostering partnerships between caregivers and researchers



www.caffeinatedcaregivers.com
[@caffeinated_caregivers](https://twitter.com/caffeinated_caregivers)

Spilling the Tea

THE WHY

A look at what pulled us into this work and the spark that started it all.

THE HOW

How we found our rhythm, leaned into our strengths, and built something new.

THE IMPACT

The ripple effect of showing up online, and what it has meant for us and others.

LESSONS LEARNED

What's stuck with us, what's shifted, and what we want others to know.



Why Spill the Tea?

ANYONE CAN BECOME AN ADVOCATE

And it doesn't have to drain you. Advocacy can start with what brings you joy, what you're good at, and what you wish existed.

FINDING YOUR PATH (AND YOUR PEOPLE)

For us, it meant creating the kind of space we were missing. One rooted in humor, honesty, and lived experience, where caregivers can feel seen, supported, and inspired to speak up.

***There are many ways to make a difference.
This just happens to be ours.***



The Why: Erica's Journey



Storytelling as survival, then as solidarity.

Writing helped me make sense of my experiences, and ultimately helped me build the kind of caregiver community my mom never had.



Turning everyday updates into advocacy.



What started as everyday conversations turned into advocacy and eventually something bigger: a space where caregivers create real change.

The Why: Alyssa's Journey



Building community through honesty & transparency.

Being honest and open allowed
me to find the community
I needed when I needed it.

And all caregivers deserve to
have this too.



Where our paths crossed...

Through shared values, frustrations, and lived experiences, we recognized the same gaps in caregiving spaces and decided not to wait for someone else to fix it. We teamed up to create what we wished existed.



The How:

Building Something New



Identifying the Gaps

There are very few spaces and media outlets focused on the caregivers of medically complex kids.

To identify the topics and gaps in information that caregivers are looking for, we:

- **Ask** the community questions and engage in direct conversations.
- **Observe** larger conversations happening in the broader community.
- **Take note** of major news topics and where their coverage lacks a caregiver perspective.
- **Pull from our own** varied experiences as necessary.



Redefining What Storytelling Can Be

- We combine storytelling, humor, and design to connect through **lived experience**.
- Our content turns caregiving realities into relatable, **shareable moments**.
- Humor (especially memes) helps **validate** caregivers while educating others.
- Every post is a chance to say, **"You're not alone,"** and start a bigger conversation.

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Bystanders at the coffee shop listening to the dark humor that me and my fellow caregivers find hilarious



