

Rare Disease Storytelling

A journalist's guide to sensitive storytelling

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2025 Rare Disease Reporting Fellowship Launch

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The Story Spark: The MND Story

The Tip off

The tip off came from a colleague in the Public Relations Industry. She is a communications officers at one of the hospitals in Kenya.

The Why

- ▶ **My interest was piqued when she mentioned that the source, a caregiver, had lost five family members to the disease.**

Before You Go: Preparation

- 1. Understand the disease at a clinical level. Research about the disease, how it presents, and common misconceptions. This prepares your mind for what is coming.**
- 2. Address gaps. Request for contact of family/source, and if possible, let them brief you about their story so you know what to research**
- 3. Schedule an interview as soon as you are able to**
- 4. If they have a blog, social media, or public-facing advocacy, review it. Understand their journey as they've told it so far. This shows respect for their time and story.**

Ethical and practical reporting guidelines

- 1. Focus on the individual, not the diagnosis. Say “person living with xx, not (xx) patient.**
- 2. Avoid sensationalism-using language like victim, sufferer, tragedy. These terms are condescending**
- 3. Prioritise interviewing the patients and family members themselves. Give them control over their story and how they are identified.**
- 4. Balance personal stories with expert input from genetic counselors, rare disease specialists and mental health professionals. If you don't have any, request source or family member to link you with their doctor.**
- 5. Ensure patient/family understands exactly how their story will be used, what details will be shared, and potential for public exposure. For children, follow legal and ethical guidelines.**
- 6. Ensure their story covers their life beyond the disease and mental health struggles. Show that they are fully dimensional beings.**
- 6. Be a compassionate listener. Sharing their story with you can be emotionally taxing. End interview by shifting to a less emotional subject, then to a happy one. Ask about favorite memories, hobbies,if they love plants,art etc ask them to show you.Do not leave your source feeling sad.**

During and After Interview

- ▶ **Go beyond basic medical facts and understand the daily logistics of diseases.**
- ▶ **In reviewing their medical documents, you may find shocking details hidden in medical jargon, and your source may be unaware of its meaning. Manage your shock, and keep it in. If they wanted to tell you about it they would.**
- ▶ **Do not promise an outcome eg this story will lead to funding.**
- ▶ **Chronic illness and caregiving can be exhausting. Do not take longer than you should. Also allow for breaks, and check in frequently if they are comfortable, and if they wish to continue.**
- ▶ **At the end of interview, thank them for sharing their story. Some will ask you to pray with or for them, do not be afraid to do it. This may be their only source of hope.**

Thank you

- ▶ **Questions?**
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