

Living life in reverse with deadly brain tumor

BY SARAH KILCH GAFFNEY
SPECIAL TO THE WASHINGTON POST

With horror, I realized one morning that my daughter's motor and language skills would meet and then surpass her father's as they progressed in opposite directions.

In those first couple years of childhood, there are so many milestones to celebrate: when they smile for the first time, roll over on their own, take their first steps, say their first word. Every inch grown, every pound gained and every skill mastered leaves us breathless with pride and contentment, marveling at this little life.

I remember how we rejoiced at every one of those well-child appointments as the pediatrician checked off each milestone met.

My husband, Steve, had struggled greatly with learning disabilities his entire life, and he had required braces on his legs as a baby. He was so relieved the afternoon our daughter was born with perfect little baby legs, no interventions needed. He was thrilled when she began walking at 10-and-a-half months, and he felt immense relief at how quickly her vocabulary expanded and the ease with which her words became phrases and then sentences.

At the exact same time that our daughter's world was exploding with possibility, Steve's physical and cognitive abilities were slowly diminishing

She was healthy and growing and meeting all those innumerable milestones, so while I was pleased, of course, I never really worried about her abilities or pace as much as Steve did. That was also probably because I was too absorbed with worrying about him.

At the exact same time that our daughter's world was exploding with possibility, Steve's physical and cognitive abilities were slowly diminishing. Our daughter was born almost exactly 18 months after Steve was diagnosed with a brain tumor at the age of 27. His original prognosis was five to 10 years because he was so young and otherwise healthy, so we took that leap into parenthood, briefly shedding the weight of everything that lay ahead.

Life was good for a while. Steve was able to continue working until our daughter was eight months old. The first radiation therapy was only for six weeks, and he didn't require another brain surgery until she was 18 months old. There was a brain injury rehabilitation center nearby that could manage all his therapies: physical, occupational, speech. The first chemotherapy he tried was oral (so he could take it at home, not hooked up to an IV in the cancer center more than an hour from our home and where we already spent far too much time) and the side effects were tolerable.

When our daughter was 2½ years old, however, things began rapidly going downhill. Recurrent treatment-induced brain swelling, a veritable cocktail of seizure and cancer meds, and tumor progression all took their toll. By her third birthday, Steve was struggling immensely with speech and mobility, had been homebound for nearly a month, and had started hospice.

Somewhere along the line, her abilities had eclipsed his; I hadn't even noticed that pivotal moment.

While she sat in his lap happily chattering away, he often struggled to say single words, even our names. Though he knew exactly what he wanted to say, his aphasia was often insurmountable and heart-wrenching.

Slowly, I watched life work in reverse.

When Steve could no longer walk, we used his wheelchair to move him about the house. As his grip weakened, we enlisted plastic cups with built-in straws. He used our daughter's toddler toothpaste so we could brush his teeth easily

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GEORGE DANBY | BDN

Not Just Opioids

Maine's heroin epidemic is in the spotlight, but treatment is still needed for alcoholism

BY CHRISTOPHER BURNS
BDN STAFF

Heroin has become a major problem in Maine. But for as serious as the heroin epidemic is, far more Mainers each year seek treatment for alcohol dependency.

In 2014, alcohol was the most common substance for which Mainers sought treatment, with 3,589 Mainers entering treatment, compared with 2,538 for heroin and morphine. The need for treatment, however, is much greater. An estimated one in seven Mainers needed but did not receive treatment for alcohol dependency, according to the Maine Office of Substance Abuse and Mental Health Services' 2015 substance abuse trends report.

The state has a chronic shortage of treatment and detox facilities for Mainers addicted to alcohol, a shortage worsened by the closure of Mercy Hospital's Addiction Recovery Center in Westbrook last August.

"The opiate epidemic has sucked all the oxygen out of the room," said Dr. Mark Publicker, a nationally recognized addiction expert who practiced at the Westbrook center. "When we

talk about addiction treatment, there's never a mention about treatment for alcohol."

Not enough beds

When Mercy's Addiction Recovery Center was open, it served as a statewide resource for alcohol and drug detox. Hospitals as far north as Bangor routinely transferred patients who needed to withdraw from alcohol to Westbrook, Publicker said.

Only a handful of centers across the state provide inpatient detox services for Mainers who need to safely withdraw from alcohol, including MaineGeneral Medical Center in Augusta, St. Mary's Regional Medical Center in Lewiston and Milestone Foundation in Portland. North of Augusta, however, there are few detox services.

"That's a real challenge our state is confronted with. It's not a rural problem, it's a statewide issue," said Pete McCorison, program director for substance abuse services at Aroostook Mental Health Center.

Most hospitals still will admit someone going through acute alcohol withdrawal, McCorison said, but few offer dedicated inpatient detox programs.

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Tired dad responds to reader comments

Life sometimes moves quickly. On March 28th, my wife and I welcomed our first child — a boy — into the world. To all those who said it changes your life: You're absolutely right.

As I talk to or make faces at my son, I recognize he does not yet understand what I am saying or doing. And I cannot wait for the day when he can smile and laugh at a funny face, recognizing his dad and engaging. But, until then, it is a bit of a one-way street — one that is a lot of fun to drive.

Meanwhile, this column has evolved in reverse. While writing with Cynthia Dill, we offered an occasionally humorous repartee on issues of the day. The arguments she made

would parallel some of our readers' comments, allowing me to address them indirectly. Yet, as I have continued on solo in Maine's premier paper, I do not always have the opportunity to respond to objections, counterpoints or tangents offered by several readers.

So, in that vein, I will use this effort — in an admittedly sleep-deprived state — to respond to some of the letters and emails I have received over the past several months from you.



MICHAEL CIANCETTE

Chances are you share some common ground with people you'd least suspect; you just have to be open-minded enough to find it

First, to the people who expressed surprise at agreement or disagreement with an argument I have offered: Don't you love the power of probability? If you assume there are only 20 policy issues in the world and each issue has only 2 possible answers, the odds of two individuals agreeing (or disagreeing) on all of them are over a million to one. Chances are you share some common ground with people you'd least suspect; you just have to be open-minded enough to find it.

Second, to the readers who accused me of being against those "from away": You mistake my position. I have no qualms with individuals who move to Maine and become part of this community — that group includes my mother and my wife. It also includes numerous friends, family members and mentors.

However, I do object to those who do not live here sending hundreds of thousands of dollars into our state to push referenda on numerous topics, whether bear baiting, casinos or gun control. If they want those laws where they live, fine — other states can make their own decisions. If those proponents want to move to Maine, pay taxes and truly become part of our state, then I support their right to be heard as much as someone born here ... even if I think they are wrong, such as Ms. Roxanne Quimby. But if people are from away, decide to stay away, and parachute in with large checks only to tell us what our laws should be, then my patience wears thin quickly. That is why I believe referenda should require statewide support before going to the ballot.

Third, to the gentleman who wrote that I am "full of [excrement]," with nothing further: Please grow up. You join the ranks of those who throw out ad hominem attacks, offering jewels such as "corporatist Koch puppet," "corrupt ReTHUGlican," and other literary gems. If you disagree with my arguments or positions,

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