WELCOME !

April 19, 2021

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Guest Speaker:

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Communication Options for People with ALS

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National Office-Care Services

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Communication Options for People with ALS

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About me

- Assistive Technology Professional
  - Specialty areas are communication, computer access, environmental controls, home modifications
    - Credentialed Assistive Technology Professional (ATP) through RESNA (Rehabilitation Engineering and Assistive Technology Society of North America)
    - Certified Living in Place Professional (CLIPP) through the Living in Place Institute
    - Certified Aging in Place (CAPS) through the National Association of Home Builders
    - Credentialed Wheelchair Service Provider (WSP) through the International Society of Wheelchair Professionals
      - Current RESNA Board Member
      - Current RESNA Faculty

- 24 years with the ALS Association
  - Greater Philadelphia Chapter
  - National Office

- I have no financial interest in the products I am discussing today

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Never underestimate the power of communication

- Communication is what makes us human. It distinguishes us from the animal kingdom. The loss of the ability to communicate is one the hardest adjustment for our PALS.

- *For the normal adult who has spoken without difficulty since early childhood, the prospect of being unable to communicate through natural speech is incomprehensible. Efficient communication with colleagues, family, and friends is taken for granted.*
  - » Beukelman and Garret, 1988

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Communication Issues for People with ALS

- EVERY person with ALS progresses differently, including speech related issues

- 50% become dysarthric
  - Mild, moderate or severe slurred speech

- 25% become anarthric
  - Unable to produce any sound or speech

- 25% able to be understood throughout the course of the illness

What do most PALS do for communication?

- There is no one right answer

- Many PALS use a combination of low and high technology

- Most PALS use multiple modes of communication

- Even with the most advanced technology, PALS will still need some low technology systems in place

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Seating and positioning

- Critical for communication, computer access, weight shifting, and LIVING
- Allows for more comfort and less fatigue and greater ability to interact with the environment.
- Promotes good posture which decreases pain especially in the neck, shoulders and back.
- Allows a person to better perform activities of daily living such as eating and brushing hair.
- Distributes a person's weight to decrease the risk of skin breakdown/pressure ulcers, caused by bad posture and lack of movement.
- Decreases the risk of the patient falling out of the chair and being injured.
- Improves a person's ability to see more of the surroundings, breathe and swallow better and have better digestion.

Dropped Head Syndrome

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AAC Interventions for Clients with ALS that can still speak

Voice and Message Banking

- If your client can still speak, tell them about voice, message, and legacy banking!!
  - Can be a difficult and emotional conversation
  - Need to get client involved BEFORE they have speech issues

Voice Banking and Message Banking

- Voice banking is the process of recording your voice for possible future use on a communication device
  - This is something that even newly diagnosed PALS may wish to consider, since it is best to make the recordings before significant speech or voice changes as the person needs to record phrases and sentences
    - Consider the psycho-social aspect when discussing

- Message banking is the process of playback of recorded messages
  - Recorded messages can be programmed into a SGD and used when needed for communication
  - With this method, only recorded messages will use the person's natural voice. Newly created messages, using spelling, will use the SGD's artificial voice (i.e. synthesized speech)

Voice Bank Comparison Table. *February 2021*

	Model Talker	MOV Acapela	Speak Unique	VocalID	Voice Keeper	CereVoice Me from Cereproc
Process	1575-3000 messages	50 messages. Can add 300 custom if desired	300 messages	1600+ messages	50-500 messages	1000 + messages
Time commitment ⊙	5- 7 hours	10- 60 minutes	60- minutes	5-7 hours	15-90+ minutes	Minimum two hours
Can add custom script	yes	yes	No	No	No	No
Bank from home	yes	yes	yes	yes	yes	yes
Premier before pay	Yes. TTS	Yes. TTS	Yes (pre-scripted)	Yes. TTS	Yes. TTS	No
Cost USD	100	99 yr or 999.	295.	1500.	250.	640.
Incorporate into SGD	yes	yes	Yes - limited iOS options	Limited options	yes	yes
Can 'double dip' from Message banking	no	yes	yes	no	yes	no
languages	English	16 languages	English	English	English and Hebrew	English
Equipment needed	Headset/computer	Headset/computer	Headset/computer	Headset/computer	Headset/computer Or iPhone	Headset/computer
Will accept and process unedited legacy audio	no	Yes, case by case, added fee may apply	yes	no	Yes* website states may be poorer quality	no
Voice repair	no	no	yes	no	no	no

