

honorable mention, non-fiction

I Don't Mess with Boats

by Mark Alan Guetzow

To fully understand my stance on floating modes of transportation, one has to understand that canoes are not supposed to sink. At least that was my understanding. I'm still pretty sure that you can fill a canoe with water and it'll simply ride low until you bail it out again. You can capsize it completely, flip it back over, and you're good to go. Yet at the age of eighteen or nineteen, I found myself soaking wet on a pier one summer afternoon because I was part of a group of individuals that discovered possibly the only way to sink a canoe. Granted, I thought it was funny at the time and I wouldn't be telling you the story if I did not still think it was. But, it does also explain why I don't mess with boats anymore.

It may not seem so bad that we sank, once you know the full story. It really was not very bad in most aspects. It is not like the canoe had some sort of catastrophic, injurious wreck; it is not like I drowned or came very close to it. I was back on dry land two minutes later and not really any worse for wear. My beef with boats stems from the fact that that particular boat actually tried to drown me. It takes a very special set of circumstances and a certain type of person to get trapped underwater by a canoe. I'll explain the necessary circumstances later. But first, let me explain why I, apparently, am that type of person.

I was diagnosed at the age of eighteen months with a type of muscular dystrophy (MD) called Spinal Muscular Atrophy, Type II (SMA II). Basically, the disease causes the muscles of the body not to develop correctly. In my case, from infancy my muscles only grew to about thirty percent of the strength that one would expect to find in a normally developed child.

The first clue that my parents had that there was a problem was when I started learning to walk. At first I started learning normally. I would stand with some help and even take a few wobbly steps before falling down. That sounds about right for an infant. Eventually, however, my falls were a lot more like collapses and my parents got worried enough to take me to the doctors to find out what was wrong. The doctors eventually concluded that I had SMA II.

Having a diagnosis, while informative, really did not do much to help. There were no treatment options available then to reverse the muscle weakness caused by SMA II. Today, there are actually a few treatments going through clinical trials. But, it remains to see if they work. The best try back then was starting physical therapy early to try and stop or slow the loss of function.

Muscle control with SMA II is sort of a use it or lose it type of thing, making it key to try and maintain what little strength and range of motion that the patient has. With SMA II, muscles remain unable to develop new muscle tissue as normal. Exercising really cannot make a patient with my type of MD stronger. Additionally, as one grows and gains body mass, one's muscles are forced to work harder to

move the same body parts. So, if you stop using a certain muscle in a certain way, it gets too weak to do that anymore and there is no real way to make it strong again. I'll give you an example.

As a very young child, I could still crawl fairly well. I remember having crawling races with my older sister as a child. Sometimes I would even win. It did not matter so much to me that I could not walk because I could still crawl around well enough to get where I was going and do whatever I needed to do in my busy days as a toddler. I still used a wheelchair to go long distances. (I remember getting my first chair when I was three.) But, usually, once I got where I was going, I would slide out of the wheelchair and take to all fours.

Now, when I was about six years old, my doctors noticed that my hips were growing out of their sockets. I did not have the muscle mass that normally keeps those joints where they are supposed to be. So, I had to have surgery to put pins in to hold them in place or they were going to grow in such a way that I'd be in constant pain.

As unpleasant as the surgery was, the worst part was not being allowed to crawl for quite a long time afterwards. Crawling would have put too much strain on my recuperating hips and possibly caused damage. Once I got healthy enough to be freed from permanent bed rest, I sort of cheated and found a way to 'scoot' on my butt to get around. It still put a little bit of strain on my hips, but I did not get fussed at too much for it. Unfortunately, it was not as good a method to get around or anywhere near the amount of exercise that crawling was. By the time I got the green light to try crawling again, the set of muscles needed to do so had gotten too weak to carry me more than a few feet.

I had to start spending more time in my wheelchair as a result of this loss of mobility. The more time I spent in the wheelchair, the weaker my arms and legs got. I became totally dependent on the chair to get around within a few years. By the time I reached the age where I was doing stupid things like experimenting with canoes, I had lost almost all of the mobility in my legs and a significant amount in my arms. I was unable to sit without support. I was precisely the sort of person that, given exactly the right circumstances, was capable of being forced under water by a canoe and unable to free myself.