Community Rooted Research

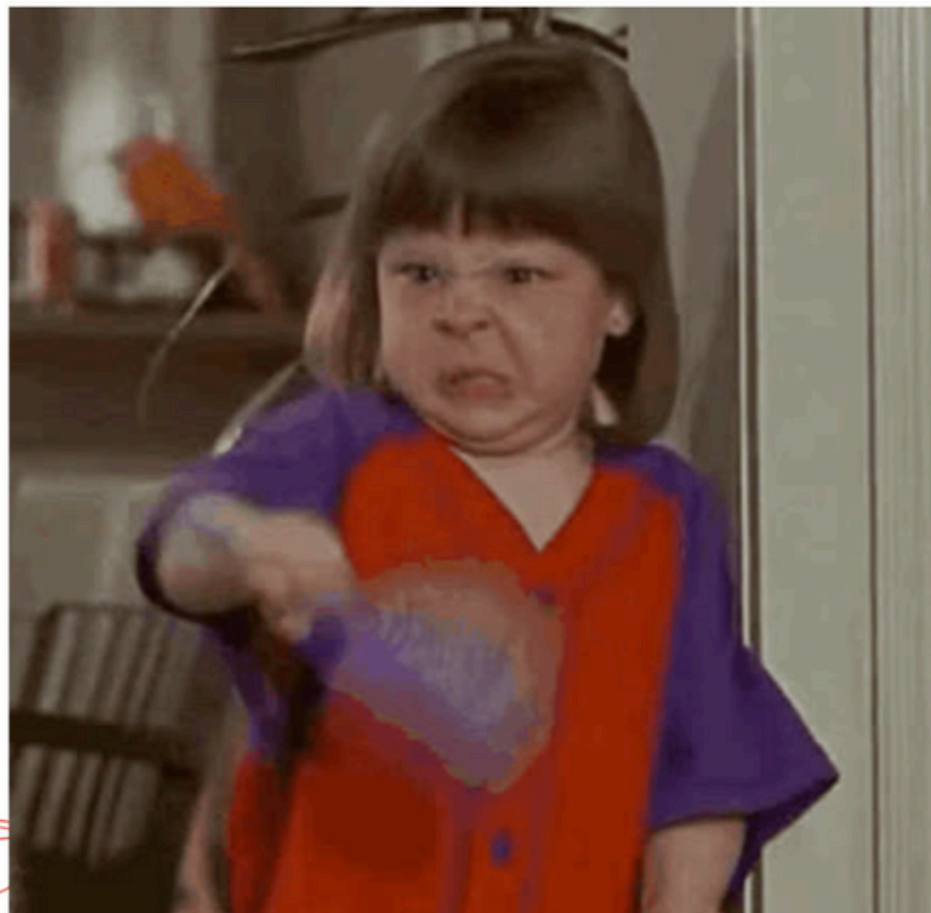
- Caregiver voices are often **missing** from mainstream media and research.
- We use community-rooted research to capture **real-time experiences**.
- **Polls and questions** spark meaningful conversations on timely issues.
- We turn **insight into action** - fueling connection, advocacy, and education.



The Impact: Community & Advocacy

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When the playground installs an accessible swing but you can't even roll your child over the wood chips to get to it



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Newsflash:

**Caregivers
deserve
care too.**



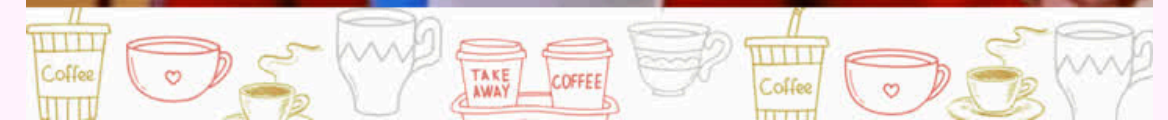
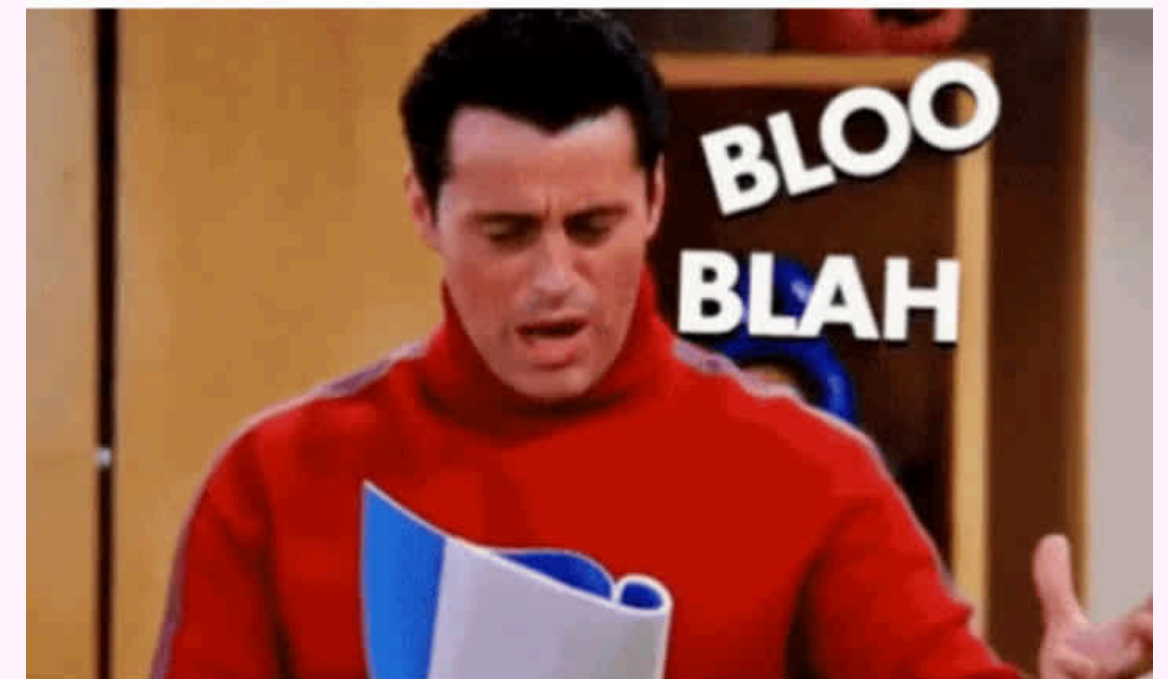
The “Unreachable” Caregivers

