

MY JOURNEY AS A STROKE SURVIVOR

- Shaping Research with My Experience
- A Personal Story
- I am Alexia, I Had a stroke in 2015, and my right side was affected. I am a survivor

CHALLENGES I FACED

- Communication barriers due to aphasia were tough. It was difficult, but I was determined to contribute.



INTRODUCTION

- My journey as a stroke survivor has shaped my perspective on research

Having a stroke made me feel like I had lost my voice, but participating in research gave it back to me, showing researchers the true value of stroke survivors' experiences

WHY I GOT INVOLVED

- I wanted my voice to be heard and my experience to matter
- Research should reflect real-life challenges, and I wanted to be part of that change

MY TEAM!!



CHALLENGES I FACED

- Communication barriers due to aphasia were tough. It was difficult, but I was determined to contribute.

After my stroke my life was turned upside down , but through every challenge (physical, emotional , and social) I KEEP fighting to adapt, grow, and reclaim my life.

MY INITIAL CONCERNS




- I feared my aphasia would make it difficult to contribute
- Would I be understood? Would my input matter?
- I pushed past these doubts and took a leap of faith!

SHAPING THE RESEARCH QUESTIONS

- I worked with researchers to refine the questions
- Ensured they were accessible to stroke survivors, including those with aphasia
- My perspective helped make the study more inclusive!



UNDERSTANDING THE METHODOLOGY

-  Learning the research process took time, but I didn't give up!
-  The more I understood, the more I contributed
-  Confidence grew as I became an active research partner

CHALLENGES I FACED

- 💡 Communication barriers due to aphasia
- 💡 Needed extra time to process information and express thoughts
- 💡 Asked for support when needed – and that made all the difference!




MAKING AN IMPACT




 My insights helped make the research more realistic and survivor-centered

 I proved that lived experience is just as valuable as academic expertise

 Research isn't just about data—it's about people!

 My stroke changed me, but it didn't take away my strength. I am still me, still fighting , and still growing!!

TIPS FOR FELLOW RESEARCH PARTNERS

-  Advocate for yourself - DON' T BE AFRAID TO SAY:
 - I'm tired and need a break!!
 - I need to go to the bathroom
 - Ask for breaks, extra time, or clarification
-  Be honest about your challenges—your voice matters!
-  Take one step at a time; learning is a process

REFLECTIONS & ACKNOWLEDGMENTS

- Research is not just for scientists—it's for all of us
- I'm grateful for my team and the opportunity to make an impact
- Your story matters—never be afraid to share it!



Thank you for listening!