A RESOURCE FOR HEALTHCARE PROFESSIONALS
ASSISTIVE TECHNOLOGY & AUGMENTATIVE/ALTERNATIVE COMMUNICATION FOR PEOPLE WITH MS

Alex Burnham, MS, CCC-SLP, MSCS

Rehabilitation Program Manager & Speech-language Pathologist

The Boston Home, Dorchester, MA

MS

National Multiple Sclerosis Society

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Introduction

Use this resource to help facilitate conversations with your patients about planning for the future. The unpredictable course of MS is a source of considerable distress for most people. Having a frank discussion about the status of their disease and what may happen in the future is important, and will likely address questions your patients may be too afraid or uncomfortable asking. Helping people to "hope for the best, while planning for the worst" may help them anticipate possible future needs and engage in appropriate planning to meet those needs. While most individuals with MS do not become severely disabled, we can't predict with any certainty what the outcome may be for any given individual. Rather than seeing life planning as a fatalistic or negative activity, encourage your patients to see it as taking ownership of the future, reducing medical and financial risk, and doing everything that can be done to assure security, autonomy, and quality of life.

Assistive technology (AT) is a broad term to describe any device, program, or physical modification to an existing system that is used to facilitate ease of access to technology or performance of activities in daily life. People with multiple sclerosis (MS) at all stages of disease progression can benefit from the recent exponential growth of AT options available to help compensate for a wide range of deficits, including reduced motor function; cognitive dysfunction; and sensory impairments such as visual impairment associated with optic neuritis, reduced touch sensitivity associated with paresthesias, or diminished hearing. The integration of some types of AT into commercially mainstream devices has greatly enhanced access to a wide range of electronic systems for people with disabilities, thereby allowing for previously unimaginable levels of independent environmental control, mobility, communication, socialization, and vocational integration. The use of AT by people with MS can be rehabilitative (i.e., helping to recover function partially impaired by disease progression) or compensatory (i.e., replacing functions irreversibly damaged or lost) but ultimately serves to meet the goals and preferred activities of the user. In addition, more complex dedicated AT systems and mobility equipment can be customized to address a range of concurrent disabilities and can be modified for operation as the user's needs and preferences evolve or progress over time (Souza et al., 2010).

When AT is indicated to facilitate control of the functions of a complex rehabilitation wheelchair (also called "power chair") by an individual who can no longer utilize traditional manual access, the elements of this assessment are integrated into a more comprehensive seating evaluation. This paper will provide an overview of other types, features, and indicators for use for AT by people with MS for communication and other functional activities beyond mobility.

For some individuals with MS, gradual deterioration of speech, voice, and/or language functions during later stages of disease progression can eventually result in substantial loss of the capacity to speak intelligibly. A particular subset of AT called augmentative and alternative communication (AAC) systems can be useful to support or replace spoken language in order to enable these individuals to express wants, needs, medical information, and complex concepts.

These devices are aids (usually computerized) designed to allow for spoken communication with others even when the user is unable to speak clearly or at all, in order to maximize daily opportunities for conversation and interaction in all environments.

Domains of function enhanced with assistive technology

Since AT can include electronic hardware, software, and modifications to both, it can be useful to categorize the most common AT options based on the type of functional impairment for which a person with MS might need to use AT to complete a particular task:

