

Create Change Through Lived Experience: The Whole Advocate™ Model

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Any movement toward positive change requires people to share their lived experiences — to give voice, raise awareness, change minds, educate or motivate. It requires advocates. But how can advocates feel confident that their stories are being heard and truly making a difference? During this session, Tim Cage and John Capecci, cofounders of [Living Proof Advocacy](#), described their model of support for advocates sharing their personal stories and Kate Callan, EVP, Head of Social Media at Evoke Kyne, shared tips and best practices to amplify your story on social media.

Featured Speakers



Dave Bjork (moderator)

Lung Cancer Survivor, Patient Advocate and Vice President of Empowerment, GRYT Health



Tim Cage

Cofounder and Senior Coach, Living Proof Advocacy



John Capecci

Cofounder and Senior Coach, Living Proof Advocacy



Kate Callan

EVP, Head of Social Media, Evoke Kyne

Key Points and Resources

Power of Storytelling to Make a Difference

- Sharing lived experiences can foster empathy and lead to action. Consider the five qualities of the well-told advocacy story:
 - Focused:** the more you connect your story to your message and goals, the more successful you will be
 - Pointed to the positive:** strike a balance between pain/problem/trauma and hope/solution/action
 - Crafted:** what is your focus or intent with your story? Use that to edit and jump forward and back in time to draw your audience in
 - Framed:** clearly define your story and purpose to take control of your narrative
 - Practiced:** give yourself time to improve your speaking skills so you are natural, genuine, clear and confident
- [Living Proof Advocacy](#) offers practical guidance for sharing personal narratives to support a cause or organization. Tactics include keeping a journal and preparing 3-5 min “advocacy talks” focused on a specific goal or message

The Whole Advocate Model™

- The Whole Advocate Model™ is a framework to support advocates center personal narratives and engage in patient centric initiatives, built around the following pillars
 - Skill:** help advocates develop and practice the communication, storytelling, advocacy and media skills needed to be effective public advocates
 - Care:** giving respect to the significant process, especially in terms of emotional and physical health and safety, of going public with a personal experience
 - Information:** urge advocates to arm themselves with the messaging, relevant facts and organizational information to support the importance of their stories
 - Context:** encourage advocates to be aware of their identities and roles, the broader contexts of their advocacy, their responsibilities and their various audiences
 - Agency:** empower advocates to identify, own and preserve their authorship, voice, experiences and the use of their stories

Applying the Model: Using Social Media to Amplify Your Story

Social media is a powerful advocacy tool; the following strategies can help advocates bring visibility to the stories they wish to tell online

- Define your goals:** do you want to raise awareness? Foster connection? Advocate for change? Defining your goals can help you ground yourself in the impact you want to have online
- Conduct research:** identifying advocates that are already active on social media can allow you to define what will make you unique
- Hone your communication style:** authenticity will create sustainability – focus on one channel and progress to more as you grow
 - Facebook* is the largest social media platform and may resonate most with an older audience; consider starting a Facebook Group to build and engage with community members
 - Instagram* offers a range of content types like still images and video; it is popular among advocacy groups
 - Twitter* is useful for written communication, trending news and conversations; it is utilized among a wide range of ages
 - TikTok* is popular among younger audiences and is useful for sharing videos exclusively
- Be consistent and engaging:** create content themes, follow, comment and reshare content of interest regularly but with a sustainable frequency
- Determining success:** set objectives, reflect monthly and adapt as needed
- Continue learning:** visit the [Pew Research Center Social Media Publications](#), [Social Media Today](#) and other advocates’ social media channels to build your knowledge base