⊙**NOTE: Time commitment based on strong voice and ease of speaking.**

Legacy Banking
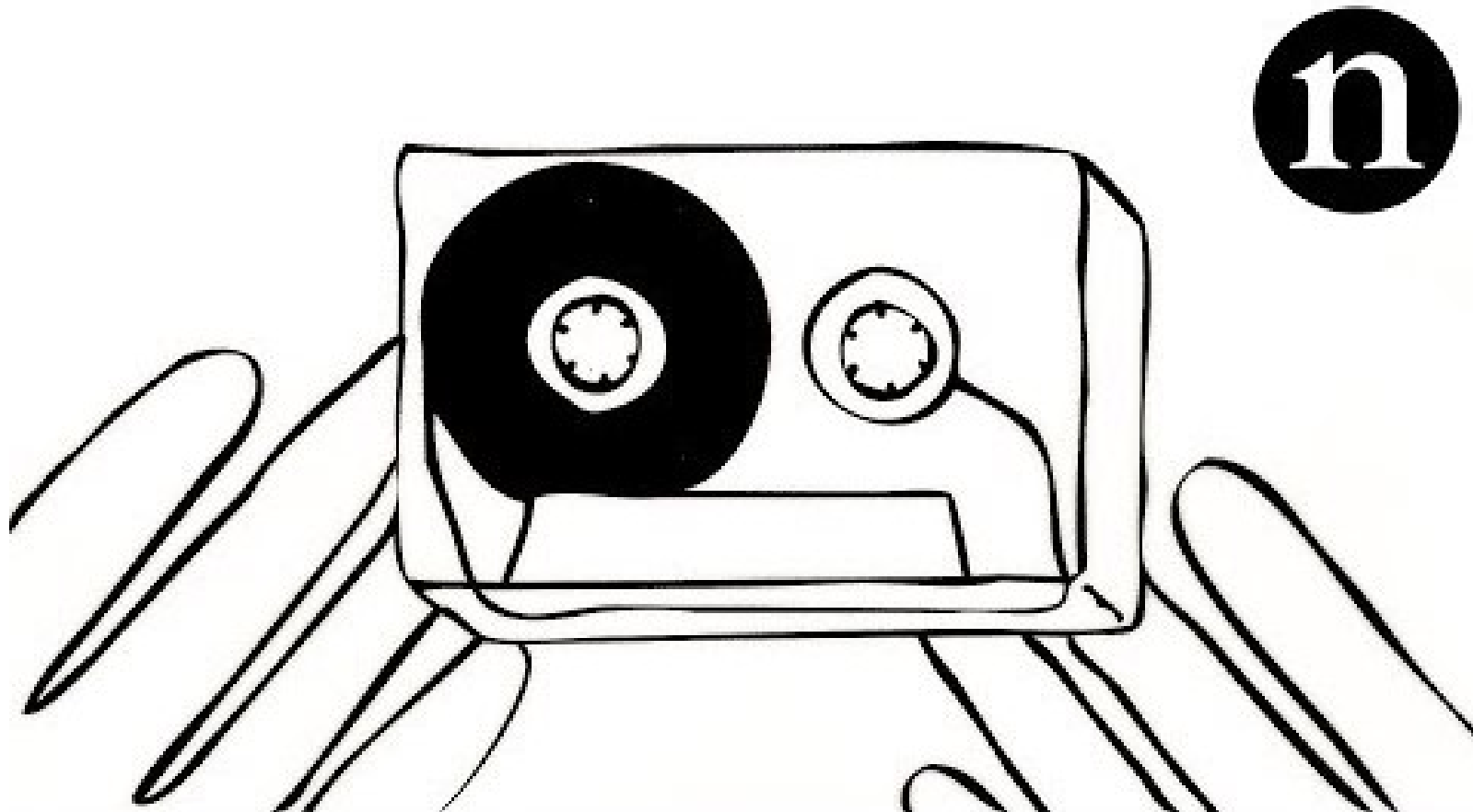
Amplification

- Using an amplifier in conjunction with a microphone for those with low vocal volume due to decreased breath support
  - Reduces fatigue
  - Preserves energy
  - Not covered under medical insurance

Amplification to reduce fatigue

- Speaking can be fatiguing
  - Uses a great deal of energy for the muscles of of respiration, phonation, resonation and articulation all at the same time.
- Amplifying a voice when when speaking means use less energy to talk
  - For many people, this means that fatigue related to speaking occurs much later in the day than it does without the amplifier
- Goal is to minimize fatigue and maximize function, a voice amplifier would ideally be used throughout the day in many environments
- Use a voice amplifier when speaking in crowds (family gatherings, social events), when competing with background noise (traffic noise, air conditioner, office noise, in the car),when speaking in large open spaces (in a conference room, restaurants, shopping plaza) or when speaking for extended periods of time.

> " I place the amplifier in the middle of the table during card games. With five of us playing cards it can get pretty noisy but with the amplifier and despite my weak voice, I am still the biggest mouth at the table! "
>
> ML, age 64

Non-Invasive Ventilation

- The aim of NIV is to compensate diaphragm weakness, alleviate hypercapnic symptoms and improve patients' general condition and quality of life. Since respiratory insufficiency limits survival, NIV also prolongs life considerably in ALS. (Jun 21, 2019)

- In general, NIV use is associated with improved survival rates and better quality of life in ALS patients. When used for at least four consecutive hours during sleep, NIV can prevent sleep hypoxia (low oxygen levels) and improve sleep quality, as well as prevent hospitalizations. (Sep 12, 2018)
    - FVC (Forced Vital Capacity) as well as other factors determine when NIV will be recommended

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NIV and AAC

- *Amplification with transdermal mic should be recommended for those that can still speak and are using non-invasive ventilation*

Call Systems for the home

- Med Labs EZ Call Bell and Alarm
    - Wired 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
- • About $300.00 and not covered under insurance
- • http://www.medlabsinc.com/Med_Labs/PA-1_ALARM.htm
    - If sleeping in different rooms or on different floors, use in conjunction with a baby monitor

Calling for help within the home

- Wireless Doorbells
  - Can be a simple as a wireless doorbell from local home improvement center
- – Approximately $20.0(
- Different radius for eac

Calling for help within the home

- Adapted Wireless Pagers
- – Can be used up to 40-100 feet away
- – Either chime only or chime and vibrate
- – $50.00+

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Electronic Doorbell

- Allows the user to press a button, alert goes off on a caregiver's cell phone.
  - Caregiver can then see the person

iPhone sold separately.

