

Why Do We Need a Global Tracheostomy Collaborative? A Parent's Perspective





A Parent's Perspective



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A Little Will ...Goes a Long Way

A Parent's Perspective



A dog lover
A baseball player
A student

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2013 MTM-CNM Family Conference



www.mtm-cnm.com

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Cindy Bissell

Founder

Aaron's Tracheostomy Page

www.tracheostomy.com

Aaron's Tracheostomy Page
The Internet's leading tracheostomy resource since 1996

HOME FAQ TRACH CARE NETWORKING RESOURCES ABOUT US

Welcome to Aaron's Tracheostomy Page

This site is dedicated to my son Aaron who had a tracheostomy for the first 4 years of his life. I hope that Aaron's Page will be helpful to others caring for a child with a tracheostomy, or to anyone seeking to learn more about tracheostomies.

Mission

To help assure the highest quality home care for children with tracheostomies.

To provide needed tracheostomy information in order to ease some of the anxiety related to caring for a child with a trach. A well-informed family will usually experience less anxiety.

To facilitate parent-to-parent networking and support. Information is necessary for parents of medically challenged children, however what often helps parents most is knowing that they are not alone.

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Donations

Pediatric Tracheostomy Home Care Guide
Cynthia M. Bissell
[Pocket Guide](#)

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Global Tracheostomy Tube Awareness Week

Hosted by: Moms of Trach Babies



TRACHIN' IT
one day at a time
Global Tracheostomy Tube Awareness Week
May 18 - 24, 2014

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Key Challenges

- Navigating the care system is often challenging
- Care systems are often fragmented, work in silos
- **Communication** is often between the family & one provider rather than inter-disciplinary
- Family is put in the middle of **collaboration** between specialists
- Lack of **coordination** of care
- Overcoming the stigmas & myths of trachs

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Inpatient Challenges:

- Decision-making vs. emergency
- Multiple services- Who's in charge?
- Caring for the whole patient:
(communication, feeding, therapies)
- Emergency protocols

Jeffrey's Inpatient Experience



Transition Challenges:

- Lack of coordination of discharge plans
- Community resources & nursing
- Family resources and impact
- Training, education, advocacy

Transition issues in Ireland

Babies 'trapped' in hospital over lack of homecare

Seven 'tracheostomy babies' in Crumlin hospital fit for discharge but cannot leave

– Irish Times, Nov. 13 2013



Transition issues in Ireland

Minister commits to protocol for timely 'tracheostomy' discharges
Advocacy group meets Dr. James Reilly over crisis



Dr. James Reilly gave a “personal commitment” to the Tracheostomy Advocacy Group- Irish Times- Nov. 23 2013

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Community & Outpatient Challenges:

- Nursing coverage & training
- Insurance coverage & cuts
- DME-access to life-sustaining equipment
- Outpatient visits-lack of coordinated care
- Community supports & education

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Community & Outpatient Challenges:

Chinese farmer keeps son alive with £20 homemade ventilator

A family of impoverished Chinese farmers have been swamped with donations after it emerged they had kept their paralyzed son alive for five years using a homemade ventilator.

