

What Jenna Left Us

by Dr. Abby Barry Bergman, Principal, The Ralph S. Maugham School, Tenafly, NJ



The story of how a school community dealt with the death of a young child

[Excerpts of this article appeared in the Spring 2001 issue of Teaching Tolerance magazine, published by the Southern Poverty Law Center in Montgomery, Alabama, and are reprinted with their courteous permission. For more information and stories about free, high-quality tolerance education materials, visit their web site at www.teachingtolerance.org]

Kindergarten registration in April proceeded as it had for so many years-- anxious parents full of questions about our school and its programs, the bright faces of children eager to attend the neighborhood school they had heard so much about, and the teachers trying to "size up" their new charges and to learn as much as possible about the incoming crop of kids as quickly as possible. Then one day in May, news had come from a local nursery school, that one of our new registrants had suddenly become gravely ill. Jenna, one of the most enthusiastic pre-schoolers, was hospitalized after some strange symptoms revealed that she had an aggressive and inoperable brain stem tumor. Reports of her hospitalization and coma left little hope of survival. Yet, like as was the case in so many subsequent episodes, Jenna's strength prevailed. She rallied, miraculously was able to go to day camp, and was ready to attend kindergarten. A few days before the opening of school, Jenna's parents visited school with her and showed her the classroom. She was not to start school the first week; we wanted to prepare her classmates for what they would see-- a sweet, adorable little girl with a small hole in her neck (from the tracheostomy) who would be coming to school with a nurse who would be attending to medical issues throughout the day.

The Beginning of Kindergarten

Jenna arrived and was greeted cheerfully by her classmates, many of whom had known her in nursery school. She was well known as a "master colorist," whose pictures of rainbows had colors in specific sequence, form, and style. Jenna's friendly, accepting nature was contagious and her continual smile brightened the classroom. Everyone wanted to be her friend and the children were extremely tolerant of her whispered utterances and nonchalant about the regular suctioning and tube feeding that took place discretely in the classroom.

Continued strength and improvement of Jenna's condition was a gift we all celebrated throughout the year. We rejoiced when her tracheostomy was surgically closed and Jenna began to eat again, with relish and joy and her voice became stronger with each passing day. Ballet and karate lessons resumed and Jenna no longer needed a nurse at her side. All that was required now was a

part-time school aide who helped Jenna to negotiate the stairs in our building as her balance was still unsteady and she listed back and forth as she walked through the halls. The end of her kindergarten year held great promise-- Jenna was "beating the odds." Her condition improved so considerably, that we wondered if she would require any assistance at all in first grade. That summer, Jenna attended day camp, ballet classes, karate, and music lessons.

A New Year and New Vigor

A new school year was about to begin. Jenna's first grade teacher, Mrs. Ann Brown, a highly gifted educator, was briefed about Jenna's condition and the wonderful progress she had made. Just to be on the safe side, it was decided that Jenna's aide would start the year with her. In reality, this person, Noori Katehakis, also an extremely dedicated and compassionate individual, assisted Mrs. Brown and the rest of the children in the class; Jenna needed no special attention and didn't want any. Medical progress and academic progress occurred in good measure. Jenna's gait was becoming better each day and she was an avid reader. Her drawings were skillfully executed and many children attempted to copy her style. She began to write simple stories (no small accomplishment for a beginning first grader) and she read them to her teachers, parents, and friends.

Among the most common utterances of any elementary school principal is "No running in the hall!" One day in October, I was standing outside of my office and through the corner of my eye, saw a child scooting down the hall-- along came the standard admonition, "No running in the halls!" When I saw it was Jenna, though, I took great delight in witnessing who was breaking this essential school rule, and Jenna's mom who just happened to witness the scene, looked at me, and the two of us laughed and laughed and realized how grateful we were that Jenna was well enough to be the child who was indeed running in the hall.