Smart Speakers

- Video Screens allow users to see each other
- Amazon Echo and Google Home
- Allows a user to call anyone that is programmed as a contact

Augmentative and Alternative Communication Options (AAC) or Speech Generating Devices (SGD)

Augmentative/Alternative Communication Options for People with ALS

- Rapid Access
  - Easy, fast, efficient and doesn't plug into a wall

- High Tech traditional mainstream devices
  - iPhones/iPads
  - Android Tablets
  - Light full-sized laptops

- High Tech SGD's (Speech Generating Devices) paid by insurance

- MOST PEOPLE WITH ALS WILL USE MULTIPLE MODALITIES OF COMMUNICATION
  - There is no ONE system
  - Rooms with the most communication breakdowns
    - Bathroom
    - Bedroom

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Why don't people use communication systems??

- "Giving in in" to the disease
- Don't need it
  - I sound just fine
- PALS don't seem to "hear" themselves anymore
- You are supposed to understand me
  - "As my wife/husband/child/parent/medical professional
- Emotions such as fear and anger
- Resistance to technology

I DON'T WANT TO!!!

Raising Sticky Hands To Heaven

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Rapid Access AAC

- **FIRST priority: Establish a yes/no and _maybe_ system**
  - Eye blinks—one blink equals yes, two blinks equals no, three equals maybe or start over
  - Look left, right or up
  - HAVE THIS WRITTEN DOWN AND HUNG ON WALL, REFRIGERATOR, DOOR, ETC…
- Letterboards
- Picture boards
- Magic Slates, Boogie Boards, write-on/wipe off boards
- Eye Gaze boards
- Use of laser pointers
  - Mounting of laser pointers on a hat or head band—letterboard placed on wall and user moves head around board to make selections
- Megabee
  - Electronic letterboard system

Rapid Access as Emergency Preparedness

- Imperative for:
  - Emergency Room visits (especially now during Covid_19 as caregivers can't be in the ER as interpreters)
  - In-patient Hospitalization
  - Nursing Home placement
  - Emergent ventilation
  - Mandatory evacuation
  - Staying in shelters

- Teaching patients and families a simple YES/NO/MAYBE system can save their life!!
  - People with ALS are used to communicating verbally and do not think about some of the most basic alternative communication systems
  - Current COVID-19 pandemic

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Insurance Funded AAC Devices

AAC / SGD's

- Medicare started paying for communication devices in 2001 and renamed them Speech Generating Devices (SGD).
- Per CMS website:
  - Speech generating devices are covered if the patient suffers from severe speech impairment and the medical condition warrants the use of a device
  - Speech generating devices are defined for Medicare coverage purposes to include dedicated speech devices used solely by the individual who has severe speech impairment
  - Speech generating devices also include software that allows a laptop computer, desktop computer or personal digital assistant (PDA) to function as a speech generating device
  - Devices that are not considered speech generating devices include devices that are not dedicated speech devices, or devices that are capable of running software for purposes other than for speech generation
- The definition **excludes f**rom Medicare coverage:
  - **<u>a device that is useful to someone without a speech impairment;</u>**
  - personal computers, tablets or mobile devices that may be programmed to perform the same functions, but do not meet the definition of DME;
  - internet or phone services, or any modifications to the patient's home;
  - specific features not related to "functional speaking", such as hardware or software used to create documents or play games;
  - video communications or conferencing software
    - Source: https://www.asha.org/practice/reimbursement/medicare/sgd_policy/

AAC Funding

- Medicare
  - Must have Part B (buy in)
  - Supplemental
    - Will pay for 20% -- if no secondary insurance, client is responsible
  - Managed Medicare
    - Often only 80%

- Medicaid
  - Every state has different coverage

- Private insurance
  - Depends on client's rider
- VA
  - Veterans with ALS that are enrolled in the VA system will get all the devices they need – covered by the VA

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AAC is not funded when…..