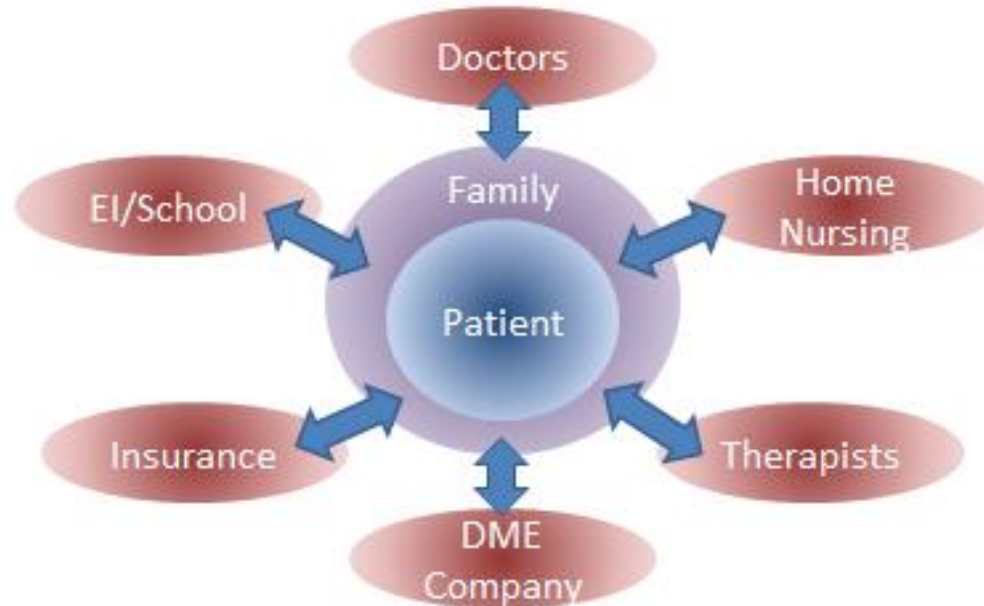
–The Telegraph Jan 30 2013



"[We] never think of giving up, not for one second" Fu Minzu, the patient's father

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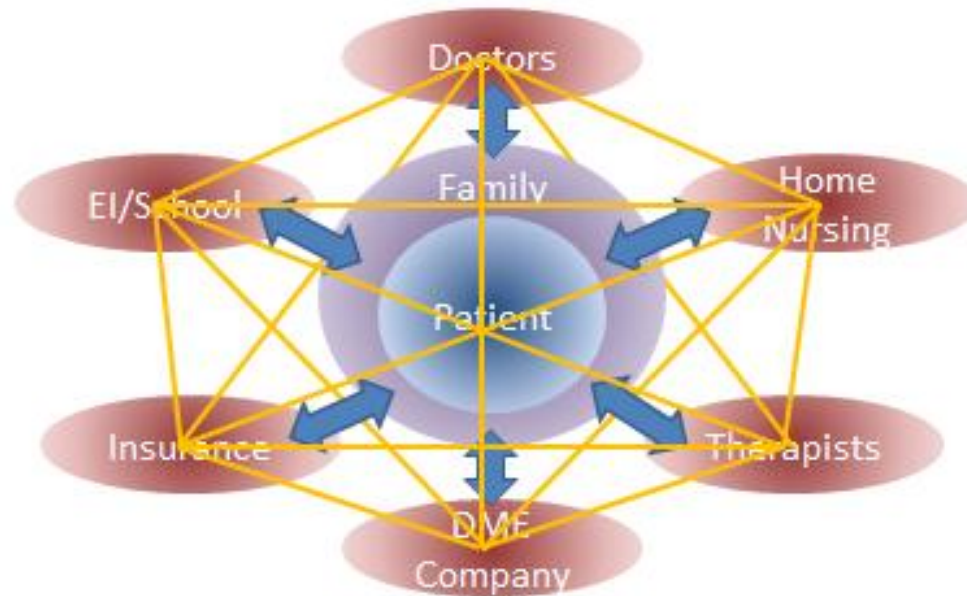
The multiple components & complexity of care in the home



Ward, E.

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The ideal team: communication, collaboration & coordination



Werd, E.

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- Promote Interdisciplinary teams
- Institution-wide protocols
- Wide staff education
- Patient & Family Involvement

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Patient & Family Wishlist:

- Partner with us to make our care plan
- Share all information with us
- Look to families to define “Quality of Life”
- Help us transform hope
- Talk to each other
- Engage us in change & improvement

Goals for GTC Patient & Family Engagement

- Patient & Family Champions
- Leaders as Advisors
- Patient & Family Membership



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Patient & Family Survey

“Tracheostomy Care: Hearing the Voice of the Family”

<https://www.surveymonkey.com/s/MGNY82Q>



Patient Safety & Quality Improvement Committee



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Patient & Family GTC Email

patientandfamilies@globaltrach.org

"Never doubt that a small group of thoughtful, committed citizens can change the world;
indeed, it's the only thing that ever has."

- Margaret Mead



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