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Preface

The connection between an understanding of the mechanisms underlying human communication and advances in electronic speech generation and microcomputers offers us the possibility of enhancing acutely ill patients' ability to communicate and control their environment. This book is the product of a collaboration of a psycholinguist with a tendency to be a tech-nerd and a speech-language pathologist with many years of experience working with children with developmental disabilities. The development of our program for implementing alternative and augmentative communication (AAC) in intensive care settings is the result of an evolutionary process. The principles underlying our approach emerged from the convergence of our individual learning trajectories. This book provides both the technical details related to our implementation of AAC in the intensive care units at the University of Iowa Hospitals and Clinics (UIHC) as well as the particular principles and strategies that we have found might enhance the communicative abilities of critically ill and often intubated patients. We feel that we learned a great deal from each case and to that end we include an account of a number of individual cases that we feel illustrate some key issues that can determine the differences between success and failure.

Psycholinguists are trained to design and execute experiments that often include presentation of speech materials and recording behavioral responses with an assortment of switches. As such, they

have familiarity with the software and hardware issues that are entailed in AAC systems designs. Many years ago, a colleague inquired whether somewhere in Hurtig's little black bag of switch technologies, he could find something for a young child with severe limitations due to cerebral palsy. The request was not to figure out how to connect this child to a traditional AAC system but rather to see if he could give the child control of an electronic toy. From his perspective, the task was fairly trivial and involved simply taking a large microswitch and using it to close the circuit from the batteries to the toy's motor. Today, numerous commercial products are available to give children with limited motor skills the ability to control toys and other electronic devices in their environment. The child and her parents were delighted, and more importantly, the child had the ability to demonstrate intentionality and the potential to use some form of AAC system. This case illustrates the important connection between the ability to control one's physical environment and one's ability to participate in effective communication.

Without language, we are limited in how we function in our environment. Language enables us to extend our reach and ability to meet our physical and psychological needs. Even though I am healthy, my height may preclude me from reaching and obtaining objects I desire that are placed on upper shelves. In the most narrow context, my linguistic abilities enable me to seek the assistance of

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others; in a broader context, language allows me to collaborate with others to develop a tool that would allow me to independently get the objects that my physical limitations would otherwise preclude. Children learn that they can get what they want equally well by moving their limbs or by moving their articulators to produce an abstract code for speech, signing, or writing. It all becomes so automatic that we are rarely, if ever, conscious of the interplay of what we do directly and what we accomplish through the use of language. Even our use of language is tied to context, such that the message is not necessarily coded entirely in the string of speech sounds or signs we produce. We see this interplay in a mother's ability to respond to her infant's cry, not because the child has differentiated a "hungry" cry from a "pick-me-up" cry, but because of an understanding of the temporal context in which a cry occurs. At perhaps the other extreme of the lifespan, one can get one's spouse to bring a desired object without using the object's name or a specific referent marker by saying "get be the thingamabob from the whatyamacallit." Again, it is the reading of the context not the parsing of the linguistic string that leads to the effective communication. Similarly, we encounter lots of cases where an individual might say "your tone of voice told the whole story" or "your face betrayed your true meaning." What is important to take away from such observations is that, when we are confronted with the loss of our primary communication channel and we seek a substitute, we often forget that our other channels of communication might have remained intact. In this technological era, we sometimes mistakenly believe that the device or prosthesis replaces the

entire communicative ensemble rather than just a single component. If your facial muscles are intact, why give up the easily produced "furrowed brow" that can quickly and effectively communicate your state of mind. It is remarkable how many individuals who are introduced to alternative and augmentative communication systems focus on laboriously producing an utterance to describe their reaction rather than utilizing the simpler and often unambiguous facial gesture. A hallmark of our approach to implementing AAC is that we try to always remember this dynamic interaction of the diverse behaviors that make up human communication. Regardless of whether we select a high- or a low-tech AAC system, a major part of an effective solution is getting users to recognize the need to combine the technology we offer them with whatever residual components of natural communication are still under their control.

Imagine that tomorrow morning, when you awaken, you are not in your bed at home but rather in an unfamiliar setting surrounded by people and sounds that are totally alien to you. What makes things worse is that you have no idea of how you got there and you quickly realize that (1) you can't move your arms and legs, (2) you can't talk because there is an endotracheal tube in your mouth, and, (3) there appear to be catheters and lines penetrating your entire body.

- How do you find out what happened and more importantly what will happen to you?
- How do you let people know you want to participate in decisions about your medical care?
- How do you assert yourself so that the medical staff and family and

friends know what your wishes are with regard to your care and treatment options?

- If you had the foresight to have left an advanced medical directive or living will, how do you let people know that you have prepared such a document and that it outlines the procedures you approve of and those you wish to decline?

One problem with advanced medical directives is that we often write them when we are in good health and have defined “quality of life” from an able-bodied perspective. That perspective makes some interventions like ventilatory support and tube feeding unacceptable and justifies “do-not-resuscitate” orders. But things may look very different from the perspective of the hospital bed or wheelchair. Having changed one’s perspective and as a consequence one’s wishes, how do we communicate what we want done here and now in the intensive care unit?

AAC was developed to allow individuals with either developmental or acquired communication disabilities to effectively communicate in a variety of settings. Over the history of AAC, resistance to alternatives to natural speech often has kept individuals from being afforded the benefits of AAC systems. This can be seen in the reluctance of parents to have their children use low-tech language boards or any system that would not lead to the use of natural speech. Likewise, individuals with acquired communication disorders have been reluctant to accept having to give up use of their natural voice. In both cases, it is the belief that AAC can only yield a limited form of communication with a broken form of language. Some of this reluctance to accept AAC systems, low- or high-tech, can be attributed to

the belief that communicative autonomy cannot be achieved with any system that does not allow novel utterance construction. Parents of children with developmental disorders as well as adults with acquired disorders worry not only about the limitation on expression, but also about the stigma that using an AAC system may impose. These are legitimate concerns but ones that can be addressed by system design, appropriate training, and counseling.

The process of doing an evaluation for AAC candidacy and the construction of a system for a particular individual is seen as a complex process requiring both considerable expertise and time. As such, it is not one which is undertaken unless there is both a reasonable expectation that the individual would benefit from having an AAC system and that the time and resources are available to undertake the effort of designing and implementing the system. Individuals with short life expectancies or individuals whose communication disabilities are seen as temporary are not often considered candidates for AAC. But the need for these individuals to communicate is no less than that of any other nonspeaking person. Because of the longstanding belief that significant time and effort are needed to successfully implement an AAC system, working with such patients has not been seen as an effective use of resources. The successful use of AAC by many nonspeaking individuals with degenerative diseases like amyotrophic lateral sclerosis (ALS) has in part called into question many of these longstanding beliefs about AAC.

