

# STAYING HEALTHY AND DEALING WITH MEDICAL PROFESSIONALS

*Help for Individuals on the Autism Spectrum, their advocates, and health care providers*

As all of us attending this Conference probably know or suspect, that despite all the focus of medical and educational professionals, and even of the media, on individuals with an Autism Spectrum Diagnosis, very little research or work has been done relating to the experience and needs of older or aged adults. This is surprising, considering that the population of our demographic is growing and more and more people are in need of medical care and other services to assist them. Hopefully that will change, people will become educated and will want to serve our population. But it may require us to push for this focus ourselves by demanding more educated responsiveness to our needs and by speaking up in day to day encounters with professionals and advocates.

## UNIQUE ISSUES AND NEEDS OF OUR POPULATION

Because of our unique social, communication, sensory difficulties, it is often difficult to interact productively with the people we are counting on to help keep us healthy and safe. For instance, adults are expected to seek help from their physician when they are ill, but we might have difficulty recognizing signs of serious illness, chronic conditions or age related symptoms. People who have depended on family members and other key social contacts, for care and monitoring of their well-being as well as providing a sense of connection and enjoyment of life, will eventually lose those people due to death or disability. There is a need for agencies and advocates specifically trained to assist us.

Many people on the spectrum already suffer from anxiety, depression and other concurrent mental health or cognitive problems. These problems often worsen due to factors such as reduced mobility, fewer social interactions, medication interactions. In addition, people on the Spectrum are likely to get the same age-related illnesses as neurotypicals, with the same needs for treatment and managing care, but with the added stress of unique symptom manifestations and responses. Many normal aging processes such as reduced mobility or memory loss can make organizing and managing daily life and self-care more difficult than it already was. Financial considerations are also a concern, with most people on the spectrum having a reduced income, people might choose not to seek care or be unable to purchase medications or proper food. Medical research has shown that people with learning disabilities have poorer outcomes health wise.

## UNDERSTANDING THE CONDITION

Additionally, people on the spectrum often have to struggle to even be recognized as having the condition. This is especially true with women. While many more men are diagnosed, seeming to fit into a generalized profile, it is likely that women on the spectrum have their own unique profile, partially impacted by society's overall treatment of women, and women's innate ability to mask difficulties. In both cases though it often falls to people on the spectrum themselves to identify themselves and their needs and for them or their advocates to educate professionals and others with who they must deal as to facts of their condition and their experience of it, rather than the outdated information and misinformation most neurotypicals have been taught or have absorbed from popular culture.

Unique issues, such as sensory impacts, trouble communicating - especially when under stress, trouble understanding, executive functioning and organization issues, unusual physiology and anatomy, different responses to medication, all need to be taken into account when diagnosing or treating people on the spectrum.

With so many people being diagnosed late in life, many of us are still struggling with understanding our diagnosis, how it might have affected life choices, employment and relationships. We may be dealing with issues of family or jobs relating to our diagnosis. It is important for people to have someone they feel able to talk to about all these feelings and concerns, as well as places that are safe where they can de-stress and re-charge their coping mechanisms. Organizations such as AANE are vital to the well-being of our population. Ideally a medical practitioner would have the patience and time required to truly get to know and hear their patient's concerns and would provide such an environment in their facility. In most cases we must look to the future for accommodations such as those.

The existence of Autism Spectrum Disorders is now part of the basic knowledge and conversation of society, but more up to date and useful information needs to reach those called upon to interact with our population. Ideally medical care providers and other professionals in our society will take it upon themselves to learn about the conditions of the Autism Spectrum, and how to have sensitive and productive interactions with our community.

#### POWER RELATIONSHIPS AND RECEIVING SERVICES

Professionals are basically People in Power. In general they hold positions which provide services to the public. But in practice they exist in a hierarchical position – i.e. on top. Power relationships influence us deeply.