A Sudden Turn for the Worse

Later in the fall, Jenna started to falter. She became nauseated in the morning, she stumbled and fell, her voice became weaker, and some of her academic skills showed signs of regression. Tests revealed that although her tumor had not grown, it had become more dense and thus exerted more pressure on her brain. New medications were going to be tried and little improvement was noted. If anything, Jenna seemed to be getting worse. Jenna's doctors determined that the only operation that might help was a "debulking procedure." Since her tumor was essentially inoperable, the debulking, by relieving the pressure on brain tissues might bring some relief. This was to occur just before our winter holiday break. In a barely audible voice, Jenna "called for a meeting" to tell her classmates about her upcoming procedure-- including more details than even an adult might fathom.

As a result of the kind of classroom community created by Jenna's teacher, the children were unusually empathetic, sensitive, and upbeat in their dealings with Jenna. Her medical problems were treated matter-of-factly and she was fully

integrated into classroom despite the medical attention that she required during the course of the day.

Jenna came through the operation, but the anxiety of other parents in the school and neighbors became apparent. Some called the office to say that Jenna was being "sent home to die; that there was nothing more that could be done." Others were more hopeful. As rumors began to spread, the need for accurate information became essential. I was able to contact Jenna's parents who simply revealed that Jenna had come through the operation and that they were hoping for the best. Finally, a conversation with one of the doctors at the hospital confirmed that although Jenna was still quite ill, she was sitting up in her bed working on a crafts project-- there was some hope for improvement.

Jenna Returns to School

Just as Jenna was unusually appreciated in our school, so too was she in the hospital. Her hospital room was like a mini-classroom-- full of stuffed animals, books, and the inevitable craft projects that Jenna did so well and with such unbounded imagination. We didn't expect to see Jenna for quite some time, but right after vacation, the first school day in January, Jenna miraculously appeared with one of the nurses we had come to know quite well. At first things seemed hopeful, Jenna came through the surgery quite well and was able to walk, although she needed assistance. New medications were to be tried to shrink the swelling of brain tissues. After a few weeks, though, it appeared that Jenna's condition was not improving. She was now barely able to walk, her voice was barely audible, and she had to overcome bouts of nausea before she was ready to come to school. Yet, Jenna loved school. It was the one place where she felt like any other child despite all of the equipment and medical personnel that accompanied her into the classroom. She thrived on the interaction of her classrooms and had formed a particularly close bond with her teacher who was extraordinarily committed to making Jenna's moments at school as happy and productive as humanly possible.

Jenna's health continued to fail. A round of experimental chemotherapy was suggested, but with the knowledge that it might not do any good. The nurses who attended to Jenna were free to share the details of this trial-- what the drugs were traditionally used for and what we might expect to see as the side effects of the treatment.

If the children were attending a special class, like music, art, or library, someone would always carry Jenna to other area-- most often her teacher. Still Jenna's indomitable spirit prevailed despite increasing obstacles. On Fridays, she joined the other girls who attended "Brownies" in the school gymnasium. She was an honored guest at birthday parties, and "play dates" continued throughout the winter.

Jenna's creative instincts were captured even when it became apparent she could no longer control a pencil. She would dictate her thoughts to her teacher and together, they would form the sentences. Her ideas reached paper. In order to execute the drawings that she used to do so adeptly and creatively, one of the classroom assistants or one of the nurses would draw, in the detail described by Jenna, just how these illustrations should look. If one line was out of place, Jenna would notice and suggest the correct placement as she conceived it.

The Downward Spiral

Despite our hopes and wishes, no one could deny the downward spiral we began to notice in the winter of Jenna's first grade year. She now felt sick most of the time, yet she still wanted to come to school each day.

The stress on Jenna's family was mounting. Well-meaning neighbors did not know exactly how to respond. The head of our parents association, in consultation with the school nurse and Jenna's teacher, decided to form an "assistance brigade." She developed lists of parents who were willing to shop for, prepare meals for, run to the pharmacy for Jenna's family, and help to care for Jenna's little brother. The community response was generous, sincere, and unflinching.