- **Motor Access:** People can experience difficulty with gross and fine motor control due to a range of progressive muscle impairments associated with MS, most commonly weakness, spasticity, ataxia (discoordination), and rapid onset of muscle fatigue. Some examples of access modifications that can circumvent difficulties with motor access include:
  - o Modulating the amount of motor input required to operate a device (e.g., using word prediction to type words in 3-4 keystrokes instead of every single letter)
  - o Using an alternative access site (e.g., switches placed near a person's face to type on a computer instead of accessing a manual keyboard)
  - o Adapting control functions to be operated by a variety of accessible light-touch switches or remote controls (e.g., operating a speakerphone remotely with scanning features to select preprogrammed numbers without using a headset)
  - o Converting the method of access to operate technology (e.g., speech recognition software instead of accessing a physical keyboard and mouse)
  - o Accommodating for difficulty with releasing motor access (e.g., when a person touches an onscreen target on a tablet computer but gets "stuck" and cannot remove the finger rapidly) by modifying the sensitivity and "dwell time" required to make a selection using a device's input system
  - o Dampening down the effects of ataxia by averaging the direction of movement (e.g., in a joystick for power wheelchair control) to operate more smoothly and accurately
- **Visual Enhancement:** Impairments in visual function from MS-related disorders such as optic neuritis can interfere with reading small text, depth perception, object identification, and shifting gaze. While some mild-moderate impairments can be addressed using prescription eyeglasses, other phenomena and more severe deficits might require the implementation of AT devices or modifications to promote visual access to objects and targets in the home environment. Some basic AT options to compensate for visual deficits using mainstream technology include:
  - o Enlarged and bold text for computer/tablet screens
  - o High-contrast color palettes (usually involving change in screen display to light-colored text on a dark background)
  - o Screen readers to read text and picture descriptions aloud
  - o On-screen magnifiers to enlarge images and icons for more accurate identification

For more severe visual and perceptual disturbances, some dedicated AT options for more accurate visual access include optical readers to convert paper-based printed text to speech output, electronic magnifiers with handheld or tabletop displays, digitized currency readers, and digitized recordings of instructions for prescription medication bottles along with pillboxes that sound an alert when a dose is due. This technology is also designed for individuals who are developmentally blind or who have low vision from other acquired disorders, and referrals can be made from vision health providers to coordinate an assessment with a specialist or organization that can assist with assessing eligibility for these more advanced AT options.

- **Sensory Integration:** Some forms of AT can address sensory changes in more advanced MS, including loss of or abnormal sense of touch associated with paresthesias, impaired proprioception (awareness of position in space), inconsistent body temperature regulation, and reduced hearing. Some compensatory AT examples to address sensory impairments include:
  - Back-up alarms on power wheelchairs or use of built-in cameras on tablet and smartphones to survey environmental barriers or visualize obstacles outside of a person's field of vision
  - Modifying the surface of buttons on appliances and AT devices with rubber bumpers, fluorescent tape, or textured material to increase ease of visual and tactile identification of specific features and improve contact
  - Vibrating alarms, smoke detectors, smartphone alerts, and other indicators to notify a person with impaired hearing of a required response
  - Mobile platform apps to track and remind users to change position, complete bowel/bladder care routines, or perform pressure relief in wheelchairs for individuals who have reduced sensation in the lower body

Several cutting-edge rehabilitative AT options are available or under development to supplement sensory information for PwMS, including access to virtual reality (VR) technology to improve mobility and balance while walking (Peruzzi et al, 2017), body-weight-supported treadmill training for robotic gait training (Gandolfi et al, 2014), and cochlear implants for individuals with profound sensorineural hearing loss.

- **Cognitive Compensation:** Changes in cognitive functioning (including but not limited to memory, attention, reasoning, and organization) even in earlier stages of MS can be embarrassing, frustrating, and/or potentially lead to declining safety and independent functioning. A variety of AT options are available to serve as cognitive "prosthetics" with mobile technology, starting with the introduction of personal digital assistants (Gentry, 2008) and continuing to expand with modern tablet computers and smartphones. Some common examples include customizable schedules and reminders designed to manage complex prescription medication regimens to linked and tagged notes with specialized software to facilitate ease of organizing or retrieving specific data. Some people with MS use guided imagery or white-noise software to limit distractions or enhance attention and focus on more complex or demanding tasks. Although current evidence on their efficacy is limited, some people also find popular cognitive rehabilitation applications, games,

and websites interesting and stimulating for different domains of cognition and for practicing attention, memory, and executive function skills (Amato et al, 2013; Bonavita et al, 2015).