Critically ill patients tend to experience a range of unfamiliar and often upsetting communication problems caused by potential cognitive, sensory, or language

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barriers that distance them from their family and caregivers. Many of these “voiceless” patients often reported having experienced feelings of anxiety, insecurity, and panic during their stint on mechanical ventilation (Bergbom-Engberg, 1993). The nursing literature notes the use of non-vocal behaviors (i.e., mouthing words, gestures, and head nods) as primary modes of communication used by critical care patients. Inconsistency in the choice of communication mode as well as a great deal of variability in nurses’ and family members’ abilities to lip read or interpret gestures can create confusion and frustration for critically ill patients, families, and caregivers during what may be viewed as the most critical period of the patient’s life. Given the medical and psychological state of such patients as well as the transitory nature of their limited communication, addressing their communication issues has not been a high priority of most hospital based speech-language pathologists (SLPs). However, the patients, family members, nurses, and others involved in the care of such patients must cope with the less than optimal communication that is a consequence of intubation and ventilatory support. Although complications with and limitations of communication in the critically ill had long been ignored, they are emerging as a treatment priority for critical care units (Menzel, 1994). The physical limitations of patients in critical care units often leave them unable to express themselves in any consistent manner and as a consequence they cannot participate effectively in their care, medical decision making, and in critically important emotional and social interactions.

The Joint Commission of Accreditation of Healthcare Organizations (JC)

now mandates that all hospitals identify the communication status of each of their patients at admission (JC requirement [IM.6.2], 2005). AAC systems can provide a means by which individuals can alert healthcare staff of their physical and emotional needs (e.g., pain, positioning, or respiratory care) with the added positive outcome of a reduced need for restraints and sedation. Thus, the use of AAC can empower patients with no functional speech and/or minimal control of motor function to become active participants in their medical care. By enhancing communication and independence in critical care units, AAC should reduce the anxiety patients often experience. Thus, the time for introducing AAC systems in acute care settings is now.

This book characterizes the issues and problems associated with the implementation of AAC in acute care settings. The presentation is based on data from over 200 cases in which some form of AAC was implemented at The University of Iowa Hospitals and Clinics (UIHC). We also include some case presentations to illustrate some of the issues that we have encountered and the implementation strategies that we have developed.

An extensive historical perspective of AAC can be found in Zangari, Lloyd, and Vicker’s excellent paper (1994) and in Beukelman and Mirenda’s text (2005). An important part of the recent history of AAC is the expansion of the etiologies of individuals that may benefit from AAC. As both assistive technologies have evolved and our awareness of the populations that can benefit from their implementation has grown, the place of AAC in the SLP’s scope practice has become more explicitly defined. Both the American Speech-Language-Hearing Association (ASHA) and the Council for Clinical

Certification (CFCC) have identified AAC among the knowledge and skills requirements (KASA) for clinical certification in speech-language pathology.

To assist the reader in implementing AAC in acute care settings, we provide a large number of illustrations of both hardware and content solutions that have emerged from our experience. The companion DVD provides full color versions of all of the illustrations in the text as well as a number of video clips that illustrate a number of bedside assessment strategies and AAC implementations. We

had the good fortune to be able to shoot many of the bedside images and the videos in the UIHC Clinical Nursing Education simulator facility. Because of patient confidentiality and privacy issues, we have opted to mostly use healthy volunteers for most of the illustrations and video clips. We do want to thank one patient for granting us permission to use a few images of him in this text. The companion DVD also provides many examples of communication board layouts that can be implemented with a range of AAC systems.

5 Switches as the First Step to Establishing Communication

The first step to establishing communication is getting the attention of a communication partner. When we are in earshot and in the line of sight of someone we wish to communicate with, we can use sounds and gestures to alert them that we need something or that we want to communicate. Hospitalized and bedridden patient may need to get the help of medical staff who are not at the bedside; thus, they may not be able to use the conventional means of initiating communication. For the hospitalized patient, being able to summon the nurse is an essential need. JC requires that each patient have access to an operational nurse call system. It is very common to see signs posted at the bedside to remind patients to use the nurse call rather than try to do something on their own and potentially fall. There are many alternatives that have been implemented in hospitals around the United States. They range from simple mechanical switches that plug into the headwall (Figure 5-1) and that are wired to the nurses station (Figure 5-2). When the patient activates the switch, a light illuminates outside the patient's room (Figure 5-3) and an audible alarm goes off at the nursing station (Figure 5-2). The call light remains illuminated until it is cancelled by the nurse on a panel in the patient's room (Figure 5-4). In settings where there is an intercom



Figure 5-1. Push button nurse call.

that links patients' rooms to the nursing station, nurses may respond to patients' calls from the nursing station. In such settings, the nurse call may be integrated into a pendant that includes an intercom and controls for the bed, room lighting, and a TV (Figure 5-5). In some settings, these functions may also be incorporated into the bed rail (Figure 5-6).

The standard nurse call systems assume that a patient can activate the free-standing mechanical switches or the buttons on the pendants or on the bed rail and that they can hear and respond to the nurse over the call system intercom.



Figure 5-2. Nurse station call enunciator.



Figure 5-3. Nurse call door illuminator.



Figure 5-4. Nurse call panel on head wall in patient's room.



Figure 5-5. Nurse call pendant.

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Figure 5-6. Bed rail nurse call button.

For the patient with limited sensory or motor abilities and who may not be able to speak, these systems pose a serious challenge. Such patients are anxious about being left alone and may attempt dangerous maneuvers to attract the attention of the nurses. Likewise, family members of such patients are also hesitant to leave the room for fear that their loved ones might not be able to summon help if needed. Situations such as these can lead to the development of an unhealthy codependency relationship, which may not be conducive to the long-term rehabilitation of the patient. For family members to be of assistance in the care of patients, it is essential that they get adequate rest and nutrition and that they can attend to their affairs outside the hospital. For the patient, being able to rest and to have some solitude may also be critical.

This may be particularly important to adolescents for whom “privacy” is perhaps most highly valued.

Because of the mechanical simplicity of nurse call systems, it is difficult for able bodied individuals to see how a simple switch may be difficult for a patient to access. Nevertheless there are many patients who are unable to use nurse call systems in their standard configurations. The most common cause of failure to access the nurse call is less related to the patient’s abilities than to the placement of the switch or call pendant. Often, after some bedside treatment or after the patient has been repositioned, the staff or family members forget to place the switch or call pendant within the patient’s reach. In such scenarios, when the patient has some motor skills they might attempt a dangerous maneuver to reach

the switch. Alternatively, they may resort to shouting for the nurse. The latter strategy may unintentionally violate politeness conventions, disturb other patients, and result in a less than cordial relationship between the patient and the staff.

Some patients discover less disturbing alternative means of signaling for help. These may involve pushing something off the bed tray or the bed itself. These are not terribly effective as the sound may not carry, and once the item has been dropped, it cannot be retrieved to be used again. Like the call pendant, the nurse on coming into the room may place the object out of reach so that "it would not be dropped again." This is often the case when the object that was dropped was a urinal or telephone. Some patients have been known to ask for a bell or a rattle (e.g., beads in a specimen cup) that they might use as an alternative. In all such cases, the key to access is the care that nurses and family members take to make sure that whatever the patient uses is within reach.

