The Need for Smart Home Technology for People with ALS
Smart Home Technology for People with ALS

• Making a home accessible is key to promoting independence

• In recent years, creating a truly accessible home has become easier thanks to smart home technology

• Gone are the days of needing to purchase a disability-specific, specialized device just to perform one simple task
  – Today the Internet and a smart phone give people with ALS access to tools that can transform their environments
    • These conveniences for non-disabled people can be life-changing for those with ALS
Devices to make your home a “smart” home

• Smart Speakers
  - Amazon
  - Google

• Environmental Control Units (ECU’s)
  - Dedicated devices JUST for home/environmental automation

• Computer
  - Software programs

• Communication Devices
  - Eyegaze devices
  - AAC Tablets

• iPhone, iPad, Android phones and tablets
Voice Recognition Devices (aka Smart Speakers)
• **Amazon Echo, Google Home**

  Voice Control Operates
  - Lights, fans, window air conditioners etc…
  - Music
  - Read Books
  - Calendars, schedules, lists
  - Control TV/DVD/Cable
  - Locks/doorbell
  - Will give you updates on weather, sports, etc…
  - Requires WiFi
Things People with ALS use Smart Speakers for

- Music
- See who is at the door in conjunction with a virtual doorbell
- Lock and unlock their door(s) or garage door
- Change TV channels
- Listen to books on tape
- Use their cell phone
- Check in on a loved on
- Call for help
- Order items easily on the web and also order local groceries
- Control their hospital bed
- Control their environment (fans, heat, air conditioning)
- Shower control
- Faucet control
- Mindfulness and Meditation
- Reminders to take medication
Energy Conservation

- When managing this disease, healthcare professionals stress conservation of energy.
- Managing fatigue is crucial when a person has ALS and smart speakers assist people with energy conservation.
- If a person with ALS doesn’t have to walk to the front door to answer it and let someone in, they will not only conserve energy but can also remain safe because walking unassisted can be dangerous for some people with ALS.
Entrance to Homes

• Many people with ALS will have home health aides, nurses, therapists, and other allied healthcare professionals visiting them in their home.

• The ability for a person with ALS to unlock and lock their door is important for energy conservation and safety and also offers piece of mind to caregivers that their loved one can let people into the house.
Smart Speakers with Screens

- People with ALS and their caregivers that use a Smart Speaker with a screen are able to call and see each other in real time.
- This is vital for caregivers that need to work and want to check in on their loved one throughout the day to ensure they are okay, haven’t fallen, or slid out of their recliner or wheelchair.
- The devices offer peace of mind for families because they know they can check in with the person with ALS at any given time.
Environmental Controls

- Fans, thermostats, lights
- Allows people with ALS to control heat, air conditioning, and f
Changing TV Channels

• Many people with ALS often have to retire from work. Their days will often consist of being on a computer, tablet, or phone and watching TV. Changing the TV channel is a priority for the clients we serve. It is a quality of life issue because people with ALS want to remain as independent as possible. Smart speakers allow the users to have full access to their TV, DVD, etc..

• Harmony Hub $69.99
  – Works with Alexa to easily control your home entertainment devices with your voice
  – Combine up to 8 remotes and countless apps into one easy-to-use smartphone app.
  – Create customized activities to control your home entertainment
  – Harmony App for iOS or Android smartphone or tablet: Simply swipe and tap to control channels, movies, 50 customizable channel Favorites
  – Closed cabinet control: Included Harmony Hub lets you control devices in closed cabinets

• Amazon Fire Cube $119.00
  – Fire TV Cube is the first hands-free streaming media player with Alexa. From across the room, just ask Alexa to turn on the TV, dim the lights, and play what you want to watch.
  – With far-field voice recognition, eight microphones, and beamforming technology, Fire TV Cube hears you from any direction. Enjoy hands-free voice control of content—search, play, pause, fast forward, and more. Plus control the power and volume on your TV, soundbar, and A/V receiver as well as change live cable or satellite channels with just your voice.
Comcast Accessibility App

Works with all eyegaze devices
Works on a PC/laptop
Works on a tablet, iphone, android
Making a Phone Call

• Using a smart speaker allows a person with ALS to independently make a phone call
  – There are limitations on using a cell phone’s voice assistant like Siri or Okay Google
    • Voice Assistants can make a call but can not hang up – using a Smart Speaker allows the caller to simply say “hang up”
Mindfulness