- SGD's are not funded when a person lives in a nursing home or is on hospice (Medicare mandate)

- For nursing home clients
  - For clients on Medicaid, check your state's AAC coverage
  - If they have private insurance AAC may be covered

- Loaner devices
  - Through your state's ALS Chapter
  - Team Gleason (www.teamgleason.org)

AAC Process

- AAC assessments are conducted by appropriately credentialed and trained speech-language pathologists – must have CCC's
- Speech-language pathologists may perform these assessments individually or as members of collaborative teams that may include the individual being assessed, family/caregivers, OT, PT, ATP, Rehab Engineers, Social Workers and others

- Documentation
  - Outcomes
  - Clinical Indications
  - Clinical Process

NAVIGATING THE AAC EVALUATION AND FUNDING PROCESS

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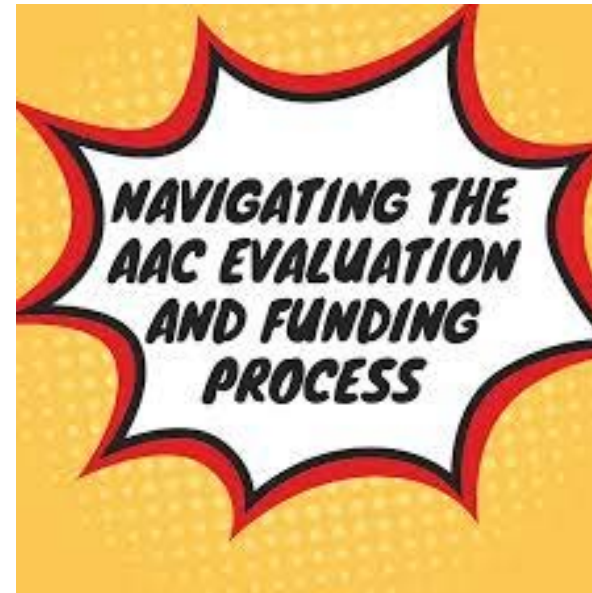
Clinical Process for Insurance funded SGD's

- Comprehensive assessment is sensitive to cultural and linguistic diversity and addresses the components within the WHO's International Classification of Functioning, Disability and Health (2001) framework including body structures/functions, activities/participation, and contextual factors.

- Assessment may be static (i.e., using procedures designed to describe current levels of functioning within relevant domains) or dynamic (i.e., using hypothesis testing procedures to optimize selection and use of AAC systems), and includes the following:

  - Review of auditory, visual, neuromotor, speech-language, and cognitive status, including observation of posture, gross and fine motor coordination, and any existing adaptive and/or orthotic devices currently used by the patient/client (e.g., wheelchair, neckbraces, communication devices and/or techniques, other specialized equipment).

  - Relevant case history information, including medical status, education, vocation, and socioeconomic, cultural and linguistic background regarding activities in which the person needs an AAC system to support communication.

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Clinical Process Con't

- Standardized and/or nonstandardized methods for assessing the individual's use and acceptance of a range of AAC devices, aids, symbol systems, techniques, and strategies. • Examination of specific aspects of voice, speech, language (e.g., spoken and written language samples, reading level), cognition, and existing communication options and abilities.

- Methods for identifying associated barriers and facilitators that are addressed in an intervention plan.

- Varied parameters of the AAC assessment (e.g., tests, materials) that depend on levels of severity, whether the patient/client is a child or an adult, and whether the expressive or receptive communication disorder is congenital or acquired.

- Selection of measures for AAC assessment with consideration for ecological validity, environments in which AAC systems routinely will be used, technology and device features, and preferences of the patient/client and communication partners (e.g., family/caregivers, educators, service providers).

- Assessment of a range of potential AAC systems in multiple controlled and natural contexts.

- Follow-up services to monitor individuals with identified speech-language and communication disorders justifying the need for AAC systems. o Cognitive-communication and language status o Appropriate intervention and support o Optimal use of the recommended AAC system o Adjustments in the AAC system as necessary

- Evaluation of the individual's ability to use the AAC system effectively in a variety of contexts, with adjustments made to the system as necessary.

Once the Evaluation is done

- Evaluation is sent to prescribing doctor
  - There has to be a chart note that AAC is needed
    - This is called a Face to Face

- Doctor signs off on evaluation
  - Must include a prescription

- SLP sends all paperwork to AAC vendor
- AAC vendor bills insurance
- Once approved, device is shipped directly to the client

- Usually takes 2-3 months from start to finish

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SGD's for People with ALS

- Insurance will only pay for current needs, not future

- Some people with ALS get SGD's that are tablet-like devices and access them via hands

- If no hands, options are:
  - Headmouse
  - Eye Gaze
    - -BOTH of these can be added on later when clinically justified. They will only be covered if they are part of an insurance approved SGD

- The majority of people with ALS opt to wait until they need eyegaze devices before they go through insurance (they will use mainstream technology as long as they can)

- Eyegaze devices are NOT funded unless the SLP can document that there are no other access methods

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Eye Gaze Manufacturers in the US

- Tobii Dynavox
  - https://us.tobiidynavox.com/

- Prentke Romich Company (PRC-Saltillo)
  - https://www.prentrom.com/

- Eyegaze Inc.
  - https://eyegaze.com/

- Forbes AAC
  - https://www.forbesaac.com/

- EyeTech Digital
  - https://eyetechds.com/

Mounts

- Insurance only funds one mount
  - Multi-purpose mounts or 2 mounts will sometimes be funded (depends on wording in the report)
- Talk about the advantages and disadvantages!!!!!
  - Wheelchair mounts can only be used on wheelchairs
  - Rolling mounts are not often transportable

Non-insurance funded devices

- Use of mainstream technology if client
  - Doesn't have insurance
  - Not interested in insurance SGD's
  - Lives in a nursing home
  - Enrolled in hospice
  - Can't get access to an SLP to do AAC eval for insurance
  - No AAC evals being performed
    - Happened during and since Covid19

iPhones, iPads

iPad Communication Apps (most run on Android too)

