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Schools ponder role as child nears death

Kids' Do Not Resuscitate orders prompt debate

By Jeff Long

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As the school bus rolled to a stop outside her Lake County home, Beth Jones adjusted the bright yellow document protruding from the pouch of her daughter's wheelchair, making sure it was clearly visible.

In bold letters it warned, "Do Not Resuscitate."

The DNR order goes everywhere with Katie, including her 2nd-grade classroom at Laremont School in Gages Lake. The school is part of the Special Education District of Lake County, where an emotional two-year discussion ended this summer when officials agreed to honor such directives.

Now, district officials find themselves in the unusual position of having planned the steps its staff will, or won't, take to permit a child to die on school grounds. Although DNR orders are common in hospitals and nursing homes, such life-and-death drama rarely plays out in schools, where officials realize how sensitive and traumatic the situation could be for nurses, teachers and students.

Katie's brain was deprived of oxygen before birth. She can't walk, talk or do anything for herself. She is fed through a tube in her stomach and has an increased susceptibility to infection. Violent choking and coughing spasms have signaled a turn for the worse in her condition.

A Do Not Resuscitate order is a doctor's directive, issued with the consent of the family, that cardiopulmonary resuscitation will not be used if the patient suffers from heart or breathing problems. It can also prohibit using such devices as a defibrillator or an intubation tube.

The new DNR policy puts Katie's school district at the forefront of a growing national debate about severely disabled and chronically ill children whose lives have been extended by medical advances -- and whose parents must face heart-wrenching decisions about the future. Two other pupils in the district have similar DNR orders.

The R in IRA stands for :

R

- a) Retirement
- b) Ron from Accounting
- c) Roll up in a little ball and cry

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Katie's order was put to the test last month, when she stopped breathing during class. Her lips turned blue and her skin took on a gray pallor. A teacher picked her up, as allowed by the DNR, and Katie soon started breathing on her own.

School officials called her mother, who arrived within 10 minutes. She brought Katie home, where a nurse from the family's hospice program met them.

"It was a little unnerving," Jones said. "It kind of put it all in perspective -- this is real."

The scare strengthened Beth and Dave Jones' resolve to face the death of their daughter on their own terms.

Although some school districts follow parents' wishes about DNRs, many others have not yet focused on how they will handle the issue. It's a topic school officials across the country are beginning to wrestle with, experts say.

In recent months, school boards in Hillsborough, N.J., and Visalia, Calif., have debated DNR orders. Milwaukee Public Schools updated its policy two years ago so that officials at least talk to parents about what's best for the child, even if the rule-of-thumb is not to obey a DNR.

Barring a court order, the policy in Chicago Public Schools is to ignore such orders and do everything possible to save a child's life, officials said.

The school debate underscores the struggle of parents as they try to imagine the unimaginable: How will their child die? Will it be on a gurney tethered to a cluster of machines that sometimes only postpones the inevitable or will it happen in their arms? A DNR order can help ease such worries, some medical authorities say.

"They have some control over this whole uncontrollable disease that their child has lived through," said Dr. Kimberly Battle-Miller, associate medical director of Hope's Friends, a hospice that has helped Katie and her family since April.

The Barrington-based hospice allows the child to remain at home rather than make frequent visits to a hospital, easing the emotional burdens on those closest to her.

On a recent morning, Beth Jones could readily see how keenly her daughter enjoyed her trips to school. The little girl was beaming up at her from her wheelchair as they waited for the bus.

"You're in a really good mood, aren't you?" Beth Jones asked her.

Two winters ago, Katie's parents felt far less in control of their daughter's fate. The child was near death every night for nearly three weeks. Katie's increasingly severe attacks were a sign that her condition had worsened.

"The light went on in my head," Dave Jones recalled. "This can't go on forever."

A friend -- a paramedic and the leader of Dave Jones' Bible study group -- mentioned that parents can face legal consequences if a child dies at home. If they dialed 911, the paramedics would swing into frenzied action with a swirl of invasive medical equipment and powerful drugs.

"The end result could still be the same, and you had the last few minutes with her as mad chaos, and her being whisked away in an ambulance," Beth Jones said. "We don't want that."

So in April, the couple met with Battle-Miller, who signed Katie's DNR order. They also discussed Katie's illness with the local fire chief to be sure paramedics understood their wishes. Then they met with school officials to plan what will happen if their daughter is stricken at Laremont.

Beth Jones will be called first, then paramedics, who will be on standby at the school in case Katie's mother decides that she wants them to intervene. Meanwhile, Katie will be moved to a nurse's office, shielding her from other students.

School nurses will be allowed to use suction to ease Katie's breathing and give her oxygen with a mask. The child can be positioned in a way that makes it easier to breathe.

But they will not perform cardiopulmonary resuscitation or use a defibrillator. Nor will they intubate her, a procedure that puts a flexible plastic tube down the patient's throat to provide ventilation.

"We're not just standing by doing nothing," said Susan Hodgkinson, nursing coordinator for the Special Education District of Lake County. "We're providing supportive measures. But most importantly, we are there loving her."

Some educators are concerned about lawsuits by parents who might later decide that something should have been done to save their child. They also "may be worried that a DNR order could be misinterpreted by medically untrained staff ... or they may worry that personnel would feel bound not to respond to an easily reversible condition," according to a study by the American Academy of Pediatrics.

Battle-Miller, who began as a pediatric critical-care doctor more than 10 years ago, has been baptized in the kind of emotionally charged emergencies that only the doctor, nurse or parent of a terminally ill child can ever really know.

Doctors, she said, are sometimes focused on one thing -- saving lives. They lose sight of the toll such action can take on patients and their families.

Taking a break from her shift on the pediatric critical-care unit at Central DuPage Hospital, Battle-Miller recalled children who were brought in for their end of life care. The doctors and staff, she said, didn't always know what to do.

She paused, thinking back on those early days of her career. "They had very unpleasant deaths," Battle-Miller said. "We were intubating a lot of these kids, preventing them from dying naturally. Some of them would die on the machine. Some would survive the episode but have to keep re-living it."

Beth Jones says she has prepared herself for her daughter's death. For now, though, she enjoys sitting with her two daughters on early mornings when Katie is well enough for school and younger sister Allie, 4, is awake enough to join them.

"I think of it as snuggle time," their mother said, enveloping both girls in an embrace.

Before the bus arrived, Beth Jones weaved a French braid into the school girl's long brown hair, while Allie held up a feeding tube. A machine could do the job, but that makes group hugs difficult.

Besides, anything that beeps isn't allowed in the Jones house.

"When we took her home from the hospital, where there were so many machines, we made the no beeping rule," Beth Jones said.

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