The reality: Many caregivers (especially those of medically complex children) cannot easily access or attend in-person events

- Online community is often their ***only community***.
- **Social media becomes a lifeline**, a way to keep others updated and connect with others.
- **Caregivers find each other** through shared interests, topics, and loose networks online.

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When my fellow caregivers and I use medical terms to each other that no one else in our lives understands



Digital Advocacy on Social Media

- Turn complex systems into **everyday language**.
- Use memes to **name what's broken**, and show we're not alone.
- We **model respectful disability language**, subtly and accessibly.
- Give caregivers language to talk about **challenges and barriers**.
- **Connect caregivers** with research, media, organizations, and each other.
- Shifting the narrative from "grateful to get anything" to **deserving better**.

Lessons Learned

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How I respond when someone says,
“You should get some more rest!”



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When someone says “Make sure you love
them while they’re still here with you”



Reflections on What Worked

- Humor **builds trust** and breaks down walls.
- **Relatability** opens the door for reflection and connection.
- Caregivers are craving both support and **solid information**.
- **Real stories cut through the noise**, and the professionals are listening.



What We Learned...

- **Staying grounded** in lived experience keeps the work focused and real.
- Honoring **one truth at a time** can deepen impact and clarity.
- **Knowing your audience** helps build stronger, more meaningful connections.
- **Utilizing one story doesn't erase others**, it creates conversations to build from.
- Focused advocacy can be expansive when it's **rooted in authenticity**.

Do you ever feel like this?

As a caregiver, I feel like
I'm constantly waiting for
the other shoe to drop....
**I can't relax even
when things are
going well.**

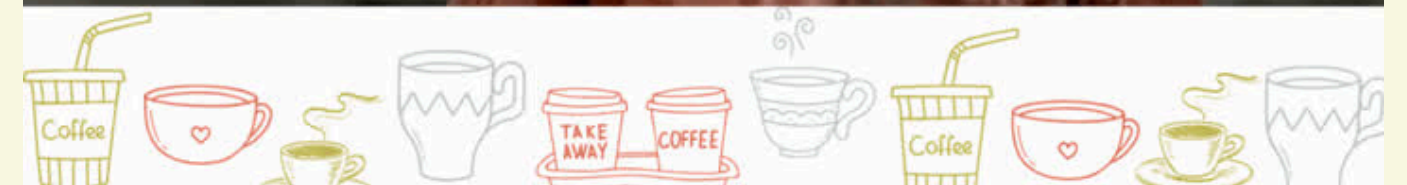


Encouragement to Others

- You don't need a big platform, just **a message and a mission**.
- Start with what's missing: **what do you wish existed?**
- Collaboration beats burnout, so partner with people who **complement your strengths**.

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When you see another caregiver who just gets you and supports you



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When other caregivers are the only ones around who really understand your life, and you appreciate them so much



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Me when I don't have to filter or tone down my reality when talking to caregiver friends



Q & A Time!

**Reimagine Your
Digital Advocacy**





Support the pediatric caregiving
community by donating to
Caffeinated Caregivers:

Stay in touch!

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