

Dementia content gets billions of views on TikTok. Whose story does it tell? | MIT Technology Review

By Abby Ohlbeiser

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“That’s a conversation that people with dementia have been having now for a while,” says Kate Swaffer, a cofounder of [Dementia Alliance International](#), an advocacy group whose members all live with the condition. Swaffer was diagnosed with younger-onset semantic dementia in 2008, when she was 49.

In some ways, these conversations echo ongoing discussions about “[sharenting](#),” family vloggers, and parenting influencers. Kids who were once involuntary stars of their parents’ social media feeds grow up and [have opinions about how they were portrayed](#). But adults with dementia are not children, and whereas children develop the ability to consent as they grow older, theirs will diminish permanently over time.

Legally, a care partner or family member with power of attorney can consent on behalf of a person who is unable to do so. But advocates say this standard is not nearly enough to protect the rights and dignity of those living with later-stage dementia.

Swaffer’s own standard is this: No one should share content about someone in those stages of dementia—whether on Facebook, in a photography exhibition, or on TikTok—if that person has not explicitly consented to it before losing the cognitive capacity to do so.

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