- * Verbally – Free
    Verbally Premium $99.00

  * Speech Assistant $14.99

  * Co-Writer $14.99

- * PredictAble - $159.99

  * Proloquo4Text - $149.00

Many of the AAC communication apps come in different languages. I have a list – if interested email me

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Healthcare communication app

FlipWriter

ⓘ
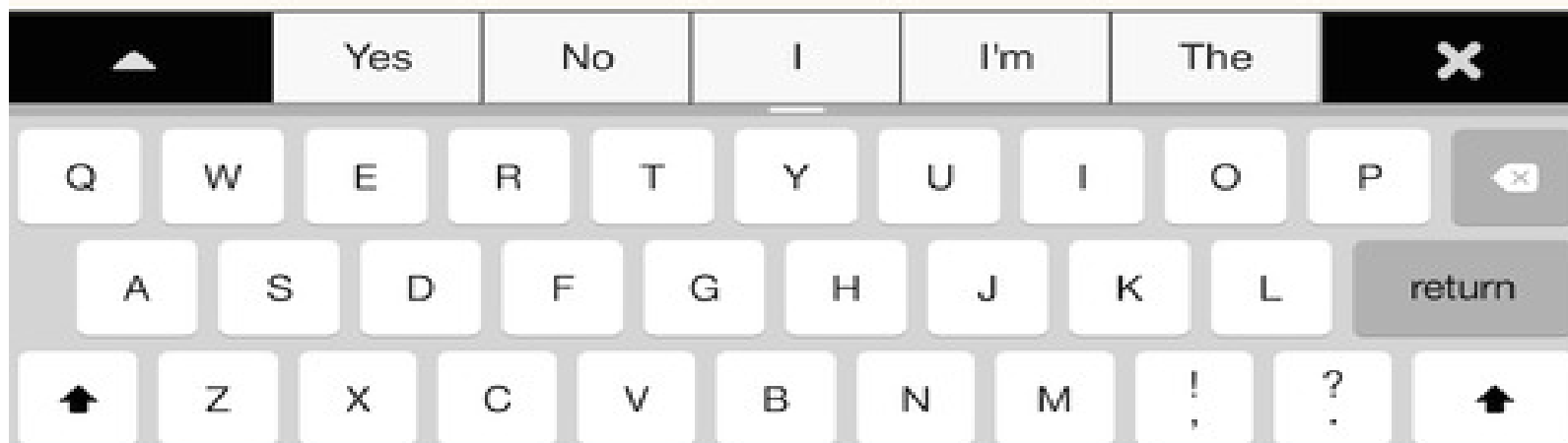
Accessing the iPad

- You can use your fingers or stylus
- Hand stylus's can be purchased at electronics store or discount stores like Five Below
  – Mouthstick and headstick through RJ Cooper www.rjcooper.com

IOS Switch Access

- Allows for HANDS FREE use of iPad and all applications through a switch (described in next slide)
- Adapter available at RJ Cooper
  - www.rjcooper.com
  - $149.00
- Tecla Shield

- What is a switch?
    - A piece of equipment that sends a current to the machine to do something
    - Switches come in a variety of shapes, sizes, and can be placed anywhere on the body where there is muscle movement
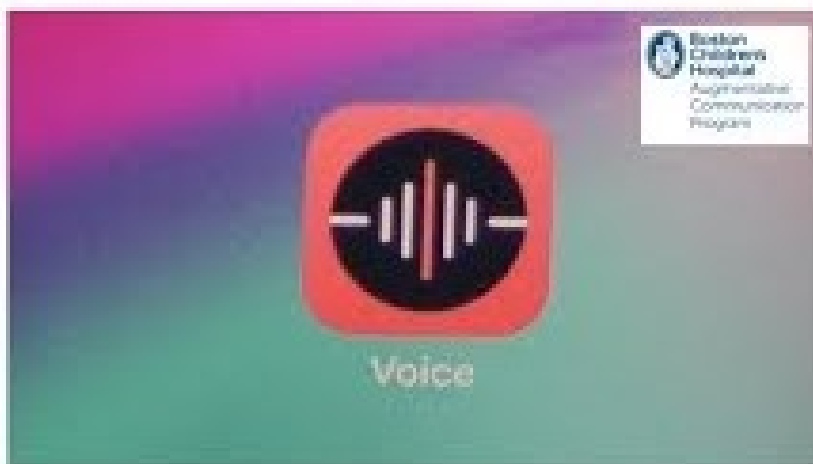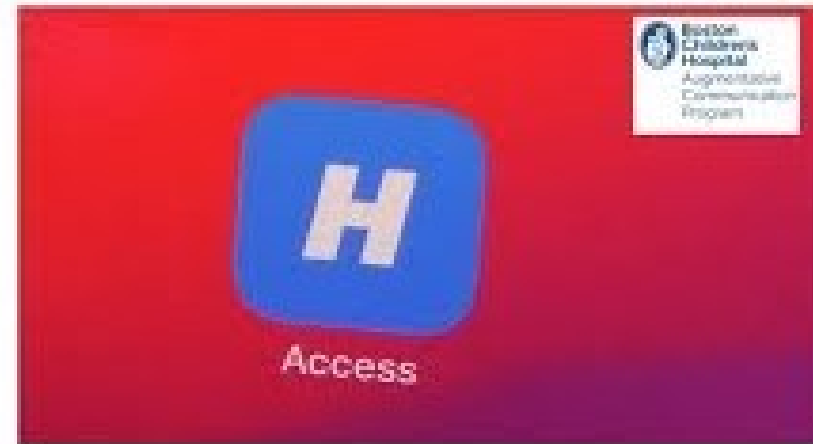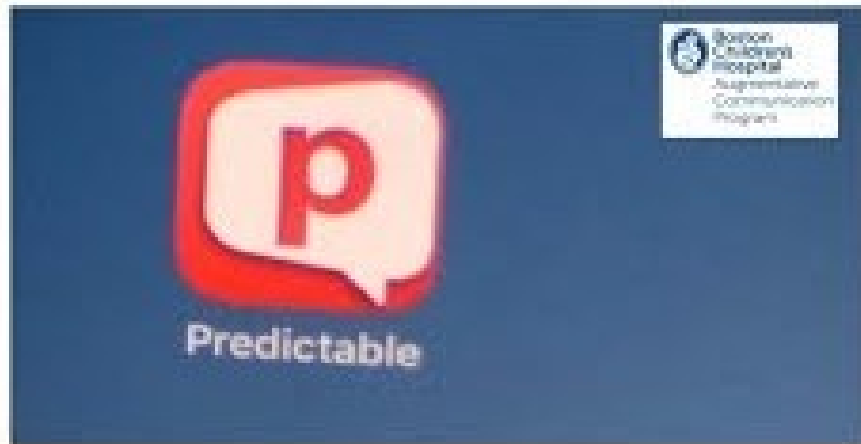
iPhone/iPad Front Facing Camera as access