We tend to defer to people who have power over us, often making it difficult to have a normal relationship or to communicate easily with them. Conversely, people who have power, sometimes consider themselves to be more intelligent, or more capable, or even more worthy of deference than “other people”. People tend to place themselves in hierarchical relationships and fulfil roles their societies expect of them. An example of this would be the way women have a lower standing than men in many societies. These dynamics exist in every society. Feelings and reactions relating to power are often unconscious and culturally based. There are societal expectations on both sides of power relationships.

The same holds true of professional relationships. Most professionals have some measure of power. People often have trouble with professional interactions and dynamics, often due to misunderstandings and beliefs, but also due to abuse of power. Unfortunately, many people who have power take advantage and bully, even physically harm those who don't. But where most neurotypicals are aware of power dynamics, many people on the autism spectrum do not sense or recognize power dynamics. Often too, people on the spectrum inadvertently ignore the normal conventions of relationships in general, including those that have a power dynamic. They may make assumptions about relationships, including levels of trust, sometimes assuming that a closer or more meaningful relationship exists than actually does exist. Misconstruing the depth or reliability of the relationship can cause disappointments or even victimization, and disruption in the ability to have or attempt to have productive one to one relationships with others.

## DEALING WITH “PROFESSIONALS”

Professionals are everywhere.

Doctor, Medical Assistant, Nurse, Dentist, Chiropractor, Psychiatrist, Therapist, Pharmacist, Physical Therapist, Social Worker, Veterinarian, Counsellor, Minister, Priest, Rabbi, Teacher, Lawyer, Policeman, Judge, Boss/Employer, Librarian, Flight Attendant, Barber/Hairdresser, Landlord --- to name just a few.

It's good to be aware of power dynamics when dealing with any of these people. Communication is key. Disclosure might be indicated.

## HEALTH CARE PROFESSIONALS

Everyone has trouble from time to time dealing with the Professionals in the Health Care realm, when they cannot relate productively neurotypicals might just change providers, or they might complain about the service they received, but people on the spectrum are more likely to be unable to recognize that a relationship is unhealthy or unhelpful and to be harmed by inept, negative or unsatisfactory relationships.

Having experienced negative treatment from a health care provider at some point sometimes causes people on the spectrum to avoid all health care providers. This is a terrible thing for their wellbeing, since most of us have an array of physical, emotional and practical needs and could greatly benefit from health care and social services. The ideal would be a holistic type of care, where all the providers work together and coordinate a person's care. Next best would be having an advocate who can help us manage and coordinate care and services. Sometimes, becoming disengaged begins with a simple missed appointment or transportation difficulty. Psychological issues: a fear of needles could mean missing a key vaccine. It's important to identify concerns so that alternative solutions can be found. Sometimes, we don't seek care because we were not treated respectfully or sensitively at a facility.

People should of course be treated with respect. But it's important for us to understand that there are many aspects of having an autism spectrum disorder that are confusing or discomforting to people not on the spectrum. Our tones of voice, body language, expressions or “stims” may seem strange or appear alarming. The fact that common figures of speech like “please take a chair” or “the doctor will be along in a minute” might be taken literally or that jokes or sarcasm might be misunderstood. They might become impatient with our tendency to sometimes to speak at great length about certain topics or interrupt. Problems we may have with making eye contact could be misconstrued. And things like not respecting personal space or asking personal questions could be thought rude. Most people don't want to be insensitive to our differences or issues, they just need to understand what's going on. We should try to become as self-aware as possible and, where possible, adjust behaviors that might be offensive or disruptive to the community around us.

## ADVOCATES

One solution is to have a relative, friend, or a trusted neurotypical advocate accompany you to appointments or procedures, and if things don't seem to be going well, or you are having trouble

understanding something or being understood, they can assist. This is especially important in situations outside your normal routine, certainly for an ER visit or hospital admission, but also for a medical test or procedure – an eye exam or mammogram.

