

American Speech-Language-Hearing Association

Last Words, Last Connections

How Augmentative Communication Can Support Children Facing End of Life

by John M. Costello

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I first began working with a boy with juvenile Huntington's disease when he was 12 years old. He is now 17, and is still actively followed by our palliative care team. During those five years, there were many times when it was unclear whether or not he would have a tomorrow. At those times communication played a vital role. He now uses limited phonation and intonation and is not using speech; with this disease, the ability to communicate can vary day to day. His messages have changed as he matured and his communication tools have ranged from a high-tech speech-generating device to simple eye gaze displays. But the spirit of those messages has remained constant—all are about connecting with loved ones, soliciting information, gaining comfort, maintaining control, and preserving dignity.

— Author, Children's Hospital Boston

Communication is the thread that connects us with one another. Without it we are isolated, alone, and unable to affect the world around us. This is particularly true for patients at the end of life, many of whom are severely compromised in their ability to communicate. Speech-language pathologists are gaining increasing recognition for their care of adult patients as they approach the end of their lives. Much less attention is paid to the role SLPs can play in supporting children with communication needs who are facing end of life.

The literature on communication and end-of-life care is rich with references and models related to intra-team communication, communication of difficult news, or enhanced listening skills by medical personnel. The most frequent role of the SLP in end-of-life care most often described in the literature relates to the treatment of dysphagia. Scant research exists that acknowledges the crucial need to support the communication needs of a child whose ability to speak is compromised.

Although data vary widely regarding the incidence of communication problems of adult palliative-care patients, one study by Jackson et al. (1996) suggests that 27% of patients who died during an 18-month period had communication difficulties; another study, which focused on patients with head and neck cancer, reported that 53% of patients had communication difficulties (Forbes, 1997). No similar studies have been completed on pediatric patients.

AAC Strategies for SLPs

Mack and Wolfe (2006) suggest that palliative care starts at diagnosis for some young patients. This timing is imperative not only because a disease course may have a defined pattern of progression, but also because in some cases a slow, progressive decline may accelerate unexpectedly. Speech-language pathology services provided as early as possible will support the child's efforts to maximize his or her communication potential and continuity of care as the child's skills diminish with the progression of the disease (Salt et al., 1999).

Communication vulnerability may be a changing condition for a person living with a life-limiting illness based upon variables including alertness, medications, and memory (Jackson et al. 1996); poor breath support and motor control for speech (Salt et al., 1999); and word-finding difficulties, disease progression, fatigue, swelling, or sores of the mouth or airway (Costello, 2000). As a result, the need for augmentative communication may be consistent or intermittent at the end of life.

The SLP should consider a broad range of augmentative and alternative communication (AAC) strategies to accommodate the needs of children whose health status may change and who have different developmental and psychosocial needs. For some children, it may be appropriate to use a multiple-message voice output display using personal-voice banked messages ([see sidebar](#)); others might use a single-message voice output aid, a talking photo album, or a non-electronic picture communication display. One child may use all of these tools and strategies at different times of the day and throughout the illness process (Hemsley & Balandin, 2003); another may use a single AAC strategy.

To ensure that a patient has the maximum opportunity to communicate with loved ones and caregivers at the end of life, it is essential that AAC strategies be made available whenever possible. Although each young patient's messages are unique—one child may say, "Hold my hand," and another may say, "Go, Red Sox!"—the core need for connection remains constant.

The following are common communication themes that have emerged in the intervention process in our clinical practice at Children's Hospital Boston:

Support autonomy when possible. Ill children frequently want to have some control over their illness and treatment and want to participate in the planning and delivery of their health care. Although young children may not decide whether or not they have chemotherapy, a child could make decisions such as who accompanies him or her to treatment or the schedule time (Orloff et al., 2004). Further, AAC strategies allow children to influence behavior of others. Vocabulary such as "not now" or "come back later" can help a child regain a sense of control over his or her environment. One of my young patients was Daniel, a 16-year-old boy with ataxia telangiectasia and chronic lung disease, who struggled with his body image as he experienced dramatic atrophy. Using a voice output communication aid with 20 recorded messages, he repeatedly selected the message, "Do not look at me!" which allowed him to assert himself and exert control in a difficult situation.

Provide care information and encourage the patient's questions. Studies suggest that children who are provided with relevant health care information report less pain and anxiety than peers who are less informed about their care (Christiano & Tarbell, 1998). In addition, a patient's ability to ask questions and solicit information about daily routines, medical care, and status is an essential coping strategy.

The need for information is illustrated in one case study of a young patient treated in our facility:

Six-year-old Renna, who had an astrocytoma of the cerebellum, used a simple voice output communication aid that featured one large target and provided a different recorded message each time it was selected. The messages included questions such as "What is my schedule for the next two hours?" and "How am I doing?" Although it was unclear whether she cared about the specific questions, Renna showed improved coping skills when able to initiate and solicit information throughout her day.