Assistive technology assessment: clinical evaluation options and outcomes

Locating a specialist or, more ideally, an interdisciplinary team who can provide a comprehensive AT assessment and customized recommendations for the most useful options for a person with MS is the first step to trying out AT options that meet a specific need. Many major teaching and VA hospitals have AT specialists or rehabilitation professionals familiar with AT who can provide evaluations and follow-up treatment sessions on an outpatient basis. Some universities run on-campus AT centers to provide similar services and to enroll candidate in research studies for future development in AT. Each state in the USA has an AT Resource Center, usually administered by a university or non-profit organization, which can provide information for locating an AT specialist and which usually offers programs including low-cost trials of equipment or subsidized loans to support individuals purchasing devices or software.

An initial AT assessment will include several components such as:
- Medical, social, and vocational history
- Client interview to determine specific needs and current strategies
- Motor, sensory, perceptual, and cognitive evaluation for accessibility
- Trials with potential options to meet specific needs
- Education with client and potential caregivers
- Referrals, if appropriate, to other healthcare providers or community-based resources to assist with managing impairments that pose barriers to AT access and for device funding.

Sometimes people with MS will have the opportunity to borrow equipment to try out at home, and other times recommendations will be made for general types of AT options that the client can purchase independently. In many cases, follow-up visits (at the clinic or at the client's home or workplace) or phone calls will be arranged to troubleshoot access limitations or device malfunctions, consider alternative AT options if needed, or proceed with implementation and additional education as appropriate. Ideally, the assessment will only be the first step towards successful and long-term use of AT in the client's home environment, since device abandonment is most common in the first few weeks and months following introduction to the technology. One study describes the importance of education on AT for the user and caregivers by the interdisciplinary team prior to providing a new device in order to significantly reduce the risk of device abandonment (Verza et al, 2006).

Techniques to promote effective implementation of assistive technology in different environments

Three of the most important considerations to optimize long-term success when recommending and introducing AT in a home setting include:

- **Does the person with MS want this specific technology?** Given the unique personalities, preferences, and functional deficits among different users, an AT option that works well for one individual might not work as well or be as well-accepted by another. Although this seems to be a simple and unnecessary question, it is critical to determine whether the person's family and/or caregivers are advocating for the use of a particular piece of AT for convenience reasons (e.g., they already own it or they prefer a particular manufacturer's brand), even though it may not be appropriate, functional or desired as strongly by the person with MS. This can result in greater resistance to or higher likelihood of abandonment of the AT. The wishes and goals of the user are just as critical as careful evaluation of motor and sensory access and limitations. One survey of AT users indicated that several factors during the assessment process (including the time and cost required to obtain an AT assessment, level of frustration with initial device trials, and inconsistent standards of service delivery from AT providers) were so frustrating that they ultimately cast in a negative light the users' perception of the usefulness of the AT (Lenker et al, 2013).

- **What resources are available to assist the person with MS with accessing, charging, cleaning, troubleshooting, and transporting?** If an individual requires some form of AT on a long-term basis, that user probably has some existing requirement for assistance in completing activities of daily living and might not be physically or cognitively capable of performing all necessary maintenance functions to support indefinite use of AT in the home environment. During the device trial process, caregivers and involved family members are strongly encouraged to participate in educational or therapy sessions in order to learn how to care for a device, charge batteries on a regular basis, or manipulate settings within software in order to optimize accessibility for the user. If the individual potentially receiving AT does not have access to consistent caregivers or individuals who can assist with the routine tasks of supporting AT, a simpler or more closed-programming (i.e., with settings features accessible only by the provider or trained caregivers behind a password firewall) device might needed in order to maximize the chances for long-term implementation – although this will likely limit the long-term utility of the AT option as the person's needs change. In addition, the cultural context of the person's home environment should be evaluated to ensure that AT options in general will be accepted, encouraged, and provided on a consistently appropriate basis to the user in order to reduce the risk for device abandonment or inadvertent damage.

