



NEXTGEN: Storytelling for Dementia Justice

BACKGROUND

Families navigating younger-onset dementia are often unseen, misunderstood and isolated. Storytelling has the power to shape how individuals understand themselves, connect with others and influence how society responds to experiences that are frequently ignored.

For those affected by younger-onset dementia, storytelling can move beyond memory-sharing to become a tool for healing, visibility and dementia justice.

METHODS

Storytelling for Dementia Justice is a participatory, lived-experience-centered approach that invites sons, daughters, children of a parent with younger-onset dementia and allies to engage in a series of workshops, led by a storytelling expert, to build on their lived experience and feel empowered to share their wisdom.

Participants are prompted to explore their personal narratives through questions such as:
What does it mean to bring light to our stories?
What do I wish my community understood so I could feel truly seen and supported?
The sessions center listening to lived experience as a means of shared learning and self-empowerment.

OUR STORIES

Sisters, Sandra & Diana Gonzalez-Morett (USA) - NEXTGEN MEMBERS

Our work in film and visual arts has created meaningful social impact, opening doors to advocacy, research collaboration, and culture change within our communities.

- Former Caregiver / Familial FTD
 - A potential gene carrier (GRN)

Results

Netflix sponsored short-film, *Pedacito de Carne*

- A narrative representation of our family's story
- The film has raised awareness for FTD and young caregivers
- Founded Go-Mo Creatives
 - *reducing dementia stigma* through the arts
 - Pets of FTD Awareness Calendar
- Spanish-language FTD support group leader and AFTD volunteer

***For our mother's legacy,
and for the future we may one day face.***

CONCLUSION

Participants gain a practical toolkit of skills to help them share their own stories with confidence. Through facilitated storytelling and reflection, we feel empowered to express our experiences and perspectives.

In turn, professionals gain a deeper understanding of the unique journey navigating younger-onset dementia. This increased insight, fosters greater empathy, reduces stigma, and supports a more informed society.

