

# Goals of Care Discussions in a Patient with Locked-In Syndrome and Hearing Loss

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## Learning Objectives

- LIS, along with other neurological conditions, pose significant communication barriers to providers
- Cost, availability, and feasibility prohibit the widespread use of high-tech AAC despite their evidence-based benefits
- Incorporation of high-tech AAC into routine clinical practice will help maintain patient autonomy and comfort, two critical aspects of Palliative Medicine

## Introduction

Locked-In Syndrome (LIS) is a devastating neurological disorder which produces significant communication deficits while preserving cognition, creating substantial barriers for providers. [1] Unfortunately, high-tech Augmentative and Alternative Communication (AAC) tools aimed at overcoming such barriers, remain limited in clinical utility by cost, feasibility, and access. [1-3] This case outlines goals of care discussions in a patient with LIS and bilateral hearing loss and the implications of these barriers.

## Case

A 53-year-old female presents with severe hypertension and sudden onset LIS accompanied by bilateral sensorineuronal hearing loss. CT head without IV contrast demonstrated central pontine intracerebral hemorrhage (see Figure 1).

Given the uncertainty regarding the patient's neurological recovery, goals of care discussions became paramount in guiding further care. Due to scarcity of additional resources, communication was limited to index cards with "yes-or-no" questions, to which the patient answered by blinking. A set of screening questions such as age, date of birth, helped validate the communication method and the patient's cognition.

With the patient's permission, her family was allowed at bedside to participate in the discussion, though strict

Input Tool	Description	Utility
BCI	Visual stimuli (such as letters) induce brain wave potentials which can be translated into verbal responses	Aiding patient with severe movement impairment (e.g., LIS, ALS) in developing speech
Eye-Tracking	Visual stimuli (live objects, images, words) can be targeted by patient's gaze	Rapid, simple communication in patients with severe motor impairment but preserved cognition (limited by easy fatigability)
Supplemented Speech Recognition	Interpret language of patients with underlying speech impairment based on speech algorithms	Comparison of patient's speech to algorithms based on others with similar conditions (CVA, cerebral palsy, GBS)

Table 1. AAC Description (adapted from Koch-Fager et al. (see References)).

BCI: Brain-Computer Interface

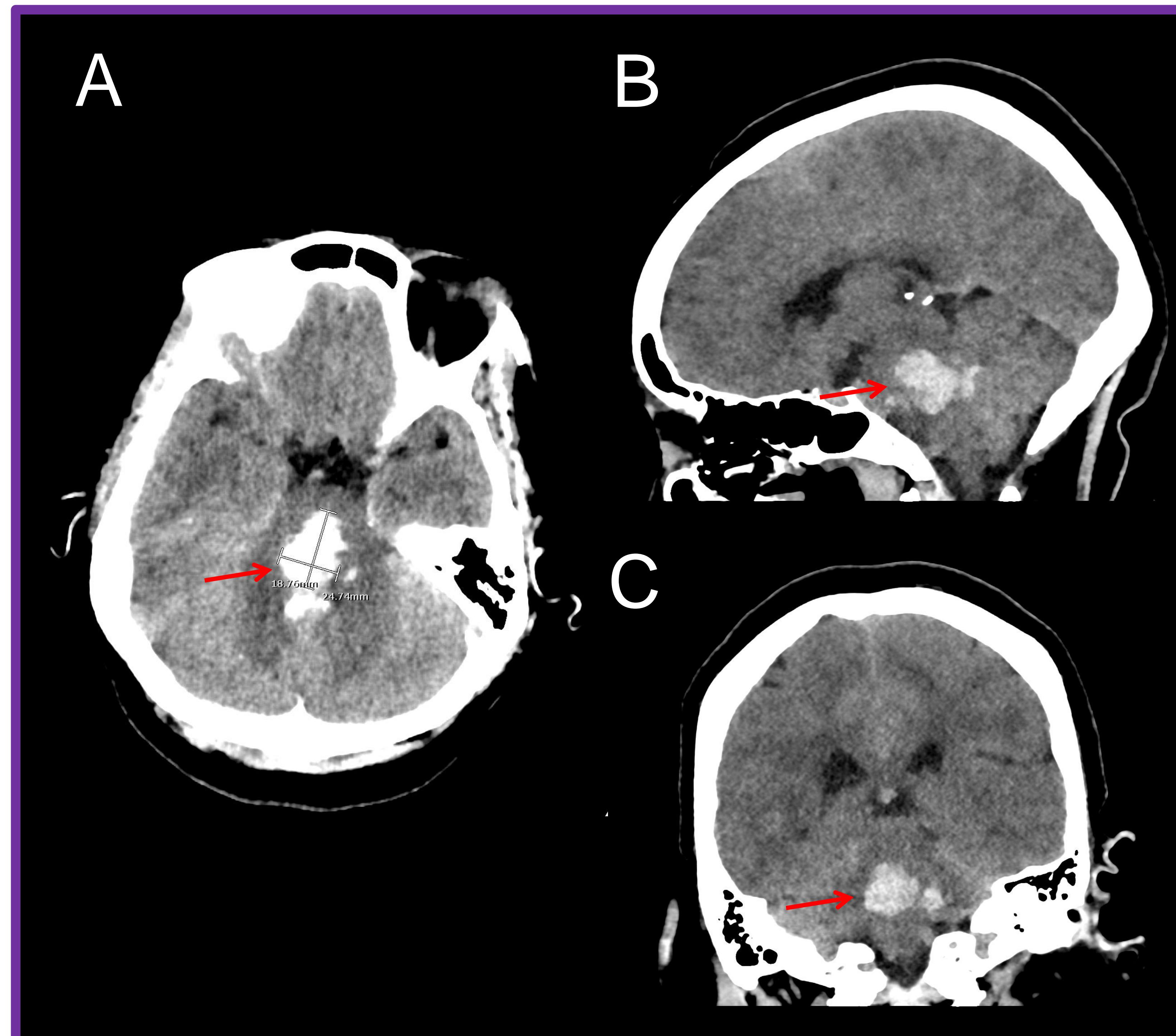


Figure 1. CT head without IV contrast demonstrating evidence of pontine intracranial hemorrhage with surrounding vasogenic edema (A – axial; B – sagittal; C – coronal)

## Case Continued

limitations were in place due to the concurrent COVID-19 pandemic. Through these techniques, the patient's clinical status was discussed in detail, resulting in a change in her initial decision of pursuing comfort-based measures of care to pursuing full restorative therapy.

## Discussion

Due to the inaccessibility of high-tech AAC, communication was limited to simplistic methods as outlined above, which came with important inherent flaws. First, the subjectivity of manually interpreting eye movements leads to the possibility of falsely interpreting involuntary eye movements, theoretically limiting their validity and reproducibility. Furthermore, the binary nature of the response system did not lend itself well to the inherently sensitive and complex nature of goals of care discussions.

High-tech AAC tools such as Eye-Gaze Deviation Measurements and Brain-Computer Interfacing (BCI) represent a group of more robust communication methods which reduce potential for bias and oversimplification raised above (See Table 1). [2] Their use in LIS and similar conditions such as Amyotrophic Lateral Sclerosis (ALS) and Cerebral Palsy have been associated with improved quality of life, caregiver satisfaction and maintaining patient autonomy and comfort. [4-10] This is particularly relevant given new data suggesting very few LIS patients exhibit a willingness to die, with the majority never considering euthanasia and none having a Do Not Resuscitate (DNR) order. [1,11]

## References



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