## DISCLOSURE

Another solution is to disclose your diagnosis. In most medical situations it is extremely important to state this fact. It is important however that the person knows not just generally what it means to be on the Autism Spectrum, but what it means for you personally: What your specific issues or concerns are, such as communication issues or sensory issues.

## HOW PROFESSIONALS CAN HELP

Understanding that we prefer structure and our apprehensive about new situations. Working with the person and their advocates, educating facility staff, being welcoming and non-judgment, Being very clear about times and places of appointments or scheduled procedures, giving both the day and the day of the week, providing a map and directions if possible, providing a photo of health providers they will be interacting with, having a quiet room where the person could wait or allowing them to wait outside if they can receive a text when it's time for their appointment, being factual and literal when speaking to the person, avoiding figures of speech and sarcasm, giving information in increments, or better yet, also providing instructions in written form, truly listening to the patient and accepting information in alternate forms if offered - such as their own written notes, helping with scheduling appointments, explaining procedures, providing stability of what to expect and who will provide the care. Allowing some time to get to know the person or ask how they have been before starting an exam or procedure, showing the person any instruments that will be used, and alerting them to any noise or other effects they make experience. Being very clear and patient about procedures where medical samples are needed, be careful when giving directions for actions or inactions, such as fasting, so they know if they can drink or not, and when to start eating again. Allowing the person to read, use a device or otherwise distract themselves while waiting or even during a procedure if possible. Explaining the importance of self care such as diet, tooth care, including the ramifications of neglect, but without shaming the person. Making the experience pleasant enough that the person will feel ok about coming back. Getting to know the person's interests, which in turn can help with planning or providing treatment. Having a conversation about exercise might be easier with someone you know likes to watch sports, discussing a genre of films might calm a person having an MRI. Not expecting people on the spectrum to understand your facial expressions: verbalizing all communications. Using checklists, to ascertain whether your instructions have been received. Giving people time to think when asking for a response. Offering educational materials about any conditions the patient has, written or online, videos, etc. Being extremely sensitive and respectful of any treatment that related to sexual organs, sexuality or gender. Many autistic people have unusual gender identities or differences. Many have also suffered abuse. Being aware of the home environment of a person who is being asked to self-treat or who is being discharged. Are they capable of self-care or can they get assistance from anyone. Choosing the least invasive treatment. Being aware of tactile sensitivities. Not generalizing about autism. Persons with autism can be very different from one another. Being diligent assisting the person with finding relatives or friends of the person in case of emergencies or serious diagnosis. Contacting appropriate social services to locate facilities for rehabilitation or other care that will be appropriate for this patient. Discussing the preparation of care plans, and the need for legal medical documents with the patient, including their advocates if appropriate. Knowing your patient's wishes. Respecting the

autonomy of the patient. If a family dynamic is impacting the patient's care and best interests, protecting the patient's interests.

## COPING MECHANISMS FOR PEOPLE ON THE SPECTRUM

If you are hospitalized, remember that the new things you are experiencing will probably become routine. Like meal times or repetitive vital sign taking. Most of the time the staff will try their best to make you feel comfortable and safe. Having some familiar things from home will help, such as a favorite blanket or stuffed animal, as will doing activities you enjoy, such as computer games, to distract you and help pass the time. Be respectful of others in your room, and also the time constraints of nurses or doctors to talk at length with you.

## SENSORY ISSUES

Most people on the Autism Spectrum have some measure of sensory sensitivity. It can be severe. These sensitivities and your reaction to them can affect the way a professional interprets your condition, making a diagnosis difficult or affecting a choice of treatment. It's important that you disclose any sensitivities so that adjustments can be made.

Tactile Issues: hypersensitivity (maybe you wear clothes inside out because of scratchy labels); hyposensitivity (you need weighted clothing or blankets or perhaps you don't feel light touch); higher or lower pain thresholds, sensitivity to chemicals (like detergents or allergies such as latex – perhaps you need to use your own personal products).

