

Enhancing Communication in Patients with Surgical Airways + Neurodegenerative Disease *Case Study Series*

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Disclosures

- Dr. Askren and Ms. Kiefer Luehring both receive a salary from the U.S. Department of Veterans Affairs as Staff clinicians.
- Dr. Askren receives a stipend from West Virginia University as adjunct faculty.
- Dr. Askren and Ms. Kiefer Luehring have no non-financial conflicts to disclose.

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March 18
Diagnosis

Mr. C – 54-year-old male

- Welder x30 years
- Veteran of the U.S. Army
 - MOS: Mortarman
 - 4 years after HS, E-4
 - Deployed to Korea, no combat
- Enjoyed cycling, hunting, camping
- Highly supportive wife
- "Not a man of technology"
- Bulbar-onset amyotrophic lateral sclerosis (ALS)
 - Dx: 30 March 2018
 - Sxs began in July 2017: Dysarthria, Oropharyngeal dysphagia
 - ALS Functional Rating Scale: 39
- Depression, grief a/w disability-related loss
- Motoric function of the limbs/trunk intact, ambulatory

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March 18
Diagnosis

October 18
Decline in WPM

Mr. C – Speech, Cognitive-Communication

- Precipitous decline in motor speech abilities (dysarthria)
 - SIT: 100% intelligible, 110 wpm* on 15 October 2018
 - Anarthric by 7 January 2019
 - ALS Functional Rating Scale: down to 26
 - Communicative Participation Item Bank (CPIB Short Form): 2**
- Neuropsychological evaluation 23 July 2018
 - Mild weaknesses in higher-level/complex attention, naming, and non-contextual verbal memory
 - Mood, fatigue

*When speech rate decreases to 60% of normal (~100wpm), pALS can expect a precipitous decline in intelligibility (Ball et al., 2001).
**Borjesson, Hartelius, & Laasko (2021) demonstrated a correlation between bulbar deficits (ALFRS-R) and speech intelligibility.


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March 18
Diagnosis

October 18
Decline in WPM

Assistive Technology Referral, October 2018

- "Not a man of technology."
 - Declined voice banking early on; none by proxy
 - Experience with IOS
 - Emerging experience with Communicator 5
- Always establish no/low/mid-tech AAC options
 - Partner-assisted scanning
 - Boogie Board
 - Personal voice amplifier
 - ✓ iPhone with text-to-speech application
- Trial series of high-tech options
 - TobiiDyanvox I-12
 - Communicator 5 software
 - Smartbox Gridpad w/ Alea & Eye-tech cameras
 - Grid 3 software



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October 18
Decline in WPM

January 19
Anarthric

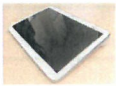


June 2018
100% Comprehensible Ambulatory & active

October 2018
100% Intelligible 110 wpm Ambulatory & active

January 2019
0% Comprehensible Anarthric Ambulatory but +progression of LEs developing

5-month hiatus

- TobiiDyanvox Indi tablet: "Too heavy"
- Boogie Board
- iPhone with lanyard + Speech Assistant (TTS)
- iPhone with Speech Assistant
- TobiiDyanvox I-Series trials (eye-tracking access)

*pALS accept augmentative-alternative communication 96% of the time (Ball, Beuke/Man, & Pattee, 2004)

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March 18
Diagnosis

October 18
Decline in S/PML

January 19
Anarthric

August 19
Not managing secretions

Mr. C - "I'm literally drowning all day."

- Primary complaint: **secretion management**
 - Absent cough (bulbar/CN X involvement)
 - Mechanical Insufflation-Exsufflation ("Cough Assist") ineffective
 - Suction limited to oral cavity/oropharynx
 - Failed: papaya enzyme, atropine, glycopyrrolate, N-acetylcysteine, Botox to parotid/submandibular glands
 - Good oral care, no PNA
- Fall 2019: Referred to Otolaryngology Team for consideration of **elective total laryngectomy**
 - Garvey et al. (2009): pALS is aphonic, dysphagic, +tracheal aspiration

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March 18
Diagnosis

October 18
Decline in S/PML

January 19
Anarthric

August 19
Not managing secretions

September 19
Referred to ENT

Winter 2020, now 56 years old

- Profound bulbar dysfunction
 - Anarthric
 - Oropharyngeal dysphagia
 - Absent cough
- Gastrostomy tube
- Progression to the limbs but still engaged in some activity
 - TobiiDynavox I-Series
- Requiring BiPAP q.h.s.
- FVC: 62% on 6 Jan 2020
- Wife continues as excellent caregiver/advocate
- SLP Pre-Laryngectomy Counseling

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Pre-Laryngectomy Counseling by SLP

- ✓ Total Neck Breather
- ✓ No restoration of swallowing
- ✓ Secretion production & management
- ✓ Psychological considerations
- ✓ Aphonia – no restoration of voice source

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March '18
Diagnosis

October '18
Decline in WPM

January '19
Aphonia

August '19
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September '19
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Pre-Laryngectomy Counseling by SLP

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- ✓ No restoration of swallowing
- ✓ Secretion production & management
- ✓ Psychological considerations
- ✓ **Aphonia – no restoration of voice source**

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Decline in WPM

January '19
Aphonia

August '19
Not managing secretions

September '19
Referred to ENT

January '20
Total laryngectomy

Mr. C, post-op

- **Total laryngectomy 28 January 2020**
- Establish means of communication
 - Inpatient recovery = perfect time to work on AAC
- Provide extensive training to spouse
 - Management of new airway
 - Facilitation, editing of AAC
- Facilitate ongoing psychology/counseling

HAVING A
COMMUNICATION
DEVICE DOESN'T MAKE
YOU AN EFFECTIVE
COMMUNICATOR ANY
MORE THAN HAVING A
PIANO MAKES YOU A
MUSICIAN.
(BEUKELMAN, 1991)

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• Tobii Dynavox I-12
speech-generating device with
eye tracking access

January 2020
0% Comprehensible

Anarthric, surgically
aphonic

Progression to limbs,
requiring alternative AAC
access



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Eye-Tracking on Training Wheels: Switch to click



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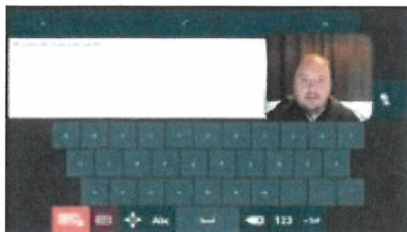
Communicator 5 *Speak* keyboard



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TobiiDynavox Dwell-Free keyboard



[Link to this YouTube Video Demonstrating TD Dwell-Free Keyboard](#)

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"Other losses are simpler and more incremental. Sometimes they are nothing more than adaptation and sometimes, like the loss of my voice, they are devastating."
 – Joe Hammond, pALS

<https://www.thevoice.com/handout/2018/01/16/voice-loss-for-pals/>

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References

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- Garvey, C. M., Boylan, K. B., Salassa, J. R., & Kennelly, K. D. (2009). Total laryngectomy in patients with advanced bulbar symptoms of amyotrophic lateral sclerosis. *Amyotroph Lateral Scler*, 10(5-6), 470-475.

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