- **How can the AT be adapted in the future if the person's needs evolve?** With a disease as unpredictable, chronic, and progressive as MS, access and content needs can change over time. A device or software option is more desirable for a person with

MS if the system can be adapted for alternative motor control, upgraded with newer and more fully featured software, or customizable to address new or worsening sensory impairments. Since the cost of many devices can be substantially higher than for mainstream systems, it is incumbent upon the AT specialist to recommend investment in equipment that can be modified rather than replaced to meet changing needs.

Ongoing follow-up communication with AT clients supports successful long-term access, and outcomes with AT can be measured with surveys such as the Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST 2.0: Demers et al, 2002). This feedback is important to determine how the user values the integration of AT into daily life and to help the AT provider gauge service delivery models – especially in an area of practice where clients often face substantial and complex medical and transportation barriers to care but will likely return in the future as accessibility needs change and AT options expand.

Management of complex communication deficits with augmentative/alternative communication

A relatively small number of people with MS who experience a deterioration of voice, speech, and/or language expression due to advanced MS might no longer be able to speak intelligibly with family, friends, colleagues, healthcare providers, and new acquaintances. For these people, different forms of alternative and augmentative communication (AAC) can be helpful to supplement or replace speech (Beukelman et al, 2007). The decision to consider AAC options for specific PwMS who exhibit symptoms of motor speech and voice disorders can be introduced earlier than the technology might be needed in order for the potential user to consider the social and emotional ramifications of partially or completely transferring one's verbal communication skills to a technological option. It can be difficult to provide a timeline or prognosis for future deterioration of voice and speech skills for individuals with advanced MS as compared to the deficits observed among people with other neurodegenerative disorders with more predictable patterns of progression such as Parkinson's disease or amyotrophic lateral sclerosis. In all of these instances, however, it is valid to introduce and explore samples from each category of AAC options to engage the user and caregivers in a robust discussion regarding communication style, goals, support, and comfort with coping with the replacement of speech with other forms of communication.

Some progressively complex examples of AAC systems include:
- **Voice amplification:** portable devices using a battery-operated speaker and microphone to compensate for chronic vocal fatigue or reduced volume, which can be used intermittently (e.g., in background noise, when fatigued) or all the time
- **Analog (low-tech) communication options:** portable but static resources to facilitate verbal communication, such as phrase boards, pen & paper or dry erase boards to write words, alphabet boards to allow for finger spelling of unintelligible words, and picture books to help communicate basic concrete information for individuals with more urgent

communication needs (e.g., when hospitalized or intubated following surgery or limited cognitive capacity to access more complex (high-tech) AAC systems).

- **Text-to-speech and visual picture board apps:** software available for regular computers, smartphones, and tablets that either synthesizes speech for what the user types into the keyboard or generates a pre-programmed audio message when a specific picture/icon or series of icons is selected on-screen. Some newer software options include scene-based options to use photos of a location or group of items that can be designated with customized "hotspots" for activation to state a word or phrase associated with the part of the picture within the hotspot. These AAC interfaces are inexpensive and are useful for basic verbal interactions or for intermittent need to supplement oral speech.

- **Dedicated speech-generating devices (SGD's):** complex AT, often in the form of a customized computer or tablet device, which combines multiple input and output formats for maximum flexibility and adaptability as the user's communication and motor access needs change over time. All SGD's can be modified to allow for alternative access input for individuals who can no longer type using a manual keyboard, mouse, or touchscreen – even if the person with MS can still operate the device by direct physical screen contact at the time when it is prescribed.   These systems are prescribed by physicians with input from speech pathologists and occupational therapists and can be very costly, although in many cases insurance coverage is available for most or all of the expenses. The coverage is available because an SGD is generally considered a medically necessary system for an individual with severe and progressive decline in verbal communication skills associated with neurological disease such as MS – similar to coverage for a power wheelchair or implanted intrathecal baclofen pump.

