



TrachCare

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Raising a Child with a Tracheotomy

By Billie Jean Chouinard

Taking a young child out for the day often requires planning and packing. For some parents, however, the packing involves more than favorite toys, diapers and blankets – it involves medical equipment vital to survival.

Before heading out on a Saturday morning with her 4-year-old daughter, Reanne, Nicole Hardy of Methuen readies herself for a tiring day. Not only will she bring the stroller to wheel her daughter around, she'll also need an arsenal of medical equipment, including a 15-pound bag with a tracheotomy suctioning device that could save her daughter's life.

"It's not easy, that's for sure," Hardy says.

And because it isn't easy, Hardy is grateful for TrachCare, a support group for caregivers with children who've had tracheotomies. Founded in Massachusetts, the group includes Hardy and other families from New England and as far away as Florida. The group has even communicated with families from 19 other countries. TrachCare meets in New England twice a year at special family events, where area parents pool ideas, share tips and sort through their feelings about caring for children with such complex special needs. The group offers more than emotional support – it acts as a resource center for everything from insurance regulations to where to purchase the latest life-saving medical supplies.

What is a Tracheotomy?

A tracheotomy is an incision into the trachea, or windpipe, to form a permanent or temporary opening for breathing. A person may need a tracheotomy for many different medical reasons – perhaps his airway is blocked by a tumor, tracheal injury or even a foreign object – but its main func-



Jessica Leahy, Elizabeth Wachta and Pascal Cheung take a break from dancing at a recent gathering of TrachCare families to pose for a picture. Pascal no longer needs a tracheotomy tube and is doing well.

PHOTO BY BILLIE JEAN CHOUINARD

tion is to open and maintain an open airway. A tube is inserted through this opening, called a stoma, to allow air to pass and to remove secretions. Instead of breathing through the nose and mouth, the child breathes through the tube.

Sometimes, a trach tube is used just to relieve bronchial mucus and secretions. Sometimes, people are able to speak with a tracheotomy if enough air passes to the vocal cords. Often, however, they cannot talk without the help of other medical devices.

Management of tracheotomies is a complex process that requires careful monitoring and consistent medical follow-up. Parents of children with tracheotomies are trained in a hospital by medical staff until they're knowledgeable and comfortable enough to bring their child home. Among other vital lessons, they need to learn how to suction the tube for body secretions, which the patient can choke on.

No Parent Should Go It Alone

Taking care of a chronically sick child is difficult, but parents say it's a job rewarded with love and smiles. And just as we all do with the routine aspects of childrearing, parents of kids with tracheotomies simply get used to the medical duties required of them.

Two such parents, Julie Leahy of Newton and Erin Ward of Methuen, founded the nonprofit TrachCare in 2004.

Leahy's daughter, Jessica, was hospitalized for the first year of her life and diagnosed with Moebius syndrome. While she wasn't expected to live past her second birthday, Jessica is now 5 and continues to defy the odds, her mother says.

"During those first few months (after Jessica was born), I started settling in and tried to understand her diagnosis," Leahy says, noting that she couldn't even hold Jessica immediately after birth because her child needed medical attention.



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Before bringing Jessica home, Leahy needed to learn to care for the tracheotomy. She transformed her living room into a makeshift hospital room.

She's proud of how far Jessica has come in recent years; the young girl can now come off her ventilator for hours at a time. But Leahy is adamant about how hard the situation can be without support. "Other parents shouldn't have to do this alone," she says. "It's hard enough to have a child with medical issues," and then there are complicated forms, regulation changes and insurance papers to understand. "It's hard not only on you personally, but on your marriage, too. Just knowing there are others out there is (therapeutic). There's hope seeing older kids with trachs."

Ward's 6-year-old son, Will, is also doing well with his own tracheotomy. A Boston Red Sox fan, he's been to a few games and his prize possession is a Jonathan Papelbon game ball. Asked if she considers her son a success story, Ward slowly, but definitively, nods yes. Though Will is in a wheelchair and his speech is very quiet, he's like any other boy his age, and more.

"Will is awesome," Ward says. "He has been so successful in school and I think, seeing him grow, that helps tell other parents that it's OK. There's hope every day."

The Comfort of Support

Pascal Cheung is a 5-year-old from Lexington who does everything a boy his age can do. But there were times in his life when even breathing was a chore. For the first two years of his life, Pascal breathed only through a tracheotomy tube.

His mother, Josephine Cheung, remembers being hesitant about going out with Pascal back then, for fear of the germs he could catch in his stoma. That's all in the past now. Pascal no longer needs a tracheotomy device.

"There's a real need to be inclusive," says Cheung, who serves as treasurer for TrachCare. "Back then, we never met another family going through what we did outside of a hospital. It was very hard."

The Internet is one of the fastest and easiest ways to get information on tracheotomies. There are also online support groups, chat rooms and Q&A sites on tracheotomy care. But, says Leahy, she knows of no other group in the country that meets in person.

TrachCare has an introductory brochure that is distributed to parents in Boston-area hospitals. Members of the group hope parents will email questions or even join TrachCare. Leslie Gaffney, the Somerville mother of 4-year-old Tinka, is glad she did. TrachCare, she says, has been like therapy for kids and adults alike.

"Any event when we can get the kids together like this is great," Gaffney says. "When (Tinka) sees other kids she says, 'They're just like me, we're the same.' There's comfort in that."

TrachCare is based in Waltham. For more information on this nonprofit organization, call 617-527-1990; email: info@trach-care.org; or visit online at www.trachcare.org. ♦

Billie Jean Chouinard is a freelance writer and mother in Beverly.