- iPhone 10 or above
- iPad PRO

- Uses front facing camera to access devices to create an "eye gaze" device
- Communication apps
    - I Have a Voice
    - Hawkeye
    - Predictable AAC
    - Jabberwocky
- None of these apps offer total access eye gaze

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Head and Eye Control of iPad

Total Eye Gaze Access to the iPhone and iPad

- Skyle
- $3000 -- much cheaper than other dedicated communication devices with eye gaze.
- Offers a choice of AAC apps, access to social media, email, and environmental control
- Protective case comes with a built-in mounting plate for wheelchair users
- Has the potential to truly make a difference for people with complex bodies
    - By making alternate access available on consumer electronics, it brings the price point way down

Mounts for iPads/Android Devices

Android Access

- Can be accessed by finger, stylus, mouse, head mouse, or eye gaze
- More accessibility features but less communication apps choices
- For eye gaze option, the tablet must be running a full version of Windows 8 (i.e Microsoft Surface Pro)

Only Predictable App

Predictable App + 3 months customer service and support

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Full Sized Laptops

- Full Sized Laptops
  - Starting about $300.00
  - Can be accessed via head mouse and
    eye gaze devices

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Headmouse

- Replaces the standard computer mouse for people who cannot use or have limited use of their hands when controlling a computer or alternative and augmentative communication (AAC) device

- Translates natural movements of a user's head into directly proportional movements of the computer mouse pointer, so as the user moves their head the mouse pointer on the screen also moves

- Has a wireless optical sensor which tracks a tiny disposable target that is worn by the user in a convenient location on their forehead, glasses, hat, etc

- Works just like a computer mouse, with the mouse pointer being moved by the motion of the user's head

- Average price $500-$2,000

- FREE Camera Mouse at www.cameramouse.com
  - Free program that allows you to control the mouse pointer on a Windows computer just by moving your head. Clicking can be done by making the mouse pointer dwell over a spot on the screen
  - Utilizes the user's existing webcam

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Tips and Tricks for Disabled Living

Accessible Computing
HeadMouse

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Eye Gaze for Computers

- Devices that turn any laptop or desktop into an eye gaze device
- Tobii PC Eye (requires Windows 8) $1,999.00

- Eye On by Eye Tech Digital $2,000 (approx)
  - http://www.eyetechds.com/eyeon.shtml

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Text to Speech Software for Computers

- FREE
  - E-triloquist   www.etriloquist.com
  - Chipspeaking   www.chipspeaking.com

- Windows 10 has eye gaze software pre-installed
  - Can use an eye gaze bar in conjunction with Win 10 to turn any laptop into an eyegaze device
    - Uses Tobii 4C gaming eyegaze
      - Note a precise as the more expensive eyegaze