In order to explain the circumstances that could put me into and sink a canoe, I have to tell you about the Muscular Dystrophy Association's annual summer camp. For one week a year, children, teens, and young adults with muscular dystrophy all over the nation leave home to enjoy the experience of spending time away from their parents. The point of camp is to place the campers in an environment where they can be more independent. Being someone who was generally dependent on my parents twenty four hours a day for help, just getting away for that week fostered a sense of being on my own for once.

Sure, each camper with muscular dystrophy is paired with a volunteer counselor whose primary job is to help the camper with meeting their physical needs, essentially doing the work of the camper's normal caretakers. But it is different when your caretaker is a young person, whose secondary job is to facilitate their camper having as much fun as possible. For a camper, it is a lot more like spending a week away with a friend than being looked after by a caretaker. That difference in perception is what fosters the sense of independence. At least, it was for me.

Counselors are allowed to start volunteering at the age of sixteen and can come back for as many years as they like. Many counselors come back year after year until their job or family life prevents them from taking a full week off every summer.

As a former camper, I can attest to how hard the counselors work. The focus is on fun. But each camper has their own set of needs to which their counselor must attend. There are several different types of muscular dystrophy, each causing varying degrees of mobility impairment. Even among persons with the same type of MD, no person is affected in exactly the same way as another. Most of the counselors are not a caretaker of a person with a disability in their day to day lives. Yet, for that week, they adapt to their camper's needs and assist with everything from brushing teeth to taking showers to transferring from the wheelchair into bed. For most of the volunteers, especially those still in high school, it is a great deal more responsibility than they are used to.

That the counselors would volunteer in the first place ought to be a good indication of what types of people they are. That so many of them choose to return again and again, is an even better one.

I will tell you a little bit about the people involved in this story to give you a slightly better understanding of the type of people the counselors are and also to help explain certain things that will come up later.

My counselor that year was a guy named Matt. Matt's MDA camp history is what is most typical. He started volunteering when he was in high school and just never stopped coming back. He was a counselor in my cabin one of his first years at camp, though he was not my counselor. Until the year of this story, he had actually never been my counselor. But, that did not mean we could not grow into being friends. He was pretty much a sarcastic smartass, which meant we got along together great. We gave each other a lot of shit, mostly. Sometimes, entire conversations would be held where we did nothing but insult one another. Other times it was just a friendly "fuck you, asshole" or "go fuck yourself" in passing.

Probably a good ninety-five percent of any other conversations I had with Matt were about the female counselors at the camp. You cannot blame us. Around the time Matt and I attended camp together, we were going through our mid-teens to early twenties. Additionally, it all took place in Texas in the Summer time, which means the girls were not exactly bundled up. And there were a lot of very pretty, very athletic female volunteers that happened to be right around our same age. What do you expect to have been on our minds most of the time? It wasn't arts and crafts.

Another counselor, Stephen, had been a volunteer for almost as long as I can remember going to camp. He was one of the exceptions to the general rule about counselors not having family members with MD. His younger brother was a camper and so was his cousin. So Stephen started volunteering at the age of 16 with a pretty good idea of the sort of thing that he was in for.

The year I met Stephen, I was maybe ten or eleven years old. Stephen's camper, Shane, was, to put it nicely, a complete pain in the ass. I'm not entirely sure if it worked for Shane at home, but he was convinced that as long as he acted bratty enough, threw a big enough tantrum, or whined long enough, he could get whatever he wanted. The kid had a particularly severe kind of muscular dystrophy that

lowers your life expectancy to about twenty years old. We all kind of figured that he was just not dealing with that fact very well and that his parents spoiled him because of it. Imagine being confronted with something like that as a ten year old or as a parent with a young child. We cut him some slack. But. There's also a point where understanding of someone's behavioral quirks melts away into pure annoyance, particularly when the people asked to put up with those foibles are in roughly similar situations. Keep in mind, there were plenty of kids at camp who had the same type of MD as Shane and did not act like they were entitled to whatever they wanted because of it. Within two days of putting up with Shane's behavior, counselors' nerves were frayed and the rest of the campers in the cabin had turned pretty hostile. Stephen, in dealing with Shane, showed that he was one of the most patient people I have ever met. But even he was getting worn out.

