

## Never Give Up! Don't Let Statistics Rob Your Hope And Joy

When a child is first diagnosed with a medical condition, especially a life-threatening one, the first question many parents understandably ask is, "How long does my child have to live?" Medical professionals respond by quoting the statistics.

Statistically, all illnesses have a somewhat predictable course or an "average life expectancy." But statistics based on the group norms may be very misleading and even disabling when applied to individual children. It's very hard to predict who will be among the many who "beat the odds."

Historically, medical professionals have been known to advise parents of children with cystic fibrosis not to worry about saving for their children's college education. And parents have been known to lower their expectations concerning their children's performance in school, sports, or other important matters relating to the future and living a "normal" life.

This lowering of expectations, with its suggestion of a "What's the use?" attitude does a great disservice to children. It encourages them to become both entitled and to feel hopeless within themselves. Achievement and self-image both suffer.

The average life expectancy for many diseases is increasing at a fairly rapid rate due to medical advances. What might be an accurate statistic today probably won't be tomorrow. While it is important to understand the statistics, it is not helpful to be governed by them. The Nash family knew this to be true:

When Liz was diagnosed with cystic fibrosis in 1973, her parents were told not to expect her to graduate from high school. She did much more than that. Liz earned a PhD in molecular genetics, interned at Johns Hopkins University and went on to become a research scientist in CF. She also volunteered as a mentor to teens with CF, who struggled with thoughts about their future and medical compliance.

Liz was optimistic, enthusiastic, and passionate about her life's work and interests. She shunned the limitations imposed by CF. As captain of her college ski team she refused to give up the sport when oxygen became necessary. She simply skied with a backpack filled with portable oxygen tanks.

As an inspiring individual, Elizabeth Nash was selected to carry the 2002 Olympic Torch through Union Square in San Francisco. Liz died at nearly 33, well past her "statistical average" at the time but her spirit lives on as her example and courage continue to bring hope to many.

With many medical conditions, there is a strong correlation between good self-care and longevity. Parents can use statistics to inspire hope and spark an "I can beat this" attitude. Parents who give off positive, "we can beat this" vibes generally raise kids with the same determined spirit. We have met many CF parents and their children who demonstrate this indomitable and inspiring attitude.

In summary, wise parents handle statistics and medical predictions by:

- Emphasizing that significant medical progress is being made in almost all areas, and that health and longevity are increasing for almost all illnesses.
- Realizing that for all individuals, the future is unknown. Many lives are shortened by unexpected illness and traumatic events.
- Encouraging their children to believe that they have every chance of being one of those children "who fall on the high side of the bell curve because you take such good care of yourself."
- Understanding that the quality of a life is measured not by its length, but by the amount of love, accomplishment, and giving that fills it.
- Understanding that worrying about the future and chewing on the mistakes of yesterday rob both today and tomorrow. The resulting hopelessness, negativity, and worry can shorten lives and certainly diminish the quality of life.
- Believing that those who bravely face life's obstacles build a character that not only leads them to be more capable people and leaders, but sets an example that enhances the lives of all with whom they come in contact.

Answering a child's questions about the course of his or her illness can be difficult. How can parents answer their child's questions with hope if they have not come to a good place themselves? The child will almost always take the parent's cues. So don't let scary statistics rob your hope and joy!

(May 2008 is National Cystic Fibrosis Awareness Month)

## About the Author

From "Parenting Children with Health Issues: Essential Tools, Tips and Tactics for Raising Kids with Chronic Illness, Medical Conditions and Other Special Needs" by Foster Cline M.D, child psychiatrist and co-founder of Love and Logic, and Lisa Greene, mom of two kids with cystic fibrosis. Visit <http://www.ParentingChildrenWithHealthIssues.com>.

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