How I Talk, and MWS

I appreciate people who talk to me like an intelligent adult, like a respected colleague or their dear friend, especially when they expect me to respond in kind with candor, intelligence, and maybe even some humor.
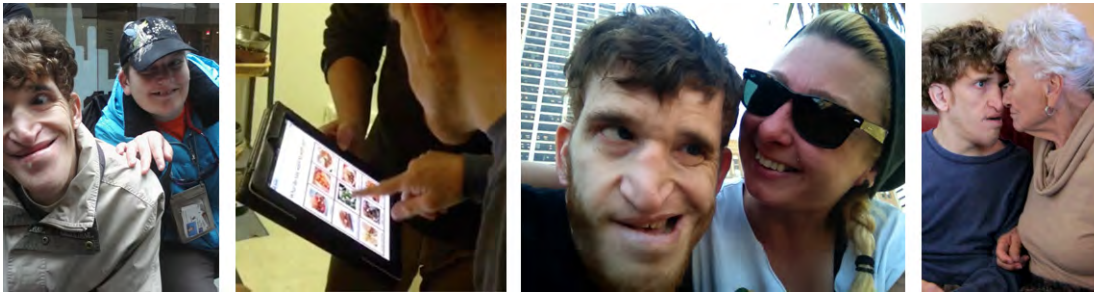
A lack of speech (expressive spoken language) is typical of people with Mowat-Wilson Syndrome.

My three spoken words, "achoo," "mummum" and "buh" along with an entire crazy arsenal of "communication systems" have the power to turn my thoughts into pretty darn articulate and to-the-point conversations (…that is, when I have the time and patience it takes to express a simple sentence).

I don't "speak" complete sentences. My style of communicating –pointing to pictures, icons and words, along with signing "yes or "no" to questions – results in a string of words and thoughts. I rely on people to interpret my words through context, while facilitating my conversation with additional questions and choices to help me to be more specific. It's not always my brain that's scrambled. What is an obstacle is trying to navigate through the not-so-intuitive pages and layers of icon grids to find just the right word or icon.


I challenge anybody to try to communicate a complex thought or response when you have only a limited number of icons and words at your disposal, and each word requires navigating to a different screen or even a different app. Making my thoughts whole is a painstaking process that can take minutes to complete a simple statement. Sometimes I just give up. For those folks facilitating my

communication, the process can be convoluted and frustrating for them too. When we hit a dead-end, my thoughts and intentions get lost in translation.

My website has links illustrating how I use my communication systems.

A good understanding of receptive language (the conversations and spoken words of others) is typical of people with Mowat-Wilson Syndrome.

I understand spoken conversation and what is read to me from books and magazines. I do not read, per say, but I do recognize and understand individual words. That means, people can assist my "speaking vocabulary" by writing down the key words-of-the-moment on a piece of paper to give me "expanded communication tags" for that situation. I can then point to those words when I respond back to them about that particular subject. Besides speaking to me, others can use a mix of my methods – the ProLoQuo digital icon and voice system, point to details in photographs, write down key words, point to objects, or navigate to a place or thing…just like I do in talking to them.
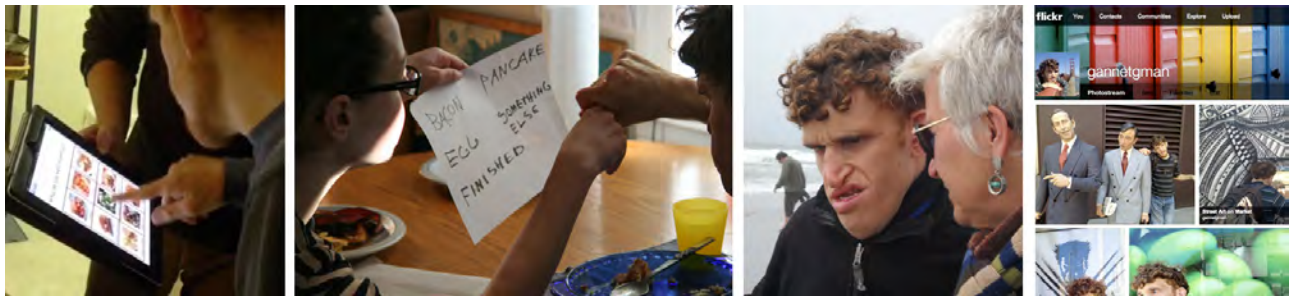
An Overview of My Communication Systems:

iPad APPS: PICTURE COMMUNICATION w/VOICE and WORDS
My primary communication tool is the ProLoQuo app that displays icons on the iPad touch screen and has digital voice output. The iPad touchscreen can also be used as a tablet for writing down word choices or questions with apps like DigiDraw. Other apps I use are specialized for storytelling, like Pictello. These apps and icon/word libraries are constantly updated to reflect my life and needs.

VOCALIZATIONS: "Achoo," "buh" and "mumum" are the main three words that I speak, and they have many meanings depending on the situation. For example: "achoo" can mean "hello", or "I love you", it's also a repetitive happy banter back & forth between myself and others. "Mumum" is a happy sound. "Buh" is used as a comment to let you know I'm present, actively engaged to the conversation, and responding. Growling means I'm pissed off.

TACTILE SIGNING: Tactile signing means that I grab a person's hand or finger and make a motion with it. I use tactile signs for: "yes", "no", "all done", "get up, I want your help", "I want that".

POINTING: I will point with my index finger or tap on something with my thumb to make a choice.

GESTURES: Patting someone's arm or shoulder is my customary greeting "hello". Foot stomping means, "I'm pissed". This is how I say "Help Me!" when something is wrong, or I'm sick or emotionally upset or tired using any or all of the following gestures: I hold a hand to my forehead, bang my head hard on you or a wall, slap my face, or bite my hand, or growl.

FACIAL EXPRESSIONS: I don't talk, so you can't read my lips, but you certainly can read my facial expressions to get a clue as to what's on my mind, or if I'm just pulling your leg.

LEADING: After I pull your hand or arm to say "get up, help me", I'll lead you to what person, place or thing that I want.

PHOTOGRAPHS: Photographs are my memory bank. Sharing photos (stored on the iPad as well as in digital photo albums online) is the best way to tell my friends and family what I've been up to. Like anybody else, I also love to look at my photo albums now and then, just for the sake of reminiscing.