I really cannot remember why or how, but I ended up with a kind of rapport with Shane. It was mostly out of self-defense, I think. I could get Shane to calm down or just distract him from whatever tantrum he was about to throw and save us all from having to listen to it. Shane and I talked a lot that second day and he calmed down. I was also good enough friends with the other campers in the cabin to get them to back off a little when they started giving Shane trouble about the way he had acted the first few days. Keeping the newfound peace seemed smart.

So that was a part of the backdrop for the friendship Stephen and I developed. I helped him with his camper, I guess. But Stephen ended up helping me out a lot, too. That year, I just did not really mesh with my counselor. It is not that my counselor was a bad guy. He did a good job taking care of me and everything, but we just had conflicting personalities. I adopted Stephen as my counselor that year, if you judge that by the person with whom I spent the most time. It was a very unusual situation.

Stephen never was assigned to me as my counselor in the years to come, but we became really good camp friends. It is the way it goes a lot of the time. You keep in touch over the phone or through email during the summer, but then you get busy with school and lose contact. The next year camp rolls around and you reconnect, picking up the friendship right where you left off and just as strong. That's the way it was with Stephen.

David is another interesting person to talk about. His younger brother by a few years, Dean, had just been diagnosed with a type of MD that has a late onset and is degenerative. Actually, I cannot describe one brother without describing the other.

Dean was in his junior or senior year of high school when he and his family got the bad news. By the time of the boating incident, Dean had started to lose some fine motor control and the ability to walk for more than a few yards. I got the very strong impression that the two brothers had been close before Dean was found to be sick. But it also seemed that that finding had only drawn them closer together.

Dean took the advice of the people at MDA and had started going to camp the first year that he was diagnosed and, therefore, eligible to attend. David started volunteering that very same year and quickly became one of the most respected volunteers. Neither brother, in my experience, ever failed to volunteer to help with or participate in anything. It is just the kind of people they are.

Both Dean and David can best be physically described, as Matt put it, as “some corn-fed country motherfuckers.”

While most campers and counselors at camp are from Beaumont or the Greater Houston Area, these guys were from a bit further west in Texas, where their family owned a farm. Both were around 6 feet tall, with David being the tallest (around 6’4”) and built like a college varsity linebacker. He was huge, in other words—but not in an obese sort of way. He was just a big goddamn farm boy. His size generally made him an asset at camp. He could easily pick up, single-handedly, campers that normally required two other volunteers to lift, jointly. And he never got tired of offering to do so.

Not to neglect Dean—he was an interesting guy all on his own. He managed to seize some good opportunities out of his recent diagnosis. One was being able to convince the insurance company that, because of where he lived and the nature of his family’s property, he needed an off-road wheelchair.

They do make them; off-road chairs are designed to allow people with mobility issues to go on hiking or camping trips. Toward that goal, those chairs have bigger wheels, are designed much more ruggedly, and have a lot more power. They are also a lot more expensive. One normally cannot medically justify buying an off-road wheelchair to penny-conscious insurance companies. Dean could though! Dean lived in a place that necessitated that kind of chair.

Dean also had the wherewithal to realize that an off-road wheelchair had the potential to be a “muddin’-wheelchair.” And he exercised that potential fully.

In case you don’t know what “muddin’” is, it is usually done in a four-wheel-drive jeep or truck. It involves a rain-soaked clearing, probably beer, and hydroplaning or skidding your vehicle around as long as possible without getting stuck. From Dean’s tales, it is really not that different in practice when using a wheelchair that is suited to such things.

I am not sure that that activity appeals to everyone, but it is a good example of the “can do” mindset of Dean and David, to put it mildly: Got MD? Invent wheelchair muddin’!

