



Care and concern for those with disabilities

One of the keys to gaining understanding of those suffering from muscular dystrophies is to spend time with them. A continuing theme that we have developed in the last few years has been to include MDA families in our fundraising events. When we meet the people we work to help, it provides a window into their lives.

But we all have feelings about meeting someone in a wheelchair. Most of us, if we're honest, are uncomfortable with what are the appropriate things to say or do. A few years ago, I came across the following information, which has helped me think about those uncomfortable feelings and what we should remember when meeting someone with a disability. Here are some basic rules:

- Any assistive device used to help a person with a disability is considered part of their personal space and should never be leaned on, picked up or touched.
- When in doubt about offering assistance to a person with a disability, ask, "May I help you with that?" or "Could you use a hand?" If they need help, they will accept it. If they do not, do not take offense. Maybe they are learning a new technique for completing a task, or maybe they just want to see if they can do it. *Never* just help without asking.
- Treat adults in a manner befitting adults, regardless of their disability. Call a person by his or her first name only when extending familiarity to all others present. Do not patronize people with disabilities by patting them on the head or hand or by talking to them in baby talk.

Conversation

- Speak directly to a person with a disability, rather than through a companion who may be along.
- Relax. Don't be embarrassed if you happen to use accepted, common expressions such as "See you later" or "Got to be running along" that seem to relate to the person's disability.
- To get the attention of a person who has a hearing impairment, tap the person on the shoulder or wave your hand. Look directly at the person and speak clearly, slowly, and in a normal tone to establish if the person can read your lips. Not all people with hearing impairments can read lips. Those who do will rely on your facial expressions and other body language to help in understanding. Show consideration by facing the light source and keeping your hands and food

away from your mouth when speaking. Shouting won't help the person understand you, but you might ask if pen and paper would help.

- When talking to a person in a wheelchair for more than a few minutes, place yourself at the wheelchair user's eye level to spare both of you a stiff neck. Grab a chair and sit with that person while you talk. Standing over someone in a wheelchair or of short stature causes you both to feel uncomfortable, as well as unnecessary back and neck pain.
- Give your whole attention when you're talking to a person who has difficulty speaking. Keep your manner encouraging rather than correcting. Be patient rather than try to speak for the person. When necessary, ask short questions that require short answers or a nod or shake of the head. Never pretend to understand if you are having trouble doing so. Repeat what you understood. The person's reaction will clue you in on whether you understood correctly. Don't be afraid to ask them to repeat the parts you did not understand.

Common Courtesies

- Offer assistance to a person with a disability if you feel like it, but wait until your offer is accepted before you help, and listen to any instructions the person may want to give to best help you both.
- When giving directions to a person in a wheelchair, walking on crutches, or to someone who uses a cane, please consider distance, weather conditions and physical obstacles such as stairs, curbs and steep hills.
- Be considerate of the extra time it might take for a person with a disability to get things done or said. Let the person set the pace in walking or talking.

The bottom line is that people with disabilities are *people* just like you and me. Treat them with the dignity and respect each one deserves. What is normal anyway?

Next time you have a person with muscular dystrophy attend a branch or state function, take the lead in interacting with them and their family. Use these basic tools to make them feel you care. It will be worth it!

Make sure to stop by the MDA booth at the convention in Minneapolis to say hello. We will be selling tickets for the Wednesday night reception that gives each person a chance to win a brand new Harley-Davidson motorcycle. See you there! ☒