Some patients on monitored units and who might be on ventilators discover that small positional changes can set off alarms. A small head position change can shift the position of the endotracheal tube and break the seal of the inflated cuff, which will set off a ventilator alarm. Agitated patients have been known to pull on the vent line and break the connection to the endotracheal tube or tracheostomy in order to set off the alarm to get the attention of medical staff. The risk of self-extubation is that such behavior creates often results in the patient being put into physical restraints and/or sedated. In many cases, the gesturing toward or tugging at the vent line is not an attempt to extubate, but the only means available to a patient who is merely trying to get attention.

Some hospital beds are equipped with sensors that detect if the patient attempts to get out of bed and then signal the nursing station. Compliant patients nevertheless have discovered that some positional changes, short of getting off the bed, will also set off such alarms. Patients' use of positional changes to use the alarms as an alternative nurse call system may be misinterpreted. Like the risk of self-extubation, the risk of leaving the bed may result in the use of physical or chemical restraints. Patients whose blood oxygen levels are being monitored with a pulse-oximeter quickly learn that if the sensor on their finger or toe is shifted slightly, the oxymeter alarm is activated and can be used to summon the nurse. Unfortunately, this can also be misinterpreted as equipment failure and result in either a silencing of the alarm or a more secure taping of the sensor on the finger and toe.

The problems related to accessing the nurse call system that many patients face result from either the failure of staff and family to ensure that the nurse call switch is within reach of the patient or the patient's failure to activate the nurse call because of limited strength, limited mobility, or excessive tremor. The former problems can be addressed with adequate staff training and family orientation to the need of never leaving a patient without checking that he or she can access the nurse call and that the call system is properly functioning. As simple as this may seem, the inability to reach the nurse call continues to be a problem in most hospitals and care facilities. Addressing the latter problems requires access to alternative nurse call technology or the ability to make modifications to existing systems that will enable the physically challenged patient to use them effectively.

NURSE CALL SYSTEMS: ALTERNATIVES AND MODIFICATIONS

The key to a successful alternative nurse call system is the identification of a switch or switch technology that the patient can activate. The most common alternatives to the nurse call pendant utilize either a pull cord or a simple push-button switch.

- The pull cord is perhaps the original nurse call system. In its mechanical version, it was connected via a pulley system to ring a bell at the nurses' station. The principle is identical to that used in "maid and

butler" call systems in upper class Victorian homes. The pull cord requires the patient to pull on the cord much the same way a pull cord on a lamp or ceiling fan is used. This approach requires the patient to be able to grasp the cord and pull with sufficient force to close the micro-switch installed in the headwall that closes the call circuit at the nursing station. One can still see such pull cord calls installed in doctors' office examination rooms as well as in rest-rooms and bathrooms (Figure 5-7).

- Simple push-button switches are usually held in the hand and activated by depressing the push button with the thumb. Patients need to be able



Figure 5-7. Nurse call pull cord.

to generate sufficient forces to press the button (450–470 g). Straps and or splints can be fashioned to hold the switch in the patient's hand (Figure 5-8) and keep it positioned where it can be activated with a simple movement of the thumb.

Two additional alternatives are commonly available for use in hospitals:

- One is a pneumatic bulb switch (Figure 5-9) that can be plugged directly into the headwall, assuming that an appropriate jack has been installed. This switch requires the patient to be able to squeeze the bulb at the end of the switch tubing (270–300 g). Like other nurse call systems, successful implementation requires the placement of the bulb where the patient can reach it.
- For patients who lack fine motor skills or the strength to use the pneumatic bulb switch, the use of a pressure plate switch (Figure 5-11A) should be considered. The standard nurse call pressure plate switch can be positioned so that any part of the body, that the patient can move and

Clipping the cable to the bed sheet is the most common approach.

When the patient is concerned about being able to reach for the bulb and when the patient lacks the motor skills to keep the bulb in the hand, the bulb can be secured in place on the patient's palm with a strap/splint or with tape (Figure 5-10). In a few cases, where the patient has no use of his or her hands, the bulb can be positioned so that the patient can grasp and squeeze the bulb with his or her lips.

- For patients who lack fine motor skills or the strength to use the pneumatic bulb switch, the use of a pressure plate switch (Figure 5-11A) should be considered. The standard nurse call pressure plate switch can be positioned so that any part of the body, that the patient can move and



Figure 5-8. Hand strap switch.



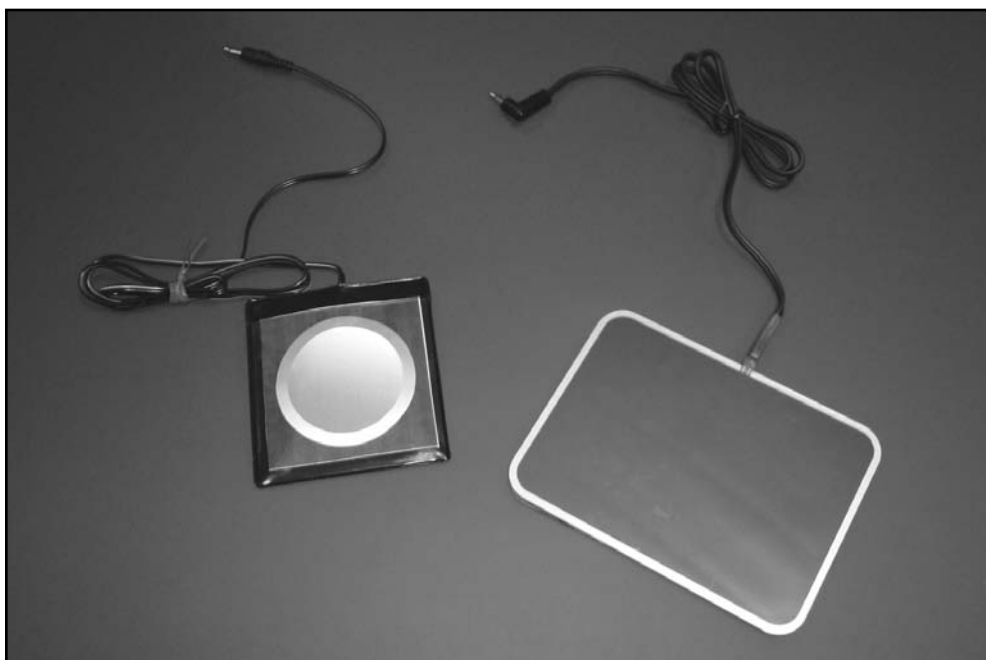
Figure 5–9. Pneumatic bulb.



Figure 5–10. Bulb with hand strap.



A



B

Figure 5–11. A. Pressure plate switch. B. Pressure plate switch.

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exert a minimum of 300 to 700 grams of force with, can be used. Pneumatic versions of this switch may require anywhere from 900 to 1000 grams of force. For many patients these standard call switches require too much force and one should consider substituting pressure plate switches

typically used with AAC systems, some of which only require 34 grams of force (Figure 5-11B). Key to the use of this option is proper positioning of the switch so that patients can use the arm, leg, or head to activate the switch (Figures 5-12A, 5-12B, and 5-12C).