Soon, Jenna could barely get to school before 12:00 Noon. It would take hours to prepare for this still daily journey from home to school. Jenna would arrive, with one of her nurses (all of whom had become integral members of the school staff) and a large suitcase on wheels equipped with medications, suctioning devices, a portable respirator, and more. She was given a seat near the center of classroom activity-- where meetings and demonstrations occurred. Jenna always wanted to participate as fully as she could in any classroom activity. When she could no longer go to the lunchroom with the others, Jenna's teacher allowed one or two other children to stay behind to eat with Jenna in the classroom. The teacher made this always seem like a special privilege-- and indeed it was perceived as such. The nurses would always pack a special treat for the children who joined in these "private lunches."

In the winter months, the children in this class began to become more and more adept at writing stories. Jenna's story, "The Rainy Day," became a class favorite. It was about a mouse that wanted to go out and ride her bike, but heavy rain prevented the excursion. Instead, all of the mouse's friends-- in the form of other animals with names of children in the class-- came over to play at the mouse's house. Finally, as the weather cleared, the "animals" went outside to ride their bikes.

When Jenna's trial of chemotherapy began, it was clear that she was going to lose her beautiful hair. When this reality was evident, her ever-sensitive teacher declared a "crazy hat week," so all children would wear hats to school-- everyone had fun! Jenna did finally get a wig that resembled her lovely long-brown hair. To

an unimaginable degree, Jenna's teacher tailored classroom activities so that Jenna could remain a full participant. When it came to decorating a picture frame with stickers, an aide from a neighboring classroom sat beside Jenna and asked her where she wanted each sticker placed to complete the project to Jenna's satisfaction.

We were all able to maintain some joy with Jenna despite the fact that we were crying inside. I remember one afternoon when Jenna was unusually sick and needed to be in the nurse's office. This room was very close to her classroom. It was reported to me that one of the little boys in Jenna's class had gotten himself into trouble and was receiving a rather stern admonition from me outside of his classroom door. Jenna, despite her discomfort, had observed the proceedings and after I had sent the little boy back into the classroom, she asked her nurse to summon me to the office. Jenna's lively mind and curiosity prevailed; she just needed to know what had occurred! I explained that the boy had banged on and opened the door of the girls' bathroom. Jenna thought that this was hilarious and with the bit of energy that she was able to muster, she giggled at the whole ordeal.

Just before spring vacation in April, though, it became evident that Jenna's days at school were dwindling. She was vomiting for most of the few hours that she spent at school and despite continued physical therapy; she could not walk at all. We secured a special rolling chair (actually a secretarial chair) that enabled us to transport Jenna from place to place within the classroom and on the same level within the school. Right after spring vacation, it became apparent that Jenna was not going to be able to return to school.

The Writing Celebration

In April Jenna's class was ready for its second writing celebration of the year. Each child would demonstrate the book that he or she had created. These were special events with parents, grandparents, and siblings in attendance. The children sat before a microphone and read their illustrated books to those in the audience. We were all hoping against hope that Jenna might be able to attend, but she could not. Her teacher, read Jenna's story, "The Rainy Day," and videotaped the presentation. Everyone applauded and Jenna was later able to enjoy the rendering at home.

Preparing For the Inevitable

Jenna remained at home for the last week in April. Confined to her bed and now on a respirator all of the time, she still had visits from classmates and members of the school staff and community. One day, I called to ask if I might visit. Jenna's mother (one of the most dedicated and valiant women I have ever known) would always ask Jenna if she was "up to receiving visitors." The answer was yes, but Jenna needed to prepare for her guest. An hour later, with a few short books in hand, the visit began. Jenna was wearing a red velvet dress and looked like she was all dressed up to go to a tea party. She looked lovely--even with the

respirator pumping away. We shared a few books, a few pieces of classroom news, and the visit ended with her characteristic smile.

Jenna's teacher and the classroom aides visited Jenna almost daily. As she slipped into a coma, the eventuality of Jenna's death seemed certain. A great sadness came over the entire staff.