Assessment for AAC use and implementation usually occurs at a specialty clinic with rehabilitation professionals who have experience with this specific segment of AT and access to different physical devices and software options for people with MS to try. The components of the evaluation are similar to the AT evaluation already described but will also include a careful inventory of a client's language comprehension and expression, residual voice and speech production capacity, cognitive skills, and motor access options. The SLP or OT involved in the evaluation might also trial alternative input devices to determine the most consistently useful equipment for AAC device access or to plan for future needs based on anticipated pattern of functional deficits associated with progressive MS. One important consideration during this assessment process is to ensure that the autonomy and personality of the user can be preserved as much as possible with the selected equipment so that the user's communication repertoire will include, but not exclusively consist of, AAC systems. It is critical to recognize that the impairment and potential loss of verbal communication, which is intrinsically coupled with one's personality and social integration as well as serving as a tool for expressing wants and needs, can be devastating for people with MS; this aspect can significantly compromise attempts to explore or introduce AAC options.

When the user has muscle weakness, ataxia, spasticity, or other obstacles to using the screen or selecting targets on a computerized AAC device, alternative access hardware will be tested during the evaluation to determine the most effective method for maximizing independent message construction for expression. Some alternative access options could include:

- a switch placed near the face, elbow, chin, or other parts of the body, allowing for direct activation
- scanning software, allowing the user to select and highlight onscreen options via external switches, eyeblink, or other motor control option
- head-tracking or eye gaze-tracking cameras, allowing the user to activate cursor movements onscreen, select targets, and even type text using the onscreen keyboard
- sip/puff pneumatic tubes allowing the user to navigate around a software interface using controlled breathing patterns in a similar pattern to physically activated switches

Assessing clinicians compose letters of medical necessity to submit for funding to insurers or aid agencies and assist with the purchase, delivery, setup, and programming of more complex software and systems to customize each AAC system for its primary user.   Most AAC devices can accommodate a high degree of customization, with integration for photos, word prediction learning, and other personalized information to help reflect the individuality of the user. Some devices also can accommodate voice banking, an emerging technology that takes the personalization one step further by allowing the person to record a series of words and phrases in one's own natural voice for later access when voice and speech have deteriorated to the point of minimal function (Yamagishi et al 2012). In this way, it is possible to express oneself in one's own voice, potentially with some digital enhancement, to individualize the language generated by the AAC device and to remind the listener that the words were created by the person accessing the system. Other experimental projects aim to combine recordings of a user's residual speech capacity into a hybrid synthesized output voice combined with "donated" voice samples from age/gender-matched peers to create unique identities for each SGD user (Jreige et al, 2009). In addition, extensive education will be offered to the primary caregivers for these clients since they will most likely be responsible for device care, setup, maintenance, and troubleshooting.

Future options and considerations for assistive technology and augmentative/alternative communication for people with MS

The field of AT has expanded substantially in recent years largely due to the rapid increase in computational power in increasingly smaller, more mobile, and lower-cost devices, integration of more accessible options in everyday appliances and devices, and better scientific understanding and awareness of residual functional capacity in people with progressive and severe disabilities. With more universal availability to wireless internet access, connectivity of more devices to the internet, and communication between different systems from different manufacturers via more robust protocols (e.g., Bluetooth), the future of AT & AAC is positive for continued development of more reliable, capable, and functional technology options for people

with MS. It is imperative, however, that individuals who require access to modified mainstream technology for independence and communication have access to resources to support the intended purpose of, the device and not just for the hardware itself. The AT/AAC operation must be the primary purpose of the device (McNaughton & Light, 2013); otherwise third party payers will be unlikely to cover the costs of the technology. This issue has often been a roadblock to insurance coverage for these forms of technology unless the device is modified to limit its ability to perform other, non-AAC functions. The familiarity that people with MS have with many of the most common platforms on which AT options operate (e.g., tablet computers, smartphones) prior to the point in disease progression when AT is being considered also makes acquisition and regular usage of AT more rapid and intuitive.

