

Club membership is unwanted

By Curtis Seltzer

BLUE GRASS, Va.—A friend from high school buried her 37-year-old daughter last week. Cystic fibrosis. Complications from lung rejection. H1N1 influenza.

She joins me and another friend from those years in a club that none of us wanted to join.

Two of the kids had genetically linked illnesses—cystic fibrosis and a degenerative brain disease. The third had cerebral palsy, which is a brain injury or malformation that occurs before, during or immediately after birth.

All three had to limp through life from the start. They were not to blame; they did nothing wrong. And neither did their parents.

Two were adoptees. Which made no difference.

It's unlikely that these children would have survived much beyond toddlerhood had they been born 100 years ago.

Technology and drugs now allow us to tamp down seizures, feed through tubes, transplant organs and communicate through computers. We extend burdened lives this way for both young and old. I'm not saying that's bad, I'm just saying we do things that we can now do, which stretches out these illnesses.

But extension is not cure. Each of these kids had been cursed with a disease that technology, drugs, knowledge, skill and money could not fix. Each set of parents had to face the absence of control and walk their child through a long theft of diminishment.

I knew that my story could not have a happy ending—Batten Disease is always fatal. With the others, there were some maybes, some improvements, some successes, some new stuff, some hopes.

I think it was easier for me to get through this situation, because I knew that we were going to lose since nothing could be done.

It has to be worse to fight as hard as you can for decades—and still lose. A road with reprieves, with hope, is more cruel than one long, steady slide. Hope holds out possibility. But all the ups in these illnesses turn out to be temporary wiggles in a trend line down.

Everyone, of course, loses loved ones. Pain and suffering are just part of how life works. Why some are loaded down with more than a fair share from birth is inexplicable. Time spent on that question is wasted.

With doomed kids, you're first haunted by the question of what might have been, of what they might have become? Did we lose the next Picasso or Michael Jordan? The next competent plumber? The next Bernie Madoff?

With the old, we ask that question from a different perspective. How would this life have turned differently if this had or had not happened? Had Humphrey Bogart not drunk and smoked so heavily, might he have been spared the esophageal cancer that took him at 57? If Hitler had experienced even modest success as a young painter, might he have found no need to join the Nazi movement after WWI?

It takes a while to realize that big what-ifs are daydreams for beset kids. What is, is what matters.

I've never been able to figure out why some kids are picked to be cursed. Some friends say that it's God's will, and we're not supposed to understand. Others say that it's mostly chance. It's just bad luck, or, more specifically, being born in the wrong place, or at the wrong time or to the wrong parents.

Very little is fair in life. A burdened child is just one example.

If you think of these kids as just being positioned at a bad spot on the continuum of life's unfairness where everyone else is standing on the same continuum, a parent might end up feeling a little less singled out and a little less star-crossed.

I suppose that a burdened child who retains mental capacity eventually stops being angry and puzzled. I've seen them make the best of their abilities and the years they have.

I'm sure they have a tougher time than those, like mine, whose brain cells died and left him blind, bedridden, unable to eat or communicate, demented and essentially vegetative.

As with all loss and pain, time wears down sharp edges. Distance helps, but distance is not comfort.

It's possible all of this was easier before the 20th Century when the death of infants and small children was relatively common. Familiarity bred familiarity.

I would like to say, as others have said to me, that they were enriched by this experience. I never felt enriched; I felt robbed. I think better people than me feel privileged.

So I now sadly accept the newest member into our club. Consider your dues paid in full.

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