Throughout her illness, Jenna was a "classified student" entitled to special educational services, e.g. nursing, physical therapy, etc. She had been given the "label" of "chronically ill." Jenna's case manager thought that it was time to help the staff deal with the grief we were feeling. She arranged for a social worker from Cancer Care to speak with the staff one day after school. Teachers had questions about what to tell children in other classes that had lots of questions and their own set of associated fears. This proved to be a very valuable session; it helped the staff to collectively explore feelings, attitudes, and how best to deal with what now seemed to be a clear eventuality.

The children in Jenna's class could not help but wonder if she would ever return to school. Jenna's teacher and I discussed appropriate responses. The children were simply told that Jenna was very sick and did not seem to be getting better. When asked if she might die, we said, "Yes, that is possible." Through our research and discussions, we decided that it was best to answer children's questions-- simply and factually. We did not provide more information than the children seemed to require, but we did honor their questions and concerns and very deliberately kept lines of discussion open. We asked about what the children understood about the situation to make sure that we were clear about their own thoughts.

The is the basic information we provided:

- * Jenna has a brain tumor -- we explained in simple terms what it is
- * She is very sick now, and it does not look as though she will return to school
- * What happened to Jenna hardly ever happens to children; it is extremely unusual
- * It is not contagious

We were alert to fears that the children might have about their own health. I called local pediatricians to update them about Jenna's situation and to alert them to the possibility that some of their patients might be unduly concerned about lumps, bumps, and other conditions that might prompt children to think that they, too, might be in danger.

Very frank discussions started with children about death and appropriate books were secured and shared. Somehow, the children seemed to accept the fact that Jenna might die. Articles were shared with the entire staff and "a library" of resources was assembled in my office.

Parents, too, needed information. A letter was sent to the school community, informing them of Jenna's failing health, explaining what had been told to the children at school, and providing a list of books and resources that might prove helpful in discussing this matter with their children. Parents were advised to answer children's questions, yet not provide so much detail as to create fear and anxiety. We asked parents to discuss these issues in a manner that was consistent with their own social and religious beliefs.

Our Crisis Response Team plan was reviewed and updated. This is a group of pre-designated individuals charged with the responsibility of dealing with crises or natural disasters in the school and community. Coordination of support and information and the development of a plan of action is one of the primary functions of this group. Membership includes the school principal, secretary, key parents, classroom teachers, special teachers, the school nurse, and various guidance personnel including counselors, social workers, and psychologists. We knew that we would convene the Crisis Response Team as soon as we might receive word about Jenna's demise. The planning procedures and responsibilities of the Crisis Response Team were distributed to all members in anticipation of the final eventuality.

The "Awesome Day"

On a mid- May morning, just before dawn, I received a call from Jenna's teacher informing me that Jenna had died during the night. The members of the Crisis Response Team were called immediately. We were to meet at 7:00 AM to plan for this day that we had by now all sadly anticipated. Coffee was made, the school secretary brought in breakfast, and the members of the group arrived, one by one, into my office. No words were needed; we were all in this together, and we knew that our goal was to ensure that the children, the staff, and the members of the parent community were provided with accurate, helpful information, and the support needed to deal with this tragedy.

The first thing we established were the facts as we knew them: Jenna died peacefully in her sleep at about 3:00 AM, the funeral would be the next day, Jenna's parents welcomed all would like to attend the funeral. Strategies for how best to deal with the students and parents were next discussed. Three guidance personnel would be available throughout the day. At least two people would speak with Jenna's classmates-- their teacher and a psychologist. We identified children in the school who might be at risk due to their closeness with Jenna, their own emotional vulnerability, or other experiences with death that might be rekindled by this sad news.

We also discussed arrangements for closely-connected staff to attend Jenna's funeral and prepared a list of coverage for these individuals while they were away from school. Plans for what to tell the whole staff and when to meet were also drafted. Finally, we developed a list of "key communicator," i.e. staff members, parents, and administrators who would be available to dispense information and access support personnel as needed.

