

## PE1651/RRRRRR

Chris Aikman submission of 14 February 2018

Like every parent of a newborn child, I thought my infant daughter was the most beautiful. And like every parent of a newborn, I was right. But I do remember, when she was a month or two old and out in her snugly infant carrier, a woman came up to see her and exclaimed, "She has the most beautiful eyes I've ever seen." I often thought of that incident in the years that followed, when the beauty of all that happened was harder to remember.

My daughter was born in 1977; she would be 40 years old if she were still alive today. Instead, she spent 32 and 1/2 of her 33 years on a continuous cocktail of powerful psychotropic medications that were intended to control her intractable seizures, and in the end she was killed by them.

Recently, a friend whose grandchild had just been diagnosed with seizures asked me to write down what I learned about epileptic medications from my daughter's experience. I have done so because of her request, and because of the hope that others may learn from the mistakes that I made. Basically, I am now haunted by guilt that my daughter never really had a chance for anything like a normal life, because of the choices that were made for her. Choices made with the 'best' medical advice of the day, which I had never quite accepted as correct, but in the end largely complied with for lack of any clear alternative. The ensuing years have revealed some of the devastating long-term effects of those medications. This will not be an encouraging report, because today I wish we had avoided most of them.

My daughter was exposed to benzodiazepines *in utero*, and also for the five and a half months that she was nursed. Her mother had been placed on diazepam at age 12, in the 1960s rush to exploit these new 'miracle drugs' to combat trauma. Her mother's medication was all prescribed under the direction of some 'leading' doctors of her day. Though she tried many times to live without these medications, she was unable to stay off them, and took rather heavy doses at times, even when pregnant in her mid-twenties. It is very likely that my daughter was born drug-dependent and remained so in those early months of her life. It is almost certain that she would have felt the stress that caused those drugs to be taken in the first place. During those early months of her life, she sometimes appeared to have small, startling muscle spasms. I suspect that what followed may have been due, at least in part, to drug withdrawal from diazepam.

At the age of almost six months, just after being weaned, she had her first major seizure, which was quite terrifying. Doctors immediately put her on phenobarbital, a barbiturate she took from age six months, and which would continue to age 16. This medication did not stop the seizures, which became more frequent. Around eight months of age, her infantile spasms were diagnosed as West Syndrome. This was treated with prednisone and ACTH for a couple of months, plus nitrazepam, a benzodiazepine she took from nine months to age 25. For a matter of weeks she was seizure-free, but the seizures returned and intensified. Around age three, I tried briefly to taper off the nitrazepam, but in the end had to return to full dose levels.

Around this time valproic acid (sodium valproate) was added to her regimen, which she continued taking for the rest of her life. So for a majority of her life, she was taking these three main drugs: phenobarbital, nitrazepam and valproate. All this time her seizures were intractable, with major seizures occurring more often than one a month, up to several per week. These seizures usually occurred in bed, during morning twilight periods, but occasionally also in the daytime.

Her development stalled around age three; at times her speech reached five-word sentences, but more usually consisted of single words or two-word phrases. She could, however, sing several lines of a number of songs. The drowsing effect of her medications were a greater problem in her life than her seizures, which occurred but rarely in her awakened state. But at age seven, something else began which proved far more problematic than either her mental handicap, her drowsiness, or her seizures. It was at that age she had her first rage attack. Her mood would change in an instant from a smiling, happy girl to one of astonishing violence, with objects being thrown and profanities screamed. These attacks typically lasted 2-5 minutes, then subsided. It was never exactly clear whether she remembered these attacks afterwards, but sometimes she would later be remorseful. These paroxysms made her life, and the life of all who tried to care for her, a kind of living hell. I'm sure we went through more than a hundred caregivers over the years. Were these outbursts a paradoxical effect of her heavy medication? I am convinced they were.

At age 16, her new physician said that phenobarbital should never be given to children. We slowly tapered her phenobarbital over most of a year, and the frequency of her seizures actually decreased dramatically at that time. You can search online and find a number of famous people who used phenobarbital as adults, who ended by taking their own lives. Phenobarbital is most certainly not the de-stressor that doctors once believed it to be.

However, her violent rage attacks continued: she was usually happy, but her mood could change in a instant. At age 19, she went to live in a wonderful group home, but these rage attacks were more than the compassionate staff and other residents could handle, and she had to move to private one-on-one care. At age 25 we slowly tapered her off nitrazepam, over a period of about a year. It might have been more successful had we done so over several years. Her seizures did not increase, and all went well until we stopped this drug altogether. Then, for the rest of her life, she suffered greatly from akathisia.