Encourage children to talk about their experience of illness with the realization that young children understand pain and death differently than older children and adults. "Magical thinking" (Hecker, 2004) is a

key characteristic for many children who are cognitively younger than 8–9 years. A child may believe, for example, that a change in behavior will influence the course of the disease ("If I don't tease my sister, I will get better") or that people in authority (parents, physicians, teachers) have the power to take away the illness.

Further, death and mortality are understood differently across developmental stages. According to Himebauch and colleagues (2004), children from birth to 2 years of age have no cognitive understanding of death. The magical thinking of children cognitively aged 2–6 years contributes to a belief that death is temporary and reversible. Children ages 6–8 years understand death as final but do not believe it can have personal meaning or that it can happen to them. Children who are cognitively 8–12 years of age understand death is final and universal but may not be able to address their emotional response or think deeply about death. Adolescents between 12 and 18 have an adult understanding of mortality and may address the emotional and existential implications of death. It is important for SLPs to keep these developmental distinctions in mind; for children younger than 12, for example, it may be most helpful to support communication about the child's concrete experience of illness.

But a child's developmental stage can present some difficult issues, as the father of a 6-year-old son with diffuse pontine glioma recalls:

As Sammy lost skills, he needed to talk about it. It was through his talking that we could understand how he was processing his illness. He would describe each loss like it was going to be a part of his future. When he had difficulty walking and needed a wheelchair, he seemed pretty accepting and said, "I can't walk anymore." But then he asked me if he could have a power chair when he grew up.

Support self-expression. Authentic self-expression is achieved through the precise integration of the intended message, the words one chooses, the intonation and inflection of delivery, and the actual voice. When the SLP is involved early in end-of-life care and AAC strategies are introduced, a child may be able to communicate more authentically through the progression of illness.

Vocabulary selection. When a child partners in selection of vocabulary for an AAC system, a richer, broader, and more personal vocabulary will be achieved. Although vocabulary needs will change with the course of the illness, three general message categories emerge among Children's Hospital Boston patients: personality and social connectedness, psychosocial/emotional needs, and medical care.

Message/voice banking. "Losing my voice is like being stripped of my personality," said one 14-year-old girl with chronic respiratory distress secondary to cystic fibrosis. When a speech-language pathology consult is provided early in the disease process, a child can record or "bank" messages in his or her own voice (see sidebar at left).

Maintain social and emotional ties. Children may focus more on social connectedness and less on the physical condition or medical management as their disease progresses; this trend is suggested by data on vocabulary selected and used by selected patients at Children's Hospital Boston. Messages such as "I love you," "Stay with me," or signature expressions ("Wubby wubby woo-woo") that have personal meaning to the most intimate communication partners are more frequently accessed.

The mother of a 7-year-old girl with astrocytoma of the thalamus told me that she will always remember her daughter's final words communicated through AAC:

The "I love you" button is what I remember most about J's communication in the end. Every time she hit that, she knew we were going to come and hug her and hold her. She used it all the time, and she used it the night before she died. It was her way of making sure we were with her until the very end.

Encourage reflection on positive memories. Augmentative communication may help some children tell stories about happier times or reflect with loved ones on positive memories. The following is an example of how a family misinterpreted the behavior of a child at Children's Hospital Boston before he received communication support through AAC:

K., a 9-year-old boy with a large extended family, showed little interest in communication. His family remained extremely attentive; despite this, K. would become extremely upset when his family excitedly discussed memories of vacations and holiday events. Initially this was interpreted as K.'s distress at being unable to participate in these events because of his illness. When provided with a way to actively contribute to the reminiscing, however, he became animated, relaxed, and happy. His communication tool was a talking photo album. K. selected numerous photos to be included in the album and co-constructed with family members his intended message corresponding to each photo. K. became an active member of his family discussions. His parents reported that he refused to let the photo albums out of his reach. When he died, his mother reported that K. had been the happiest she had seen him just a few days before his death because he could tell stories of happier times that made everybody laugh.

Concern for those left behind. Children facing death are concerned with those left behind. In a plenary address given at Children's Hospice International, Lyman and colleagues (2008) noted that children who are dying express concern about what will happen to family, pets, and belongings once they are gone.

Supporting children who cannot speak to express these same concerns through AAC is critical to the emotional health of the child. As one mother recalls, "Every day for three weeks, she pushed the button that said 'Take care of Sissy' [family dog]. She needed us to tell her continually that Sissy would be okay."

Another mom struggled to decipher the meaning of her son's communication: "He kept hitting the button that said 'okay' and I didn't know why he was doing it because we didn't ask him anything. And then I realized, he was asking me 'Will you be okay?'"

SLPs may serve a rich and vital role in supporting communication for children living with life-limiting illnesses. Matching a child's strengths and needs to high technology, low technology, or no-technology solutions is an important operational component of this process. A vital responsibility of our profession is supporting the communication needs of a child to have control and to connect with loved ones in as authentic a manner as possible.

Through consideration of the developmental, psychosocial, and medical needs of each child in collaboration with the entire team including family, physicians, nurses, and other care providers, meaningful communication may be supported at this most important time.

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