**A****B****C**

Figure 5-12. A. Arm switch activation. B. Foot switch activation. C. Head switch activation.

When none of the standard options discussed above can be used, alternative switch technologies that have been used in traditional AAC applications can be adapted to control the nurse call systems.

STANDARD SWITCHES

- **Jelly Bean/Spec Switches:** These are mechanical switches (Figure 5-13) that come in a range of sizes can be used much like the push button and pressure plate switches. These switches varying in the force and displacement required to activate them. These switches would be plugged into the headwall jack in place of the standard call switches. Like the conventional switches, proper placement for access is critical.
 - **Rocker Switches:** These mechanical switches have a central fulcrum (Figure 5-14) so that a movement
- to one side or the other closes a different switch. Such switches allow the user to control two devices or a device that accepts dual inputs.
- **Tongue Switch:** This small switch (Figure 5-15) has a small coated lever that can be displaced by a movement of the tongue. This switch must be placed in close proximity to the mouth so that the tongue can reach the lever.
 - **Sip and Puff Switches:** These switches (Figure 5-16) utilize either the mechanical pneumatic principle used in the pressure bulb switches or an electronic pressure sensing circuit. These switches can respond to both positive pressures (puffs) and negative pressures (sips), thereby allowing two alternative responses with a single switch. In these cases, the straw at the end of the tubing must be positioned so that the patient can grab it with his or her lips.



Figure 5-13. Jelly Bean/Spec switch.



Figure 5–14. Rocker switch.



Figure 5–15. Tongue switch.



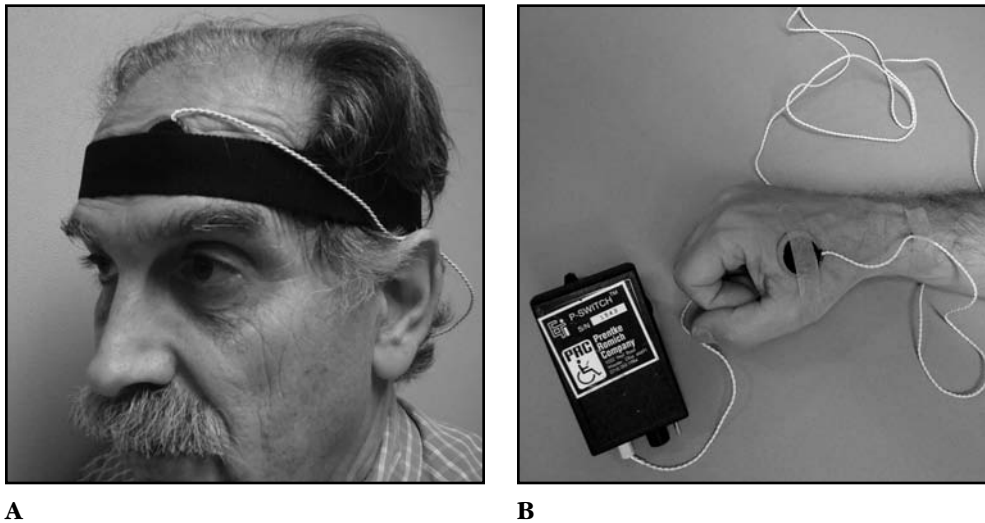
Figure 5–16. Sip and puff switch.

ADVANCED TECHNOLOGY SWITCHES

- **P-Switch:** This switch (Figures 5-17A and 5-17B) responds to small muscle movements. Its small circular transducer can be placed on the skin over the muscle that the patient can intentionally twitch to activate the switch. Common placements include the forehead where a rapid raising of the brow can be used or on the hand where a thumb movement can be used. This switch responds to the velocity rather than the displacement, so a slow movement will not activate the switch.
- **Charge Transfer/Proximity Switch:** These switches respond to the body's natural capacitance (Figure 5-18).
- **IR-Blink Switches:** These switches utilize infrared (IR) light reflection to detect motion (Figures 5-19A and 5-19B). An infrared light source illuminates the target area and an infrared detector sense the reflection of the infrared light. When used as a blink switch, the change in reflectance associated with eyelid movement can be used to trigger the switch. The problem with most such switches is that they cannot distinguish the natural blink from the intentional gesture. Such switches can sometimes be adapted for use on other parts of the body. In this case,

They sense the capacitance and only require that some part of the body come in close proximity to the switch plate. No force is required to activate the switch.

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A

B

Figure 5-17. A. P-switch forehead activated. B. P-switch hand activated.

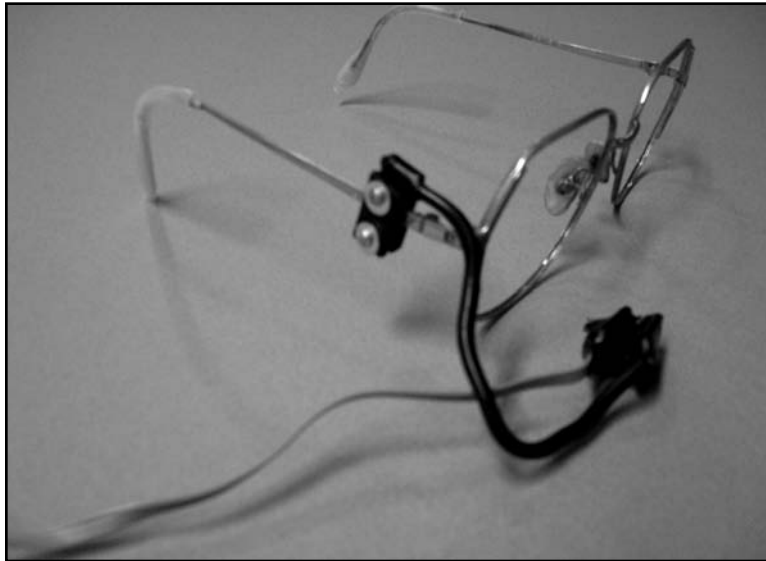


Figure 5-18. Charge transfer/proximity switch.

the voluntary movement by the patient changes the distance between the IR source and the body surface reflecting the light.

- Voice-Activated Switches: These types of switches utilize a Schmidt

trigger circuitry that senses the voltage change from a microphone signal. The onset of a vocalization causes a spike in the voltage that can be used to trigger the switch. A head-mounted microphone or a

**A****B****Figure 5–19.** A. IR blink switch. B. IR blink switch.

throat microphone can be used (Figures 5–20A and 5–20B). These switches sometimes are used in settings where the patient can make an abrupt sound by banging on a hard surface like the bed rail. This kind of

a configuration allows any physical gesture that the patient is capable of making to create the noise to trigger the switch. Of course, the limitation is that any abrupt noise in the patient's room will activate the switch.

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A



B

Figure 5-20. **A.** Voice-activated switch-throat microphone. **B.** Voice-activated switch-head mounted microphone.

