ALLY/PRACTITIONER/CRP - SPECIFIC Template letter/email to send handout to personal healthcare team and to friends and family who are healthcare professionals, 9.2024

Dear <Insert Healthcare professional Name>:

As you may know, I am a passionate advocate for nonspeakers and their rights. <Use this space to include your personal information, journey as an ally/practitioner/CRP, and relationship to the speller cause.>

My purpose in contacting you is to give you some information about nonspeakers. I hope that this information will be useful to you in the care of your nonspeaking patients.

Nonspeakers cannot use their mouths, lips, and tongues to produce the sounds containing information that is speech. Their minds are full of ideas, but they cannot execute the motor (muscle) actions to vocalize them. Scientists call this apraxia. Nonspeakers call it the brain-body disconnect. In order to communicate, they use a letterboard or keyboard to spell out their thoughts and ideas by pointing to letters, one at a time. With this method, they can say anything they want.

There are over 500,000 nonspeaking children and 1.8 million nonspeaking adults in the United States. This includes 1/3 of all autistics, 50% of all people with Down syndrome, and many more people with other motor-sensory conditions.

There are many myths about them, including:

- Their inability to speak is the result of low intelligence
- They are not interested in other people and do not understand human emotions
- They cannot learn to communicate using methods other than vocalized speech

These incorrect ideas prevent them from getting an academic education, receiving healthcare that includes their input, having good jobs, and exercising agency and autonomy in their lives.

Enclosed is a handout for healthcare professionals created by my nonspeaking friends at the Spellers and Allies Advocacy Network, an international organization that advocates for the rights of nonspeaking individuals. It includes information about their communication needs, and what you can do to foster a collaborative relationship with them as patients.

Finally, I am requesting that you help me and my nonspeaking self-advocate peers educate other healthcare professionals by doing the following:

- Train your staff about nonspeakers
- Pass this information on to your colleagues
- Connect them to organizers of professional education for others in your field so that we can give a presentation to them
- Connect them to thought leaders who might be interested in learning more about nonspeakers!

Please use this link or QR code to complete a very brief 5 item questionnaire that will give them feedback about the handout and let them know if you can help connect them with organizers of conferences and other thought leaders.

Thank you for your desire to know more about nonspeakers. We need more <insert HCP field> like you who will see and hear us.

Sincerely, <Your Name>