I started off talking about canoes and I’ve talked about a ton of other things besides those boats. But, I had to talk about the people involved so that you could understand why a person with muscular dystrophy would ever attempt to sit inside a canoe on a lake. One last thing, though. I have to explain the type of place where that could happen.

Aside from trying to foster independence by getting the campers away from home, camp was also about allowing campers to do things that they normally would not have the opportunity to do or would even attempt to do. This particular location had been built with that specific purpose in mind.

Everything there had been designed with the goal of making it as easy as possible for someone with a disability to do what able-bodied people could do. First off, everywhere in the camp is wheelchair accessible. Much more thought than simple accessibility was put into the design of the camp, however. For example, the archery range was specially designed with simple places to latch the bows for someone without the strength to hold up the bow and pull. It took some figuring out for each individual, but even

someone with severe muscle weakness could actually shoot a bow and arrow with reasonable accuracy and range. It was one of my favorite things to do. The ropes course had been specially designed to be able to hoist mobility-impaired campers up to the top of the climbing tower and so they could ride the zip line across the field safely. I did that at least once every year.

And, of course, there was the boating dock.

The boating dock had been designed with the knowledge that from a physical standpoint it is very difficult for everyone involved to put a person with a disability into a small boat, like a canoe. Lifting someone from a chair down to something at water level that happens to be relatively unstable because it is floating is torture on the backs of the volunteers. Being lifted usually is not very comfortable, either. Sometimes, it hurts. So the docks had ramps built into them right down to just below water level. The dock staff could pull the canoe up onto the ramp and the people doing the lifting could have all the time in the world to adjust the camper comfortably in the boat, as painlessly as possible for everyone involved.

In my case, this took a little bit more doing than it did even for the other campers because of my inability to sit without support. I was not all that sure it could be done, but I was willing to give it a shot. I really was not too much worse off than the dozens of other campers I'd seen go out onto the lake that week. And, camp is about trying things you would not normally do, right? So, I decided to go canoeing.

The volunteers did some thinking before they set me in the canoe and we did a little bit of trial and error afterwards to get me situated just right (all on the safety of dry land).

What we came up with was to have me sitting between the two middle seats on a beanbag chair, supported by my counselor, Matt, sitting on the seat behind me and straddling me. Another counselor in our cabin sat in the front and was simply in charge of paddling. We still needed somebody else to sit in the back to paddle and to steer, since my counselor would be too busy just helping me stay steady to do that task. Every other counselor in the cabin was either out on the lake with a camper already or busy doing something else with their own camper elsewhere. Stephen was my cabin leader that year (think head counselor for that cabin). But, generally the cabin leaders stay on shore at the dock to keep everyone organized.

Dean and David were not in our cabin that year, but had come by the docks to chat and check things out. Dean did not need anything at that particular time, so David volunteered to sit in the back of the canoe as soon as he heard we were a man short.

Everybody got settled in and ready to go and the staff at the boating dock started gently pushing the canoe back toward the water. Gravity and momentum took over and we were ready to slide out onto the lake's surface and paddle away.

That did not happen. Nobody realized it at the time, but those particular canoes we were using were rated for five hundred pounds. Put into real terms, the boat was rated for considerably less weight than that of two full grown men, a camper, a beanbag chair, some extra cushions, and one "corn-fed country

motherfucker.” The boat never really leveled off when it hit the water, just kept going backwards at the same angle as the ramp and started to slip under water aft first.

I’m not exactly sure how deep the back of the boat went in, but I do know that most of the boat filled up with water to some extent. When the canoe was about three-quarters of the way off the pier, it rolled over on its side.

The way I was positioned in the canoe meant I was already sitting a little sideways. When the boat went over, I luckily went into the water back first, rather than face first. My body shifted in the process, though, and my legs got tangled up in the seat ahead of me and were wedged under it by the beanbag chair and cushions.

I had a life vest on, of course. It kept my shoulders pushed up toward the surface of the water. But the position of my body meant that the boat was pushing me the opposite way and kept my shoulders and my head pushed back just a little bit too far. I remember looking up above me and seeing only about two or three inches of water between my face and the surface. I could see the blue sky right above me and the afternoon sun off to the side. I could see some activity on the pier a few feet away out of my peripheral vision.