- Recent research demonstrates that patients with amyotrophic lateral sclerosis (ALS) have a higher risk of developing depression, both immediately before and after being diagnosed with ALS.
- While the study, “Depression in amyotrophic lateral sclerosis,” which appeared in the journal Neurology, could not state exactly how or why the two diseases are linked, it suggested that the findings may influence how clinical trials are designed because depression may impact whether patients are willing to participate in studies.
- To combat the psychological issues people with ALS and their caregivers experience, many healthcare professionals recommend mindfulness and meditation. Mindfulness-based programs may help improve anxiety and depression in patients with amyotrophic lateral sclerosis (ALS), according to results of a study titled Meditation training for people with amyotrophic lateral sclerosis: a randomized clinical trial.
- published in the European Journal of Neurology. Since ALS is a progressive and irreversible disease, patients may experience increasing levels of depression over time, which greatly decreases their quality of life. Previous studies had suggested that one of the approaches that may improve anxiety and depression associated with ALS is mindfulness.
- “Mindfulness is a meditation technique that trains a person to bring his attention to the internal and external experiences of the present moment,” Lou wrote. “It encourages non-judgmental openness, curiosity and acceptance. The basis of mindfulness practices is that experiencing the present moment non-judgmentally and openly can counteract the effects of stressors of the past or future that can cause depression and anxiety.” (source: ALS Today)
- Smart speakers and apps allow both the person with ALS, their caregivers, and their family members to use mindfulness and meditation apps which can improve their quality of life and reduce anxiety and depression. It may seem strange to turn to a virtual assistant when you feel lonely or depressed, but tech companies know this happens, and are already building a framework to help their users find the help they need — whether it's a particularly well-timed joke, or phone numbers for a potentially life-saving conversation.
- How to Meditate With Amazon Echo and Alexa
Environmental Control Units
Environmental Control Units, or ECUs as they’re commonly called, enable persons with physical disabilities to participate in a broad range of everyday activities at home, at work, in classrooms, in health care centers, and in hospitals through a variety of user-friendly interfaces, including the touch of a button or the sound of the user’s voice.

ECU’s can be:
- Home Automation system
- iPad apps
- Independent units
- Not covered under medical insurance
Home Automation for people with ALS

• Consider the access
  – Tablets/touchscreens are only accessible through hand function
  – If you want a system for the duration of progressive disease, you need to utilize a PC based system
    • Laptop/desktops can be modified so they can be accessed without hand use
Dedicated EADLs

• SAJE Technologies
  – Pocket Mate
    – Voice or Switch Activation
    – Controls over 250 Functions
    – lights, appliances, beds, doors, telephone functions and infrared controlled devices
  $3995.00

• Mount
  Gooseneck $120.00 - $199.99
SiCare Pilot

- Portable
- Control and operate numerous appliances and devices
- Activated totally hands free – voice or switch
- Control:
  - TV, VCR, Stereo, CD
  - Answer/dial phone
  - Turn lights on and off
  - Appliances
  - Open powered doors
  - Open blinds and windows
  - Air-conditioning
  - Heating
  - Bed controls
- $6,999.00
SiCare One (Formerly SiCare Light II)

• Input
  – Speech
  – Dual switch or single switch with scanning
  – Internal microphone
  – External keys for caregiver use
  – Control a television, telephone, lights, door systems
  – $2499.99
REACH by Breaking Boundaries

- **REACH** (Remote Electronic Access & Control - Hands-Free) is a system that allows the user to independently control dozens of products in their home.

REACH is different than many other EADLS as it provides a screen so that the user can actually see all the commands available rather than memorizing the entire menu.

- Large variety of input methods for control
- Touch control, voice control, head control, switch scanning
- TVs, Lights, Fans, Telephones, Blinds/Shades, Door Openers, Video Intercom, Adjustable beds, Nurse Call Systems, etc...

- $6,450.00
SpeakEasy ECU

• The SpeakEasy ECU allows the user to control their home by voice from their computer.
  – Use Dragon or Microsoft Speech Recognition to control the buttons on each screen just by saying the names out loud.

• Set up as many screens as needed to control lights, fans, TV, DVR, bed and/or door opener.