Example of E-triloquist
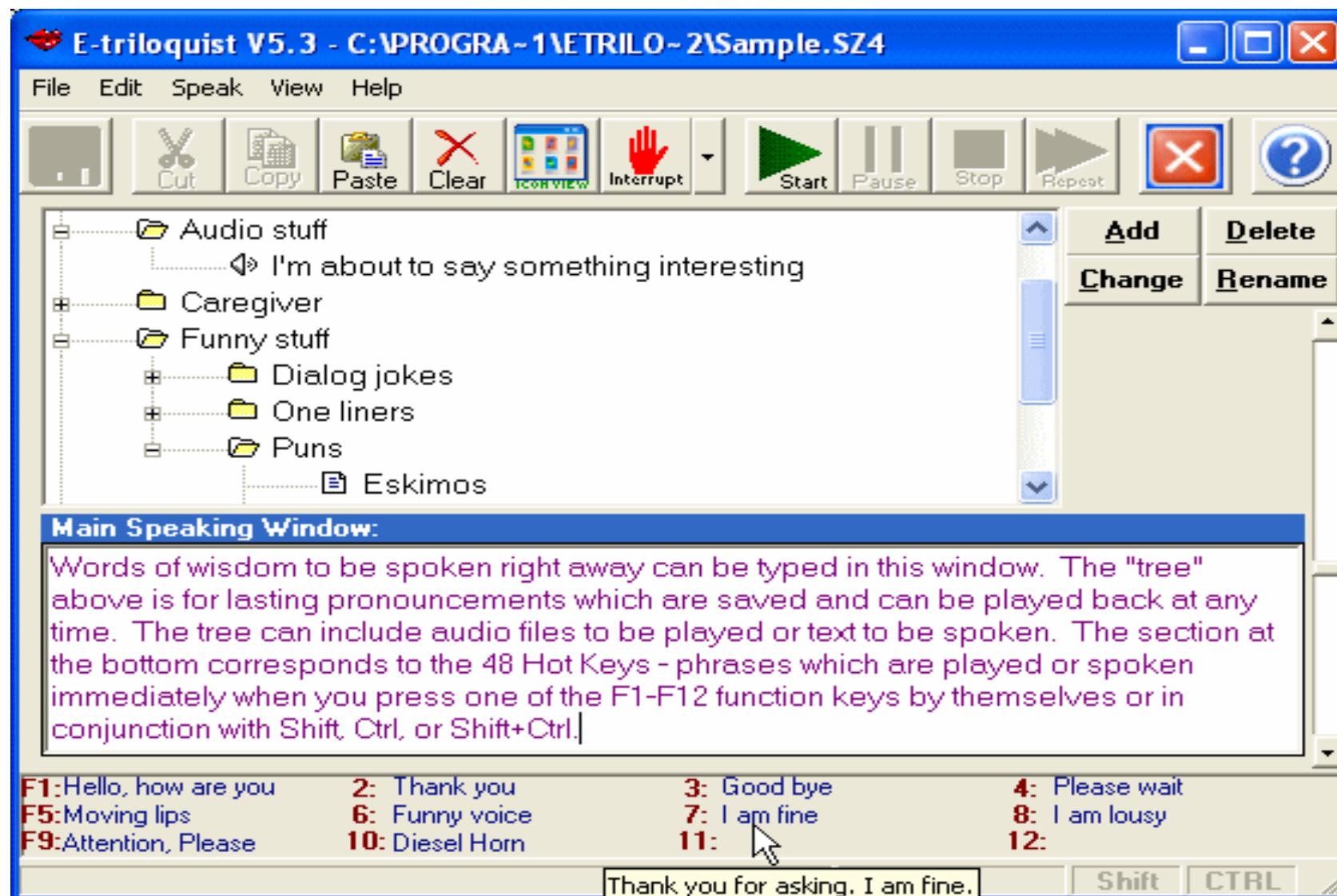
Locked In Syndrome

- Patients with the locked-in syndrome are awake and conscious but have almost complete immobility and loss of verbal communication. Etiologies can be acute (e.g., brainstem stroke — the most frequent cause [60% of cases]) or chronic (e.g., amyotrophic lateral sclerosis. (Sep 1, 2019)

- Two types:
  - Locked In Syndrome (LIS)
    - Complete paralysis of all voluntary muscles except for the ones that control the movements of the eyes. Individuals with locked-in syndrome are conscious and awake but have no ability to produce movements (outside of eye movement) or to speak (aphonia). Cognitive function is usually unaffected. Communication is possible through eye movements or blinking (source: NORD)
    - Total Locked In Syndrome (TLS)
      - The absence of movement including eye movement
- Eyelid issues
  - May not be able to open eyes

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Brain Computer Interface

- Brain-Computer Interface
    - Brain-computer interface (BCI) is a computer-based system that acquires brain signals, analyzes them, and translates them into commands that are relayed to an output device to carry out a desired action.
        - In principle, any type of brain signal could be used to control a BCI system.
    - Research only – no commercial products available

