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When Breathing is a Battle: The Emotional and Practical Burdens of Raising a Child with a Tracheostomy

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Editorial

Taking care of a child with a tracheostomy is a time of tenderness, optimism, and great struggle. It is also an emotionally charged rollercoaster for families, where the burden of care, finances, and social distance are everyday challenges. As life-saving, tracheostomy can also be very burdensome for the entire family.

Daily Challenges of Care

Families become immediately familiar with coping with their child's tracheostomy: how to suction, remove tracheostomy tubes, and watch for complications. It is physically taxing to continue this responsibility with little time to rest. The concern for infection or emergency is a constant distraction, compounding everyday burdens of care, but the tasks are not limited only to medical work. This emotional trauma can be overwhelming. The parents are always worried about their kids' well-being, and managing the uncertainty associated with chronic illness. The demands of continual care can feel withdrawn as they neglect social relationships or self-care.

The Financial Burden

There is an on-going cost for medication, equipment, and treatment that can rapidly add up for families. The constant necessity for new tracheostomy tubes, suction machines, and so on, puts huge strain on family budgets. Even with insurance, most families experience such hefty out-of-pocket costs that they have to make tough budgeting and resource decisions.

The financial burden might deny a family their options and opportunities. Parents lose money because they are required to shorten work hours or completely give up their careers to look after their children. Both increased medical expenses and decreased wages can lead to a stress-induced cycle not only in the caregiving department but also in the family [1].

Social Isolation and Physical Limitations

Tracheostomised children are socially isolated. The free airway has to be monitored and may reduce activity in daily life - making play dates and school absence challenging. People worry about their child's susceptibility to infections, so physical activity that most kids love is largely restricted. Therefore, they may struggle to make friends or attend school, missing out on important social opportunities and developmental opportunities. Loneliness can be intense and leaves the child (and sibling) alone with others [2].

For parents, social isolation can come at the same price. This is exacerbated by the stress of care, and the social network of families is cut off to the extent that they must fight their own battles alone. The denial of others outside their situation can only compound the sense of loneliness and lack of group support [3].

The Path Forward

And yet, many families can be extremely strong. They become their children's voices, finding the information, support, and people they know can help them get there. It can be easier with the help of a network of friends who can provide emotional as well as practical support.

Families also need healthcare professionals. The education of tracheostomy care and family engagement with social services can lessen some of the burden. A strong support network can also help families to more comfortably oversee the emotional and practical side of care.

Conclusion

Parenting a tracheostomy child is an experience full of love and hardships, but also brimming with moral and material imperatives that could impact every aspect of the family. Taxes, social isolation, and limits to movement add to the drama.

With greater knowledge and empathy within communities, we can guide families through these struggles and allow tracheostomised children to flourish. In this breath-fighting battle, we can also see a testimony to the power of love, determination, and the bond of parents and children that can

never be ruptured.

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