I did not panic or feel afraid, though. It was actually the second time I’d been in a canoe and the second time one had tipped. The first time was a few years earlier during my brief stint as a boy scout.

On a camping trip, I’d been out on a lake in a canoe with the troop leader, “Squeaky,” and my father. Squeaky reasoned that if I did get to go canoeing with the troop, eventually I would be in one that flipped. So, he warned me that he was going to intentionally flip that canoe to show me what that was like in a controlled situation.

The point was that no matter what happened, Squeaky and my dad would be there to help me within ten or fifteen seconds. Whenever it happened for real, someone would be just as close, so I would know that there was no need to panic. Squeaky was a man with excellent foresight, it turns out.

When my canoe sank at MDA camp, I remembered that lesson and did not panic. I remember thinking of that experience with Squeaky and my dad and then realizing that there were three able-bodied people in the canoe this time. I remember thinking how annoying it would be if being underwater did turn into a problem, with the surface a mere two inches away from my mouth. But, I just blew bubbles to keep the water out of my nose and trusted that someone was going to help me before my lungful of air ran out.

Momentarily, I heard a big splash behind me and a few seconds after that, hands were under my shoulders, pushing my head up.

Stephen had been watching everything from up on the shore. According to everyone there, he’d taken off running before those of us in the boat even realized we had a problem. He dove, action-hero-style, over a stack of canoes and paddleboats on the dock, over everyone else already in the water, and into

the lake to be the first to get to me. I'm not exactly sure how he did that, but several people said it was pretty impressive.

With my head out of water, it was only a matter of getting my legs untangled from the damn boat and lifting me up onto the conveniently water-level boat ramp. I'm pretty sure that at that point I was already laughing about it. Those of us who had gotten a dunking got dried off on the pier as best we could and then went back to the cabin for a quick shower.

We were late to dinner because of that shower and MDA camp staff is particularly conscious of people not being where they're supposed to be. I guess inquiries were made and the story was told. The camp director practically ran up to me when I got to the dining hall, pretty excited about the whole thing:

"Mark! Are you ok?! Why didn't you come to the clinic so the doctor could look over you? You can't just go on without telling us about something like that. Was your head under water? You have to file an incident report!!"

I did not actually consider it an incident at that point. No harm was done and the lake felt pretty good after being in the sun all day. Once I assured her I was fine, I got to go to dinner. I think I still had to see the doctor later and dictate a report, though. That probably took longer than the whole sinking thing did, from start to shower. But, I understand that they need to keep people safe and have records of them being so. MD parents can freak out over little things like this.

The final thing I've been told I need to talk about is how the next day I tried again. I think it was something like, "You got back in the canoe? You need to tell that part because it shows how fucking nuts you are!"

I did not really think it was too crazy to try again. We had learned several important lessons about proper weight distribution in canoes and how not to put me, in particular, into one. Still, I admit I was a more nervous about it the second time. But the fact that I was nervous about it was kind of the point of doing it again.

Some things I do because they make me nervous. How I dealt with heights is a good example. I used to be pretty scared of them. I'd get scared near the edges of balconies or even in really tall glass elevators. But then I decided I kind of liked the little rush of fear that these things sent through me. So, I started going as near to the edge in these situations as I could and look down. Eventually, I stopped being scared at all. Remember the zip line? I did that every year just to prove to myself I was over heights. Fuck heights.

So when a boat tried to drown me and made me nervous about trying it again, I had to try it again. Because, you know what? Fuck that boat. We figured out how to do it with one fewer person in the canoe and with only normal-sized individuals. We got into the water just fine and we paddled around the lake. It was really wobbly because I am really wobbly.

We drove that boat around the lake for a good ten or twenty minutes and got back on the dock safely. But I still don't fuck with boats. Two out of three times of trying to ride a canoe, I fell out of it or sank in

it. I would do it again, if I had to. I would ride in a canoe with those same people, just to prove to them I trust them. But in the meantime, I am not going to seek out a boat and ride it. I did that already the third time and I won. In the meantime, I just don't mess with boats.