■ Speech Recognition Circuitry

- Free-standing remotes with X-10 control options (Figure 5-21): Some universal remotes that are on the market allow the user to use voice commands to control a range of electronic devices including X-10 modules like the universal relay

module that can be interfaced with standard nurse call circuits

- Computer-based systems: PC-based systems using voice recognition software can be configured to control electronic devices using either an RF (radio frequency)- or an IR-control circuit that can



Figure 5–21. Voice-activated remote.

directly or through an X-10 system control a range of devices including the nurse call system. Windows XP now incorporates a voice recognition option. A number of home automation systems that are on the market provide “hands-free” control via X-10 modules.

- **Head Position Switches (Figure 5–22):** These switches sense the patient’s head position and can be interfaced with computers or AAC devices and function as mouse alternative. These switches either utilize a reflected IR signal or an RF signal picked up with multiple receivers mounted on a head band. The head movements are converted to the *x-y* movements of a conventional mouse. The head then can control the on-screen cursor. When used in conjunction with another switch, the patient has

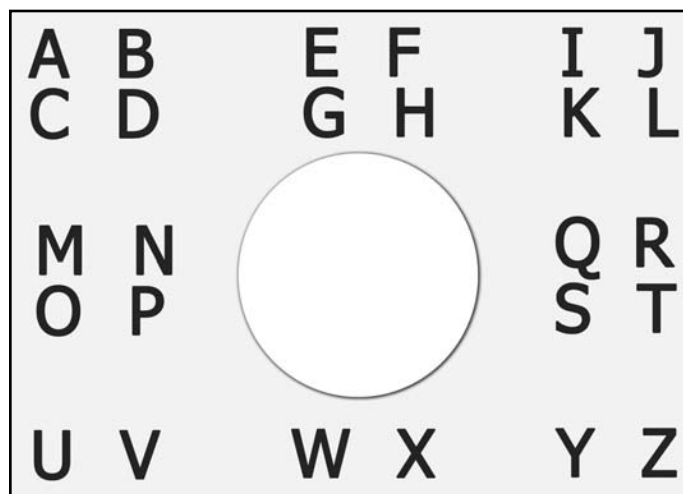


Figure 5–22. Head Tracker-SmartNAV.

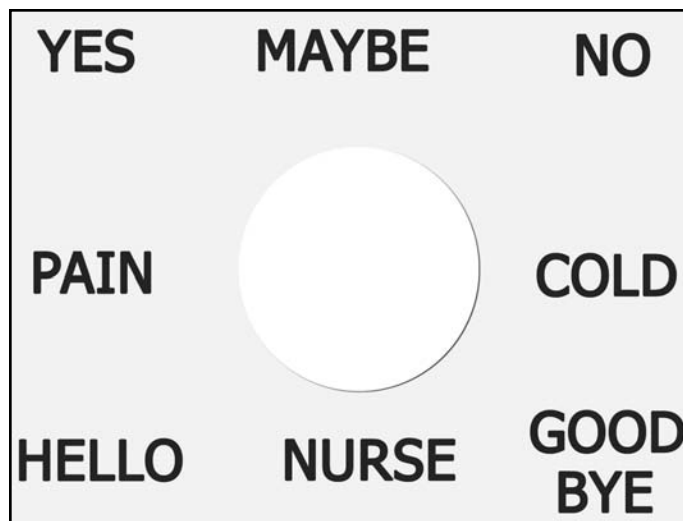
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a full mouse alternative with the other switch functioning as the mouse click. When no other switch activation is possible, the system software can be set to use a dwell function to serve as the mouse click. Thus, when the head is held steady for the specified dwell time, the software issues a mouse click.

■ **Eye Movement/Gaze Switches:** In patients whose motor abilities are restricted to their extraocular muscles, eye gaze is the only voluntary gesture that can be utilized. In such patients, gaze shifts are often utilized to indicate a simple yes/no response. The use of a Plexiglas ETRAN board (Figures 5-23A and 5-23B) allows



A



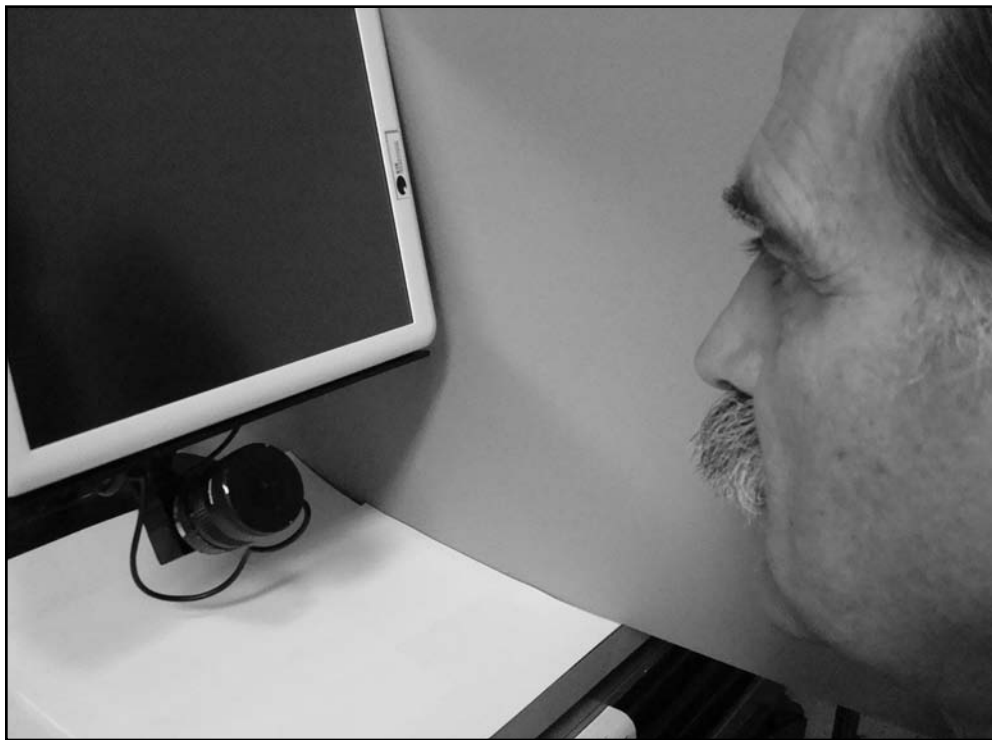
B

Figure 5-23. A. ETRAN—Gaze directed communication—alphabet. B. ETRAN—Gaze directed communication—phrases.

the patient to communicate with a trained partner by making selective gaze shifts to locations on the board on which either letters, whole words, or icons are displayed. When the ETRAN is laid out for spelling (see Figure 5-23A), the patient must make a series of directed gazes to identify the selected letter. For example, if the patient wanted to spell the word “dog,” in order to select the first letter of the word, the patient would first look to the upper left and then to the lower right. This system requires training of both the patient and the communication partners. Another key to successful use is the positioning of the ETRAN (see Chapter 7, Figure 7-3).