One particularly promising new frontier in expanding access to AT involves direct biological interfaces with a user's body to interpret signals for control in order to replace motor control lost to diseases such as MS. One team has recently explored control of a robotic arm designed to facilitate daily living tasks through surface electromyography (sEMG) of muscle groups still partially under active control by users unable to operate a traditional manual joystick with promising results (Fall et al, 2017). Another group has demonstrated successful activation of a robotic arm from a brain-computer interface directly mapped onto the motor control regions of an individual with quadriplegia who operated the arm solely through thought (Shaikhouni et al, 2013). Although these interfaces are still experimental, they represent some of the future integration of AT into bio-interfaces that will continue to maximize the access and independence of AT users including people with MS with progressive and severe disabilities by drawing from remaining strengths and capacities instead of emphasizing loss and deficits.

Summary

With most people accessing at least some digital technology at home, work, or school on a daily basis, the ubiquity and potential options for AT and AAC for people with MS with specific disease-related impairments are more realistic and functional than ever. Progressive changes in movement, sensation, cognition, and communication can limit the functional independence of individuals with MS without integration of AT into daily routines. Manufacturers have also been increasingly responsive to the complicated and variable needs of different users and have integrated accessibility settings modifications available for customization to help turn everyday technology into AT or an SGD with minimal additional software or peripherals. The use of AT does not need to be complicated or time-consuming, especially in earlier stages of MS in which the need for customized technology can be quite focused or intermittent. The early deployment of AT in the course of disease progression also promotes ongoing comfort and ease of access for people at later stages of the disease in which more complex or frequent AT or AAC access might be indicated. No matter how much AT a user elects to access in daily life, the future for AT options, cost, and resources for evaluation and customization is positive and supportive for people with MS and others who have progressive neurological disorders and their caregivers.

Additional resources regarding assistive technology and augmentative/alternative communication

- AAC information from the American Speech, Language, and Hearing Association (accrediting body for speech-language pathologists): asha.org/public/speech/disorders/AAC
- The Assistive Technology Industry Association (webinars, resources, conference): atia.org
- AT information from the American Occupational Therapy Association (accrediting body for occupational therapists): aota.org/About-Occupational-Therapy/Professionals/RDP/assistive-technology.aspx
- Augmentative Communication Program at Boston Children's Hospital (resources available for adults with complex communication needs): childrenshospital.org/centers-and-services/augmentative-communication-program
- Center for Assistive Technology and Environmental Access at Georgia Tech: assistivetech.net/index.php
- The International Society for Augmentative and Alternative Communication: isaac-online.org
- National program directory from the Association of Assistive Technology Act Centers (searchable by state): ataporg.org/programs
- The Pass It On Center: The National AT Reuse Center (links to state-specific programs, webinars): passitoncenter.org
- The Rehabilitation Engineering and Assistive Technology Society of North America (resources, conference): resna.org
- Rehabilitation Engineering Research Center on Augmentative and Alternative Communication: rerc-aac.psu.edu

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Patient resources

AbleData: abledata.com
Living Well With MS: Considering Assistive Devices: nationalmssociety.org/LivingWell-AT
Assistive Technology and the Workplace (video)- youtu.be/RBWZWYzzIoY

Other resources for
Talking with Your MS Patients include:

Cognitive Dysfunction
Diagnosis of Multiple Sclerosis
Progressive Disease
Elimination Problems
Sexual Dysfunction
Depression and Other Emotional Changes
Initiating and Adhering to Treatment with Injectable Disease Modifying Agents
Family Issues
Reproductive Issues
The Role of Rehabilitation
Life Planning
Primary Progressive MS (PPMS)
Palliative Care, Hospice and Dying
Wheeled Mobility

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