### Vestibular Issues:

Trouble with sports or doing exercises, balance difficulties, feeling agitated – needing to move around; needing to fidget or rock in order to destress; problems with coordination or fine motor skills that might be misconstrued as being on alcohol or drugs!

Problems with Hearing and Sound: loud or sudden noises, certain tones and pitches of sound that cause strong reactions, or hearing sounds that no one else seems to hear or notice, whirring of machines, clocks ticking etc., not seeming to hear nearby conversations or not being able to hear when more than one person is speaking – might be taken as deafness!

Proprioception ( Problems with Movement) or gait and fine motor skills, dropping things – doesn't mean you have some new neurological disorder.

Visual: May need to avoid bright areas or you prefer bright areas. May notice visual cues others miss. May have blurry vision at times. Maybe you need to wear sunglasses or require a night light. Vision tests might be especially uncomfortable.

Taste: Hating certain textures or food proximities, liking only bland or spicy food, maybe you like odd food combos. It's normal for you. However, not eating or eating too much is not normal.

Smell: Easily over powered by smells like perfumes, household chemicals and soaps. Smells might be a way you recognize people or places. You might have trouble recognizing dangerous odors – spoiled food, gas leak.

Ask for accommodations. Be specific.

## BODY-AWARENESS

It is good to have some general knowledge of anatomy and physiology, as well as familiarity with any chronic medical conditions you personally have and the treatments you use. As people age, new health conditions may appear or physical symptoms you are accustomed to feeling may get worse. Additionally, it is important to educate yourself about proper nutrition and hydration. And to simply take care of your body as best you can. Exercise regularly. Get enough sleep. Stay hydrated. Practice good hygiene. Take medications responsibly. All these things will make your body stay healthier and last longer! If you don't feel well, or something changes in your usual experience of your body, don't put off being seen by a doctor, dentist, foot doctor, etc. Most things get worse the longer you wait.

## PAIN THRESHOLD

People on the spectrum sometimes experience pain differently than neurotypicals. They may have a higher or lower pain threshold (the point they notice pain and feel distress). Pain can be dull or sharp but it is always a sign that something is wrong. Sometimes we get used to aches and pains, and our bodies might be harmed by masking pain with drugs like aspirin. Strong pain medications can be addicting and cause problems for our very existence. Additionally there are often differences in neurological anatomy of people on the spectrum, nerves might be in slightly different locations: a nerve in the back might affect a slightly different area than the norm, if nerves in the jaw are located differently it might affect a dentist's ability to numb our mouth for a procedure. Be sure to mention such differences to your provider.

## COMMON ISSUES OF AGING

Unfortunately no one lives forever. It is important to accept that our bodies don't stay in perfect shape but in fact slowly break down, and wear out. We can do a lot to keep ourselves healthy, Most of us know the basics: get enough sleep, eat nutritious food, avoid junk food, drink enough water, get frequent exercise, don't smoke, socialize, think positively. But unfortunately some illnesses and conditions still arrive to impact our daily lives or cause us harm. Some are just normal things that happen to everyone, others might have genetic/family causes, some might be environmental, or lifestyle related, but many have causes that scientists are still investigating.

### Common conditions of all older people –

Visual changes and impairments, menopause, sexual changes, hearing loss, tooth decay and loss, incontinence, mobility difficulties, memory loss, arthritis, minor falls, bangs and scrapes.

Help is available to treat or assist you with all these conditions. There is no need to let age-related conditions limit your ability to function and enjoy life. But you have to seek help and work with your medical providers.

### More serious conditions –

Type 2 diabetes, cancer, heart attack, stroke, Parkinson's disease, serious falls and head injuries, accidents.

Never put off seeing your doctor or seeking emergency care because of fear. People often engage in denial that something is wrong. It's better to be safe than sorry. All these conditions can be treated, most with great success, due to advances in understanding and new treatments.