Until recently, transducing eye movements required expensive and complex laboratory based systems that required a great deal of effort to keep calibrated and as such were not available for use with patients. Newer video-based approaches to eye-tracking (Figures 5-24A, 5-24B, and 5-24C) have reduced the size of the system and the calibration problems. These systems, like the head position systems, allow eye gaze to serve as the control of the computer cursor.

Having an assortment of switches available will ensure that patients with a range of physical challenges will be able to access nurse call systems, patient-controlled analgesic pumps (PCAs) as well as a range of AAC systems. However, because of more severe limitations of their motor



A

Figure 5-24. A. Video eye tracker—ERICA. *continues*



B



C

Figure 5–24. *continued* **B.** Video eye tracker—Dynavox EyeMax.
C. Video eye tracker—MyTobii.

systems, some patients may need adaptations made to commercially available switches as well as to switch mounting systems that can keep the switches positioned so that patients can easily and reliably access them. These adaptations are addressed in Chapter 7.

IOWA SMART SWITCH

For patients whose voluntary movements are very limited and possibly obscured by tremor, most commercially available switches will either not detect the movement or be unintentionally activated by the tremor. The Iowa-Smart Switch (Figure 5-25) was developed to address the needs of such patients. To detect only the intentional gesture and not respond to tremor or unintentional gestures, the switch uses a small microprocessor to

process the transducer signals based on the kinematics of the intentional gesture. The switch was designed to accept inputs from pressure transducers, charge transfer circuits, and infrared detector circuits. This wide range of transducers allows for use of the switch anywhere on the body where a reliable movement can be elicited.

Like conventional proximity switches, the charge transfer circuit requires only minimal displacement and no force to activate. It senses a capacitance change when some part of the body comes into proximity of the switch. We have successfully used such switches with traumatic injury patients who are quadriplegic, with patients with progressive neurodegenerative diseases, as well as with patients who may be temporarily incapacitated. Because such transducers are extremely sensitive, the Iowa Smart Switch can be programmed to respond only to patterns



Figure 5-25. Iowa Smart Switch.

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of transducer state changes that fit the temporal kinematic characteristics of the intentional gesture. By setting both a minimum and a maximum time for a transducer state change, we can effectively preclude a tremor from activating the switch. The beauty of this approach is that we can detect a low amplitude gesture that may be buried in a higher amplitude tremor.

The pressure transducer circuit can either be used to detect small changes in oral pressure with either an open straw or with a sealed bulb. It can also be used to detect small forces that can be generated by any part of the body that is positioned to compress a sealed bulb. The Iowa Smart Switch can be programmed to accept only a particular change in pressure that has a particular time course. Thus, a patient can keep a small pressure bulb in his or her mouth and only activate the switch by squeezing the bulb with a certain amount of force or hold that pressure change for a designated time interval.

Finally, we have been experimenting with an infrared (IR) transducer circuit that also requires minimal force and displacement. Thus, any gesture that can create a tissue displacement or movement that results in a change of reflected IR, is

sufficient to activate the circuit. A common placement of such circuits is in proximity to the eyelids. In this setting, as the eyelid closes for a blink the amount of IR light reflected by the eyelid changes. In order to distinguish between an involuntary blink and an intentional wink, the Iowa Smart Switch can be programmed not to respond to the rapid sequence of reflectance changes associated with the natural high velocity blink or to the slow nonreversing reflectance change associated with drooping eyelids in a tired patient.

Thus, with the appropriate switch technology ranging from simple mechanical switches to microprocessor-based solutions like the Iowa Smart Switch, it should be possible to provide even the most physically limited patients with switch access as long as the assessment has identified a reliable voluntary gesture. Although solutions like the Iowa Smart Switch use the latest digital chip technology, they can only be successful implemented if the switch is mounted appropriately so that the patient's access to the switch transducer is maintained. Chapter 7 addresses the issues of finding an appropriate mounting system that will ensure that the patient has continuous access to the appropriate switch/transducer.

10 Bad News— Communication Issues

Sophocles gives us one of the earliest (442 BC) literary references to the problems of delivering *bad news*. Being blamed or worse, being killed, for being the messenger who gives bad news has been a recurring theme in eastern and western literature. Shakespeare makes reference to such unwelcome messengers in a number of his works (*Henry V*, Pt. 2 and *Antony and Cleopatra*). It is not just the potential of physical harm that messengers fear; it is also dealing with the psychological consequences of the message on those who receive it. The messenger becomes the “bad news” and so has to be the target to the reaction to the news.

Fear of a negative reaction often leads one to avoid talking about the possibility of a negative outcome. When there is no way to avoid talking, one is nevertheless torn about what to say and how to say it. We fear broaching the topic as well as how to respond when the topic is inescapable. Physicians, nurses, and family members are uncomfortable and patients often do not talk or raise questions for fear of having to confront the answers they will get. Everyone seeks the “right” or “good” way to deal with the *bad news*. Unfortunately, avoidance merely postpones the inevitable and delaying the news may do nothing to diminish its potentially devastating impact.

If one could, one would prefer to say “you will recover” or “you will live” but for many patients in acute care, the reality is that they may not leave the hospital with all their physical and mental functions intact. Life as they have known it has ceased. They may never walk on their own, breathe without the help of a respirator, or be able to talk and carry on the daily activities that defined their lives and identities. Unfortunately for some, even such a drastically altered life is not in the cards. For them, life will be measured in hours or days.

Conversations about dying are not easy, even when the patient is able to speak. All participants in such conversations weigh their choices of content and form and proceed with extreme caution. Each side is concerned about the feelings and reactions of the other. Often, once the topic of impending death has been broached, conversations move with greater ease.

For the patient who is incapable of speaking or writing without some form of assistive technology, the situation of dealing with “bad news” is all the worse. They have no way to indicate they understand what they are being told and no way to ask questions or express their feelings and wishes. AAC solutions can provide patients with an opportunity to participate in such end-of-life conversations.

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The problem is: how does one program an AAC system to allow for such conversations? Thus, we are burdened not only with how to tell the patient about his or her impending death but also with the challenge of what options to provide the patient so that he or she can play an active and interactive role in the subsequent conversations. The problem we face is that, just as there is no one perfect way to deliver bad news, there may be no single set of responsive options to provide in an AAC system.

In so many respects, the problem with the “bad news” scenario is no different from any of the other scenarios that we need to address in building AAC systems. The approach to building systems to deal with such scenarios needs to be based on an understanding of what a patient might want to know and talk about as well as how to give the patient a means of expressing his or her personal voice. Ethical and legal issues must also enter into how the systems are built and structured.

Let us start with these latter issues, as they necessarily influence how we will deal with the content and voice issues. The first and fundamental question deals with “who tells what to whom” (Fitch, 1994). In the typical American hospital, if there is such a thing, a member of the medical staff will meet with family members to deliver the bad news to them prior to delivering the message to the patient. Whether for fear of the “shoot the messenger” reaction or out of direct concern for helping people cope with the information, the task of being the messenger is left to the member of the care team who would have the most natural rapport with the family members. In some settings, more than one member of the medical team participates in such

meetings (Curtis, 2000, 2004; Curtis et al., 2001; Curtis et al., 2002). One may deliver the unwanted news while the others provide the hand holding and the shoulders to cry on. There is no question that there is wide range of how such meetings transpire. The range of empathy and an understanding of how the information in the message will be processed by the family members play a critical role.