All teachers in the school met moments before the opening of school and they were provided with a bulletin outlining the sad turn of events as they entered the school. Guidance personnel were deployed by grade level and teachers were given the choice of whether they wanted to conduct conversations with their classes alone or along with support personnel. Signs of what to look for in children for whom this news might trigger other forms of grief were outlined.

As children entered the school, the news had already spread to some segments of the community. Parents congregated outside of the school office and support personnel were there to discuss their feelings, the appropriateness of whether or not children ought to attend the funeral, and the signs of stress to look for in children as a result of this news. A letter to all families was prepared including a list of suggestions for how to discuss this tragedy with their tragedy as well as list of resources for parents and children.

Among the points included in this communication were:

- * Speak to children in simple, truthful language.
- * Avoid euphemisms such as "She's gone to sleep and won't wake up." Young children take things very literally and such statements might lead to their own fear of going to sleep.
- * Give children the space and opportunity to express their feelings and LISTEN to what they say. Let the children "take the lead" in these discussions.
- * Mention that although we will never see a dead person again, we can share our happy memories of them.
- * Over a period of time, be prepared for more questions and concerns, especially as children process the information and their emotions.

Finally, parents were asked to call the school office if they witnessed any extreme reactions on the part of their children and to seek assistance from the support personnel who were made available to help us with this school crisis.

The parents who were members of the Crisis Response Team kept a reading of the "pulse" of the community and reported needs and concerns within the parent body. A meeting for parents to discuss how best deal with their children following

this sorrowful event would be planned. An evening session in which the three counselors, the principal, teachers, and parents came together to discuss the very sensitive topic of how to discuss death with children and what signs to look for that might signal more complex problems. We reinforced the fact that as time passed, children's reactions might change and new questions would emerge.

The announcement of Jenna's led to "an awesome day" for her classmates. As Jenna's teacher reported, there are many meanings for the term awesome, but it aptly described how the children spent their day. It was a day of remembrance, dignity, respect, and fun! After the children were told about Jenna's death, they began to discuss their fond memories of her. They sang songs, all day long, that Jenna loved. Through the halls, we could hear the children singing Louis Armstrong's "What A Wonderful World." The children sang with gusto and enthusiasm. Stories were shared throughout the day as they used the occasion to celebrate Jenna's spirit and contribution to the classroom community.

A special corner of the classroom, called "Jenna's wall," was set up. Children drew pictures of their times with Jenna, wrote notes to her and her family, and posted "artifacts" representing Jenna's influence on the class. Items were posted on Jenna's wall for the rest of the school year.

The Funeral

Jenna's funeral was a celebration of her short, yet significant life. Jenna's father asked key people in Jenna's life to speak at her funeral-- her relatives, nurses, friends, teacher, and me. Person after person spoke about the impact that Jenna had upon their lives-- how she made more of an impact in her brief six years of life than many people do in a lifetime. Everyone was amazed at her courage, strength, and creativity.

Jenna's parents provided a wrapped flower bulb for each person who attended her funeral. Members of the community gathered back at Jenna's home throughout the week to visit her family, offer words of kindness, and remember Jenna's short, but significant life.

Not one who ever believes in the supernatural, it was difficult for me to acknowledge what countless individuals had seen and reported-- for one week after Jenna's death, a rainbow was seen over her house. So real was this vision, that neighbors were called to stand at the front of the house to substantiate what so many others had seen.

The "Aftermath"

Jenna's presence in the classroom continued throughout the rest of the school year. Every year, each of our classes performs a play for the school. The first grade play was dedicated to Jenna and her mother mustered the courage to attend. Jenna's brother, Jesse, was registered for kindergarten and her parents

expressed (as they did so often) appreciation for the school's role in helping Jenna to attend class for as long as she did-- despite some of the medical complications.

