What Nonspeaking Neurodiverse People Want Healthcare Professionals To Know

- *We understand everything.*
- *We are listening, even when it may look like we are not*
- *We are highly intelligent and love learning.*
- *We are deeply interested in relationships and understand emotions.*
- *We want you to see us as who we truly are!*

"I can communicate everything I want to say now because my family believed in my capability. I can talk with my art teacher and improve my painting technique. I know many other nonspeakers who are artists, writers, poets, songwriters, bloggers, college students and graduates. The 2.3 million nonspeakers who remain in silence deserve the same opportunities to succeed."

-Teo Musso, California, USA

Why We Cannot Speak

Nonspeakers cannot make our mouths, lips and tongues make the coordinated movements in order to produce vocalized speech. **Apraxia** is the neurologic condition that prevents us from executing our brain's instructions to our motor systems. We call this the mind-body disconnect.

We may be able to repeat parts of what we hear or to say highly practiced phrases over and over, but we cannot speak with our mouths everything that we want to say.

"Have you ever misplaced your car keys? You know where you want to go. You know how to drive You have a car but you have no keys. Talking is like that for me. I have no keys to make my body do what I want it to do. It feels frustrating, just like misplacing your keys is frustrating. Only my keys are permanently misplaced."

-Joel Nyland, Washington, USA

"Medical visits are challenging. It is important that my healthcare providers be patient and accept my method of Communication. Being able to convey how I feel and my preference for treatment is essential for my health. Finding healthcare professionals who respect my mode of communication is the key to success."

-Sarah Ackerman, Pennsylvania, USA

Spellers & Allies Advocacy Network

The Network is the advocacy branch of the International Association for Spelling as Communication. As a collaborative effort of spellers and our allies, we work around the world to enable nonspeakers to have access to the communication methods of our choice so that we can say whatever we want and have agency in our lives.

Contact us at spellers-allies@i-asc.org
Learn more at https://i-asc.org/advocacy/

I-ASC
International Association for Spelling as Communication
ACCESS, AGENCY, AUTONOMY

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Practical Suggestions To Enhance Interactions With Nonspeakers

1. Speak to us directly first, then to our communication partner or caregiver. Use age appropriate language!

2. We need access to our communication method and communication partner or caregiver in all settings.

3. Predictability helps decrease our anxiety. Tell us what you're going to do before you do it, and ask permission before touching us.

4. Let us use our body regulators (fidgets, pacing, flapping, vocal stimming, etc) so that we can remain calm.

5. Be patient with us. Schedule extra time for our appointments.

6. Use patient portals. They give us time to gather our thoughts in advance and to communicate in between appointments.

7. Approach us with an attitude of respect and curiosity.

8. Those of us with some speaking ability may not be able to express our thoughts OR our verbal responses may be incorrect. Trust only our spelled communication!

9. Combine visual and auditory elements to explain things to us. We understand and learn very quickly!

10. Don't assume that because we have support, we are not capable of decision making. Ask for our consent for everything. Exceptions may be needed for minors or guardians.

Being Able To Say Anything We Want Changes Lives!

"After so many years of silence, being able to communicate means I can engage in life! I can give my input on everything from what card to play in a game to discussing how medications affect me. I'm a participant, not just a bystander in my life."

-James Scannell, Pennsylvania, USA

Help Us Educate Other Healthcare Professionals

- **Connect us to other healthcare professionals.**
  - *We want to educate them.*
- **Connect us to organizers of conferences for professionals in your field.**
  - *We want to give presentations to their audiences.*
- **Connect us to thought leaders in your field.**
  - *We want to inform them of the patient experience of nonspeakers.*
- **Connect us to the families of nonspeakers who do not yet have full communication.**
  - *We want to bring them hope!*

More Facts About Nonspeakers

1. Please refer to us as nonspeakers, instead of nonverbal. We are very verbal. We understand and use the full range of language.

2. The thoughts that we spell on our letterboards and keyboards are the only true expression of what we intend to say. Please ignore our repetitive vocal scripts.

3. Our communication partner helps us stay focused and calm. The words we spell are our thoughts, not theirs.

4. Many of us experience frequent anxiety. OCD and prior trauma are common. Healthcare settings can increase our stress.

5. Our sensory differences may make it difficult for us to stay calm. Noise, lighting and commotion may be challenging.

6. Our faces and body language may not communicate to you the intensity of our pain. Each person's pain sensitivity is different. Ask us about our pain!

7. Our apraxic bodies do not always do what our brains want. We sometimes move and act in ways that we don't intend.

8. We can't always execute motor actions on commands for exams and treatment.

9. We can feel the energy and attitudes of those around us, so stay calm.

10. Autism and other developmental disability diagnoses don't explain all of our symptoms. Be alert for other treatable conditions!