A good outcome is not just a consequence of having empathy and being informative. We know it is painful to hear a loved one will die or be permanently disabled and we presume to know enough about the patient’s condition to explain the patient’s condition. Knowing the right message and the right way to deliver it often are more a function of who we have to tell than a function of the specifics of the patient’s condition. One of the most poignant examples of this can be found in the disastrous failure documented in Anne Fadiman’s chronicle of the miscommunication between doctors and a Hmong family in her book, *The Spirit Catches You and You Fall Down* (1997). Although the case Fadiman describes involves a collision of cultures, it points out that the assumptions that underlie doing the right thing need to be carefully thought through. In this case, a failure to understand who the medical team was talking to and how the messages they were providing were being understood led to a cascade of tragedies. All too often, the message is provided to whomever is available in the waiting room and does not take into consideration individual family and cultural traditions about medical decision-making (Waters, 1999).

In the situation where the communication must involve patients in acute care, who because of their medical condition

may not be able to speak or write, the success of that earlier conversation with family members is all the more critical.

In the case of children or adults who are deemed incompetent, there is a tendency on the part of many to take the position that they need not get the whole bad news. This is often a joint decision taken by family members and the medical team. With infants and toddlers, the bad news message is never delivered. With young children, there is great reticence to deliver the message, and with adolescents and teenagers, there is trepidation about the reaction to the message. The decision about whether or not to deliver the message is based on feelings that the child might either not grasp the import of the message or that the child would not have the means to psychologically deal with the import of the message. The risk of not having the bad news conversation is that given the nature of acute care and the patient's condition there is a likelihood that the news will slip out in unintended ways at inopportune moments when the patient's family and primary care team may not be available to cushion the blow. A lot of individuals come in contact with patients, many of whom may not be part of the primary care team or immediate family. These individuals may or may not be aware of what the patient knows. Statements they may make directly to the patient or in conversations they may have with others that may be overheard by the patient can "spill the beans" with all the negative consequences. In one case, while the parents and medical team were discussing a teenager's prognosis and how to tell her about her condition and the treatment options, a surgical resident entered the patient's room to do a prebiopsy exami-

nation and proceeded to discuss the procedure and the possible outcomes of finding evidence of lymphoma. The patient's reaction and screams could be heard by the horrified parents and medical team in a conference room way at the other end of unit. This patient had the means to communicate her reaction to the *bad news* and had the means to participate in the subsequent discussions about the treatment protocol and its potential outcomes. What would have happened if she had no means to communicate? This case exemplifies the need to make sure that everyone is aware of what a patient has and has not been told.

In the case of competent adults, the tendency is to provide them with information about their state as soon as it is available. Prior discussion with family members often occurs and delivering the news is often done in their presence. The desire to not be the lone messenger delivering the bad news often postpones the message until family members can be present. The problem that often arises is that the patient's care is ongoing and everyone on the unit may know of the patient's condition with the exception of the patient. So, as in the case of the child with lymphoma, some trauma patients in acute care settings discover that they may have a life-threatening condition or that they will be permanently disabled from interactions with medical staff who are unaware of what the patient has or has not been told. In both the accounts of Julia Tavalaro (1997) and Jean-Dominique Bauby (1997), there are instances in which they recount their reactions to such indirect ways in which they learned of what people thought of their conditions. In their cases, their inability to speak or write left them helpless and

unable to either solicit corroboration of the information or to engage in a conversation in which they could express their feelings or engage in an active way in their treatment.

In Bauby's case, individuals would tell him things but not solicit any response or acknowledgment of comprehension from him. In a scene in the film based on Bauby's book a physician entered his room and in a cavalier manner said that he would have to suture one of Bauby's eyes shut; the doctor then proceeded to do it with no thought of Bauby's reactions or desires. To make things worse, the doctor talked about coming back from a great vacation skiing. Remember Bauby is a locked-in syndrome patient who cannot move anything but his now single open eye.

In our society and dominant culture, patient autonomy is considered highly important. Except for young children and incompetent adults, in the end, it is the patient who should decide what treatments to accept or reject. Thus, we accept that the patient plays a significant role in decisions about whether they should be resuscitated in the case of cardiopulmonary failure or whether they should receive transfusions. Where this construct of autonomy faces the most challenges is in cases where decisions involve the withdrawal of life support. Here, moral and ethical beliefs of patients, family members, and medical staff often collide and the belief in patient autonomy may not trump these other beliefs (Waters, 1999). Who decides whether a ventilator-dependent patient does or does not continue to be kept on the ventilator? There are many who might want to keep the 'truth' from the patient. This can place staff and family members in an ethical dilemma (Fowler, 2004).

Assuming that a patient can neither speak nor write, the challenge facing the person designing the AAC system for the patient is how to provide an easy way for the patient to actively participate in what may be "end-of-life" or "end-of-life as you have know it" conversations. To meet this challenge, it may be useful for the communicative needs of such conversations to be broken down into expressions of comprehension, expressions of reaction, and expressions of desires.

Expressions of comprehension are those that allow patients to affirm not only that they have understood what they have been told about their condition and what the prognosis is, but also allow the patients to ask questions to gain a further understanding of the situation. For example, a patient who has been told that he has sustained a spinal cord injury that has resulted in his being placed on ventilatory support may, in order to truly understand his situation, want to ask whether he will have to stay on the ventilator. Expressions of reaction are those that allow patients to let people know how they feel about the news they have received. Understanding how a patient is psychologically responding to the situation may play a critical role in the approach to treatment; including, among other things, management of depression and anger. Finally, and perhaps most importantly, expressions of desires allow the patient to become an active participant in critical decision-making about treatment goals.

For the patient who is limited to providing a gaze shift response to indicate yes and no, the approach to giving the patient the ability to provide these three different types of expressions will be limited to how well the conversational partners are able to construct their ques-

tions so that the patient's communicative needs are addressed. The following is an example of an interaction with the patient and how such questions may be structured.

Staff: Hello Mr. Jones, we have some things we would like to tell you about your condition. So that we are sure you understand what we are saying and so we can know what you want, I will be asking you some questions. I want you to respond using your yes/no response of looking up for yes and down for no.

Patient: (looks up)

Staff: We have reviewed the x-rays of your spine and it looks like you have sustained some significant damage. The reason you are on the breathing machine is that the nerves that control your breathing have been damaged. Do you understand what I am saying?

Patient: (looks down)

Staff: You sustained damage to the control of the breathing system, so the machine is doing the breathing for you. Do you understand?

Patient: (looks up)

Staff: Right now we don't know if you will be able to breathe on your own. Do you understand?