• Can also use mouse to click buttons

• $995.00
Bedmate by SAJE Technologies

- Independent Voice Operated Bed Controller
  - NOTE: voice control only – no switch
- No additional devices needed
- Plug and Play Installation
- $1,995.00
Alexa control of hospital bed

Communication Device

IR Controls embedded in communication devices
  Can program on software
  OR
  Use synthesized voice to control smart speakers
Smart Phones and Tablets

• A user can control ALL aspects of their phone via voice control in both Android and iPhones

• Android
  – Google Voice Access

• iPhone/iPads
  – iOS13
Google Access (free)
iPhone/iPad
ECU’s that work without Wifi

- Zwave devices (requires a computer and that the computer be ON)
  - As the smart home's popularity explodes, more and more connected devices are being added to people's houses. A lot of these devices – sensors, lightbulbs, heating controls, locks, plugs and the like – pack in Z-Wave to talk to each other. A much lower power alternative compared to Wi-Fi, but with a much bigger range than Bluetooth, Z-Wave operates using low-energy radio waves to communicate from device to device.

- Unlike Wi-Fi, where devices have to connect to a central hub (usually a router, or another access point), Z-Wave devices all link up together to form a mesh network. There's usually one central hub that does connect to the internet but the devices themselves – sensors, bulbs and so on – don't have Wi-Fi at all, they just use Z-Wave connectivity to talk to the hub, and that connectivity doesn't have to be direct; the mesh network means signals can hop from device to device.

- You can have up to 232 nodes on this mesh network.
ECU’s that work without Wifi

• There is a great need to provide smart home technologies to people that do not have access or can’t afford Wifi
  – More than 60 million urban Americans don’t have access to or can’t afford broadband internet
    • About 23 percent of people in urban areas don’t have access to or can’t afford broadband versus 28 percent in rural areas.
  – 35% of those living in Tribal Lands do not have internet access
Zwave devices

- Fibaro Button
- Kwikset Obsidian Smart Lock
- Oomi Dual In-Wall Switch
- Logitech Home Harmony Hub Extender
- August Smart Lock
- Zipato Bulb 2
- Abode Gateway
- Yale Keyfree Connected
- D-Link mydlink sensors
- Somfy ILT Series blinds
- ADT Security Hub
ECU devices without a computer or internet

- Hubitat Hub
- Hubitat is an inexpensive hub that talks to a variety of smart home devices. It’s also customizable to almost the same extent as SmartThings, making it a strong option for tinkerers and developers. The major difference, however, is that Hubitat is capable of running everything offline, including rule-based automation, manual smart home control, and even geofencing.
- Butterfleye or Ooma Smart Cam
- Abode Security for Smart Home Devices
• Home Automation Without Internet: Your Questions Answered

• Team Gleason
  – www.teamgleason.org
  – Axion ECU offered free of charge
    • Client must pay for the electrician to install
Calling for Help

• The most crucial assistive technology that can be in the home
  • – ALWAYS ALWAYS have a way to call for attention
  • – What type of call do you need to make?

Within the home

In the home and also the yard

Call out for help (911)

• – What dexterity does the user have?
• – If user can still speak, baby monitors (especially those with video) make great call systems
  – WebCams (aka nanny cams)
• – If user has limb movement, any type of bell…cow, dinner, etc…will attract attention
Call Systems for the home

• Wired or wireless device
• – Wired device has a call bell for the PALS and an alarm which will emit a loud beep until the user releases the bell
• • Med Labs EZ Call Bell and Alarm
• • About $125.00

http://www.medlabsinc.com/Med Labs/PA-1-ALA RM.htm
Calling for Help in the Home

- Wireless Pagers
  - Can be as simple as a wireless doorbell from local home improvement center
  - Approximately $20.00
Adapted Wireless Pagers

- Can be used up to 40-100 feet away
- Either chime only or chime and vibrate
- $51.95-$67.95
Emergency Alert System (monitored)

- Two-way 24-hour a day
  - 365-days-a-year emergency response service designed to provide assistance and reassurance to people in need

- Monthly service charge and an installation fee
  - Installation around $80.00
  - Monthly fee around $50.00

- User wears a transmitter and there is a fixed communicator unit that is placed in the home
  - Users call for assistance by pressing a small, portable, waterproof button worn around their wrist or as a pendant
  - The communicator unit, which is attached to the subscriber's current phone system, is then activated and automatically dials the service

- Incoming calls can be answered
Non-monitored Emergency Alert Systems

Affordable emergency alert devices that are easy to use
– Connect to your telephone
– Dial "911"
– Call up to 5 telephone numbers of your choice
– Send an emergency pre-recorded
– About $225.00 or less
– http://www.teleemergency300.com/
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