Electrode strips
(implanted)
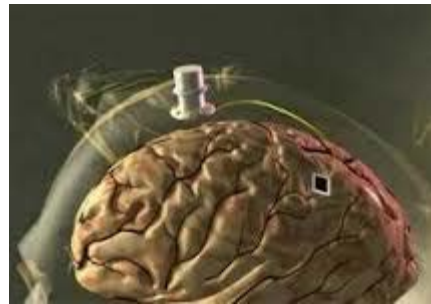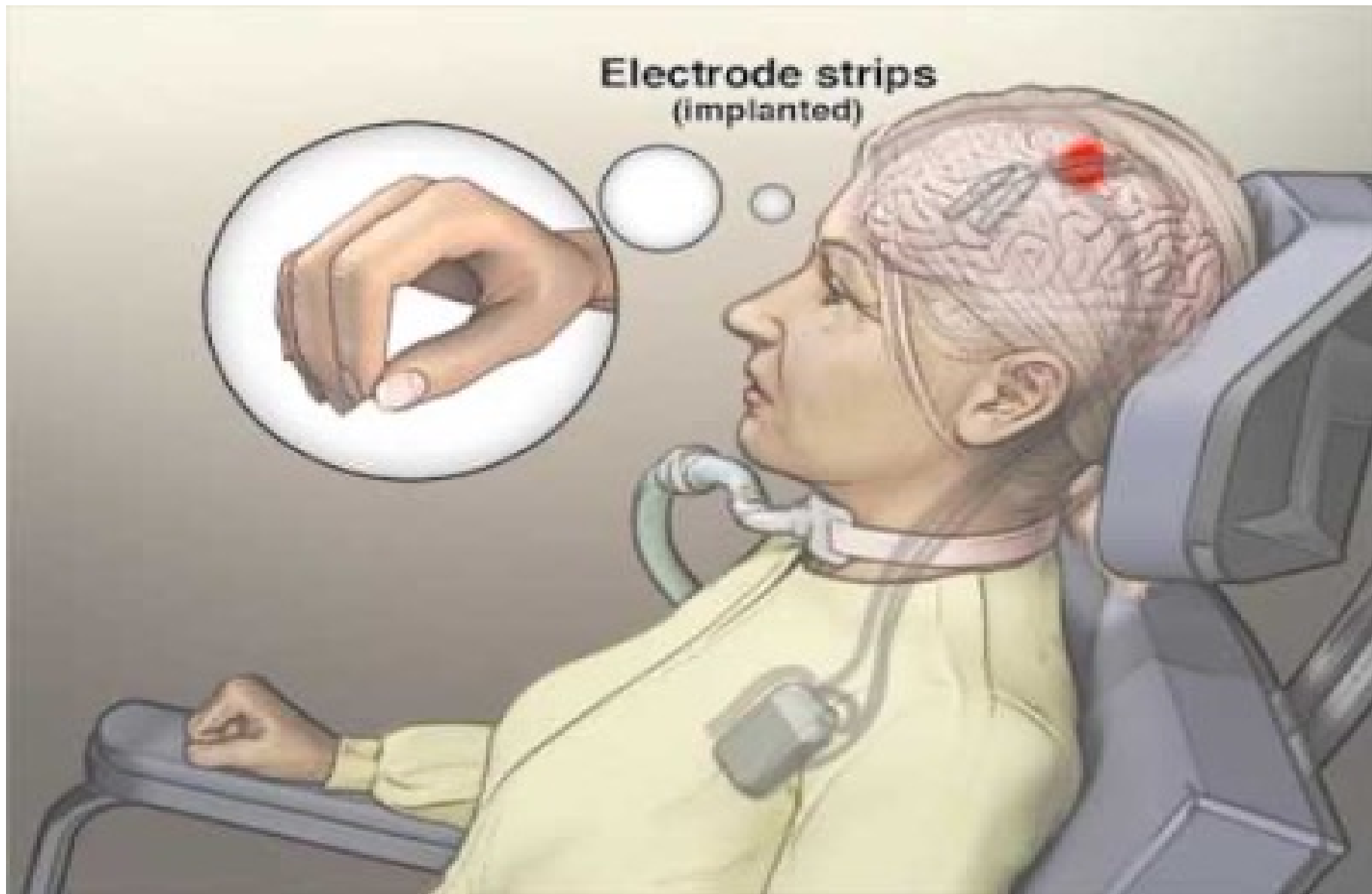
Resources on You Tube

- *My Tobii eye gaze user*:
- http://www.youtube.com/watch?v=Oev92bys2qI
- *Headmouse*:
- http://www.youtube.com/watch?v=VKsIoZ9oa_Y
- *Natural Point head mouse:* http://www.youtube.com/watch?v=ZHZ9p3ydNBc&feature=PlayList&p=5BD0CF9D639DB3AB&playnext=1&playnext_from=PL&index=7
- *Lightwriter:* http://www.youtube.com/watch?v=Mn3Oi3NAIS4&feature=PlayList&p=5BD0CF9D639DB3AB&playnext=1&playnext_from=PL&index=4
- *ALS and the impact of losing speech*: http://www.youtube.com/watch?v=nD6QZGOOgIs
-
- *Use of a letterboard*:
- http://www.youtube.com/watch?v=Y2UiP1DAej4
- *Chin control of computer*:
- http://www.youtube.com/watch?v=rU8T66940Ig
- *About AAC devices—Dynavox video:*
- http://www.youtube.com/watch?v=Eb_URYj_L_k
- *Laser Pointers for communication use:* http://www.youtube.com/watch?v=AooDQOzdOyE
- http://www.youtube.com/watch?v=s0jlCq9QaM4
- *Partner assisted scanning with a letterboa*rd:
- http://www.youtube.com/watch?v=pLb6-Oi3uR0

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Resources

- National ALS Association
  - www.alsa.org

- Have assistive technology questions? -- Email me!!
- Alisa Brownlee
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  - LinkedIn: Alisa Brownlee