Valproate never had any significant benefit for her, nor significant side effects, as far as I could discern. However, its harmful side effects today are recognized, and are of concern for many people. Doctors always maintained that it was helpful as a 'mood-stabilizer'. No such benefits were ever apparent to the rest of us.

After age 25, she went through a whole sequence of drugs, hoping to address her ceaseless akathisia: methylphenidate (Ritalin), lamotrigine and buspirone are the ones I remember, but there were many more. Nothing seemed to really help. Lamotrigine was a nightmare: her whole body became covered with skin rash.

She was taking gabapentin (Neurontin) at the time she stopped breathing in her sleep. It turns out this is a rather common experience (see also: “Government plans to classify gabapentinoids as class C drugs”).

I don't remember hearing the acronym SUDEP before we lost her. Sudden Death in Epilepsy, SUDEP, has become a relatively recent topic. All of which is to say, the 'cure' is more dangerous than the 'disease', although strictly speaking epilepsy is a condition, not a disease.

In summary, all of these medications were bad. Having said that, benzodiazepines are amazingly effective for stopping seizures in the short term. They have no net benefit in the long term. Their lack of long-term benefit was known at least by 1980. But doctors insisted on prescribing their long-term use, even as their severe withdrawal effects were widely becoming recognized in the UK and Europe. In North America, doctors never let on that there was an extreme dependency problem with benzodiazepines until decades later.

What do I think can be learned from her story? Doctors tend to the viewpoint that children's seizures represent a lifetime condition, requiring lifetime medication. That, I feel very strongly, is exactly the wrong viewpoint, especially for young children. Many children's seizures can be a short-term condition; some even outgrow the intractable infantile spasms that characterize West Syndrome. I would propose that it is more productive to view seizures as something the child may and can outgrow. By imposing these horrendous medications indefinitely, a favorable outcome is precluded.

My daughter was a pioneer, or guinea pig if you like, in testing the long-term effects of some of these drugs from the earliest age. Since then we have learned something from the experiences of others. On the positive side, the occurrence of infantile spasms can often be arrested by administering pyridoxal phosphate, the active form of vitamin B6. There are even more encouraging stories about success in treating childhood epilepsies with medical cannabis. It seems to be effective without the destructive withdrawal symptoms of the other anticonvulsants. On the negative side, we now have hard numbers that show long-term benzodiazepine use is associated with increased mortality.

As a parent and scientist, but one who is neither a physician nor a pharmacologist, I have come in my own mind to see things this way: All psychoactive drugs to me represent a “borrowed happiness.” They may offer some short-term benefit, but it usually has to be paid back when you try to break the dependence. If you don't pay back the happiness debt, things don't get any better either. There may be nothing wrong with borrowing happiness if circumstance allows you to gradually pay it back. If you can never pay it back, a lot of suffering ensues.

Did her drugs cause the violent mood swings, now known as Intermittent Explosive Disorder, that marked her adolescent and adult life? I'm sure they did, although this might not always happen with others using the same drugs. I know of at least a few cases where the results of the same medicines were even more dramatic and tragic.

If I may use what will seem to professionals to be a crude analogy, consider what happens with the most-frequently used drug, alcohol. People react to it differently, depending on their inner selves: some become quiet, some become happy, some become violent, some involve all three.

Forty years after her epilepsy started, I have come to believe I could have given my daughter a real chance to heal. I should have taken medical leave from my work, and concentrated all my effort on securing a safe, calm home life for her, 24/7. No child can prosper without an atmosphere where he or she can feel constantly safe, bonded and surrounded by love. Hospitals, wonderful as they may be, are not exactly that kind of environment. Had I followed that path, I might have been successful at gradually tapering her off her medications. As it was, I became a single parent, and she went through dozens and dozens of caregivers, none of whom could cope with her seizures, and later, her rages. With the insecurity of care she experienced, plus the damage of continued medication, she never really had a chance.

I have a beautiful grand niece of kindergarten age, now recovering from seizures and from medication. Her prognosis looks very good.

To close on a positive note, I believe there many good reasons for hope. But it won't be found in medication alone.

I loved my daughter very deeply, and an incredible amount of care was given to her by a host of caregivers, with the best of intentions. It saddens me deeply that we ever believed that medications alone would provide a 'cure'. There are some promising therapies out there, yet I doubt that any medication alone can suffice to resolve intractable childhood epilepsies. The real cure must lie elsewhere. The foundation of that must lie in providing the warmth and security that all children require and deserve.

Postscript: I suggest checking out these hashtags on Twitter:

#epilepsy #lamotrigine #gabapentin #sudep