If you are diagnosed with a serious condition, tell a trusted friend or relative and allow them to assist you in dealing with both the physical and emotional affects. There might be support groups for people with this condition.

### DEPENDENTS AND PETS

If you, a person on the spectrum, are responsible for the well being of family members, your spouse, children, grandchildren, etc., then it is important to consider all these same issues as they relate to your ability to care and advocate for them. And to expect and demand that the care they receive is the best it can be. It is important that you feel, and that you appear, competent to be the provider and advocate. If you think you may need help dealing with health care system, discuss the situation with a trusted friend. Consider bringing that person along. It is important to note that medical providers and social service providers are legally bound to report suspected neglect or inability to provide proper care to the authorities. You don't want your abilities to be misconstrued.

Many of us have pets or service animals, and must deal with veterinarians and their staff. The same issues that might arise in dealing with human medical care providers can arise in these situations. If possible, try to build up a relationship with a vet or clinic, including a comfort level for your needs, before a crisis arises.

### EMERGENCIES

Since the definition of emergency is unexpected, and your ability to communicate in an emergency might be impaired, it is a good idea to wear an ID bracelet or carry a wallet card that lists Autism Spectrum Disorder along with any medical conditions you have. An emergency contact person should also be listed. If you are able to communicate your condition to emergency providers in their vehicle or at the ER, by all means do so. It is possible that injury, illness or stress might make it hard to talk. Emergency rooms are equipped with non-verbal communications devices. You might be able to signal a need for something to write with or other aid. Try to stay calm.

### EDUCATION, EDUCATION, EDUCATION

An excellent way of getting better care, is to provide information about Autism/Asperger's to the professional. Often the person will think they already know everything they need to know about it, even though it is unlikely that they are aware of the most current thinking on the subject, much less any first person accounts of having the condition. It is important to be polite, and to delicately suggest that there many aspects of the condition and many new studies, and be ready to offer some printed material for them to review (nothing that takes too much time to read). Offer various types of information, including books, movies, websites, organizations, such as AANE, that you find helpful.

#### TO SUM UP –

It is important to recognize that we ourselves are responsible for taking care of our own physical selves. Most of us live in a healthy, safe, environment and community, have or can obtain safe shelter, adequate clothing, healthy food and clean water, and are capable of self and home care. If we need any of these basics we need to take steps to obtain them or communicate our needs.

As adults, we are responsible to care for our own basic health needs. Most of know what constitutes a healthy lifestyle but we all need to decide for ourselves how diligent we will be in making good choices. Aging is a natural occurrence but managing it alone can become gradually or suddenly more difficult. It is important to ask for help, whether with managing our day to day activities or for a health concern. Getting older is not easy. There may be troubles ahead. But there will be good days as well. The way we choose to spend our time will affect the time we have. Staying active and taking care of ourselves to best of our ability will provides many benefits and improvements in outcome and longer life, even in regard to serious medical conditions, like memory loss, type 2 diabetes, cardiac health, and so on.

Enjoying activities of any kind, hobbies, special interests, arts and crafts, sports, reading, learning, meditating, doing things with other people, will all help keep our minds and memories focused, our relationships vibrant, and our bodies active. Social activities make friendships possible. Just talking with other people gives us alternative views of our own situation, and the sense that we are not alone with the things we are going through - sometimes even giving us a sense of humor about ourselves or our issues. Activities, particularly those outdoors, also help with depression and keeping a positive outlook.

It's important to educate ourselves and take control of our lives and future to the best of our ability. To the extent that we can help educate the community around us, including the professionals who serve us, all the better. If we can assist or advocate for others in our community that would also be a wonderful thing to do. Whatever you do, enjoy what you are doing.

Just because we are getting older, doesn't mean we have to OLD.

Abe Lincoln said something about aging that's worth remembering:

“It's not the years in your life that count, it's the life in your years. “

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AANE CONFERENCE ON AGING AND ASPERGERS September 9, 2017  
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