Community members prevailed upon Jenna's family to establish a foundation in her name. Indeed plans for this effort were initiated when Jenna's death was clearly an imminent reality. Appropriately called "Jenna's Rainbow Foundation," contributions came pouring in. The primary intent of the foundation is to provide funds for children with terminal diseases.

Parents came to school and spoke with Jenna's teachers and me and thanked us for the dignified and sensitive way in which we handled all of the events surrounding Jenna's death. The community had felt supported and came together for a single goal-- to help Jenna's family and to support the children who unfortunately had to experience this tragedy in their young lives.

Each year, our parent body hosts a spring event for the community. It is a fun-filled evening of games, crafts, athletic events, and wonderful food with delicious dishes brought in by countless families. It is a major undertaking and helps to bring the school community together. One of the major activities of this event was the creation of "Jenna's Wall." One of the retaining walls behind a play structure was decorated with flowers painted by all of the children. Parents prepared the background structure for this mural scene and an inscription to Jenna was also placed in a corner.

At the end of the school year, the children in Jenna's classroom needed some "closure," for what they had gone through during the year. Another wall display on which children wrote more notes to Jenna, drew pictures, and recorded their memories was developed.

During the summer, Jenna's Dad came to see me to develop plans for the construction of a park on school property-- a gift that Jenna's family wanted to give to the school. The construction of this park is now in the planning stage and will undoubtedly become a lasting tribute to this girl whom we all so loved and admired.

The Memorial Ceremony

As a new school year began, we continued to talk about Jenna. We knew we needed to remember her in a concrete way--a way that our children might relate to. On November 5th of the year following Jenna's death, the day that would have been her eighth birthday, we gathered the entire school in front of "Jenna's Wall" for an official dedication. A group of talented violinists, accompanied by our music teacher, provided appropriate music as we assembled. We remembered Jenna, her spirit and all that she meant to us. After greeting the children and Jenna's parents, I reminded the children about the creation of "Jenna's Wall" and the beautiful flowers that she so loved to draw. Jenna's kindergarten teacher,

Michaele Salmon, was called upon to share her memories of Jenna's bright kindergarten year. Then Ann Brown re-assembled Jenna's class, spoke of the impact that Jenna had upon the group, and led the children in song. Of course, it was "What a Wonderful World." Then, Jenna's aide, Noori Katehakis, took Jenna's brother (now a kindergartner) and together they released a bunch of colored balloons. All the children turned their eyes to the sky as they watched the rainbow of color sail through the blue sky on this crisp autumn morning. Finally, all of the children, filed past Jenna's wall with a respect and dignity that was reminiscent of mature adults.

What We Learned from Jenna

Jenna gave more to us than any of us ever gave to her. She was the bravest and most valiant child I have ever known. She was a model of courage, dignity, and strength. She cherished her moments in school and was a full and active participant in classroom life-- she loved to learn, and despite tremendous challenge, she only wanted to attend school each day.

She engendered the love, joy, and laughter of her classmates and inspired all of us to gather strength from her own struggle. Her indomitable spirit prevailed and she never complained about the pain and discomfort she experienced.

Jenna's remarkable and extraordinarily gifted teacher and her colleagues created a caring, loving, and totally unique environment in which Jenna could learn and enjoy school and contribute substantially to classroom life. The modifications that she so naturally made in her program allowed Jenna to realize her fullest potentials despite her limitations and for her classmates to derive many benefits from this interaction.

It is no coincidence that on the last day that Jenna was able to be in school, she pronounced; "I want to be first grade forever."

Jenna taught us all of life's important lessons. She brought out the best in people and helped us to see how we could go on-- to grow and to learn despite tremendous obstacles-- and to have fun along the way. All of the children in Jenna's grade experienced the reality of death. Many came to understand death as part of a life cycle. They learned that we can live while dying.

It is so very unfortunate that we had to confront this death, yet what Jenna left us are rich, rich memories. This was an unique experience from which we all could grow and gather strength. The dignity and courage that she displayed is a model of all humanity.