Patient: (looks down)

Staff: Is there a question you want to ask me about that?

Patient: (looks up)

Staff: I will try to guess what question you want to ask. Okay?

Patient: (looks up)

Staff: Are you asking if you will need to stay on the ventilator?

Patient: (looks up)

Staff: We don't know at this point if you will be able to breathe on your own. I know this must be upsetting.

Patient: (looks up)

Staff: Do you have any questions you want me to address?

Patient: (looks down)

Staff: Is there anything else you want me to explain?

Patient: (looks down)

Staff: We'll let you rest now. Okay?

Patient: (looks up)

This first conversation allowed the bad news to be presented and afforded the patient an opportunity to indicate a level of understanding, a reaction, and some control. However, one should not assume that the patient has a full understanding of the gravity of the situation or of the consequences of maintaining or withdrawing ventilatory support. Any decisions about maintaining or withdrawing treatment require repeated conversations that should be witnessed by a number of individuals including family members so that there is a consensus on how the patient responded. Just as with advanced medical directives, in these situations one should always attempt to verify the patient's choice prior to taking action.

One of the questions that is very difficult to ask is: "Do you want to have life support withdrawn?" It is a difficult question for all involved and unfortunately is one that ends up needing to be asked in

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situations where there is disagreement among family members about the wishes of the patient with regard to end-of-life decisions. In one case, that we refer to as the "dueling siblings" case, a retired gentleman fell and sustained severe spinal cord injuries. He was effectively rendered a quadriplegic and could not breathe on his own. The two daughters differed radically in what they thought their father would want. One said that her father had been a vigorous and active man who would not want a vegetative existence. The other said that her father was a fighter and that he would never want to give up no matter what his circumstances. Each daughter wanted to be the decision-maker and each could not accept the decision of the other. The nursing staff, on the basis of their interactions with the patient, was confident that the patient was sufficiently aware of his situation and needed to be part of the conversation. It was apparent to the impartial observer that he was tracking the situation and that he was distressed by the siblings' conflict. The Assistive Technology Service established a communication system that allowed the patient to demonstrate a level of competency that would indicate that he could participate in these end-of-life decisions. The outcome was as good as one might hope. The patient indicated that it was his wish to be withdrawn from life support. By itself, that was comforting to one sibling and accepted by the other. However, giving this intubated patient a means of communicating allowed him not to only play a significant role in this most difficult situation but it also enabled him to indicate what he wanted each family member to do after his death. In the end, it was the ability to have those final wishes made explicit that left the

patient, family, and staff able to accept the outcome of withdrawing life support. In this case, perhaps because all parties respected the patient's right to autonomy, everything worked. However, there are many cases where the outcome may not be so well accepted.

When everyone genuinely accepts the patient's right to participate in the decision, then posing the question of withdrawal of life support can take the form of asking the question and verification that the patient understands the consequences. In situations where one party or the other questions the patient's ability to rationally decide, the form and content of the alternatives presented to the patient become controversial. Some might argue that the patient can only be asked if he or she wants to live and that, by asking a question about withdrawing life support, we are unduly directing a patient or putting words in the patient's mouth.

In a similar vein, some might argue that, no matter how alert and competent the patient may appear, there is no way they can give truly informed consent to have life support turned off. However, it is unclear that family members under stress are in any better position to do so. For most people, patients, and family members, this is a novel and most likely unplanned for situation. They do not know what questions to ask or really understand what all the alternatives are. Typically, hospital staff, from their experiential base, lay out the possible scenarios for the family members.

So why is laying out the options on a communication board for the patient any different? The key is that everything should be contextualized for the patient. Just as hospital menus are tailored to the dietary needs/restriction of patients, communication boards also need to be

tailored to a patient's particular medical status. One would not want a patient to first encounter the possibility that they are dying by reading across the set of utterances on a communication board and seeing the phrase "Am I going to die?" On the other hand, it is a legitimate question that many patients want to ask. So how and when does one give a particular patient access to such a question? A good rule of thumb in making decisions about the content of an AAC system is to determine that the patient understands how an AAC system works and that the selection options are to give the patient the widest range of options given the knowledge of what other patients in comparable situations have asked and wanted to talk about. What that means is that if one makes the phrases "I want to be taken off life support" and "I want to be kept on life support" available, then one should provide an explanation of why they are included and that they are there so that patient can indicate what he or she wants.

If a patient is limited to asking yes/no questions, then one has to consider how to ask the question. For many patients unfamiliar with physiologic systems, their answers to the question "Do you want to live?" may not be the same as answers to "Do you want us to keep you on the ventilator?" So it may be prudent to approach the end-of-life decisions from a range of questions rather than a single one focused on the withdrawal of a medical intervention. Likewise, for patients who can use an AAC system, it is essential that they have the multiple response options available to them. So, as painful as it may be for family members to see some of those phrases in the AAC system, it needs to be presented as a means to provide an opportunity of

expression that a patient with the ability to speak would normally have. Absent a technology that can read the patient's mind, alternative message options are the only way to ensure that a patient can make his or her wishes known. A set of options for a communication page for potential end-of-life conversations may, among other things, include:

Questions:

How bad is my situation?

Will I be able to breathe on my own?

Will I be able to move my arms and legs?

Will I be able to eat regular food?

Statements:

I want to live.

I want to live no matter what.

I want to stay on life support for now.

I want you to do whatever is necessary to stay alive.

I don't want to stay on life support for long.

Take me off life support if . . .

Take me off life support, I want to die.

It is probably unwise and insensitive to generate a one-size-fits-all template to use with all patients facing an end-of-life decision. How these options are actually phrased and organized, as well as how the context for the end-of-life conversations is presented, all need to be informed by the physical and cognitive state of the patient and the family members as well

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as their cultural background and its approach to death and dying. The only way to avoid the pitfalls exemplified in the case of the Hmong child with epilepsy (Fadiman, 1997) is to ask questions and be attentive to the responses of the patient and family members when confronted with elements of the bad news. Most importantly, one needs to think twice before proceeding with an approach if responses do not seem to fit with our expectations.

Although we accept that we often have no way of knowing enough about any individual patient or family to anticipate every issue that might come into play in the *bad news* scenario, many clinicians have never systematically considered how a bad news scenario would play out in their own family. It may not seem natural to think about how you might tell your child, parent, or other family member that they are dying or that they will be permanently disabled. Thinking about how you would approach such

a situation not only gives you a sense of what your patient's family members may be experiencing but also lets you make explicit what you might consider your options to be. To get a patient's perspective, think about how you would want to get the bad news if you were the patient and consider what kinds of follow-up questions and discussions you might want to be able to participate in. Considering these scenarios in the abstract may provide only a loose approximation to the real cases one would encounter in clinical practice. We should not succumb to the societal reticence to talk about death and dying. We need to consider how we would talk with our patients and their families and how we would construct an AAC system for a patient. If we do not do this, we are likely to stumble at a time when there may be no time for a second chance. Our patients and their families may not be prepared for the bad news conversation, but we cannot afford not to be.