



## Facts & Arguments Essay

# My disabled son's first time at camp

**Part of me was terrified leaving him at overnight camp without me for three weeks. But he was in his element**

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The decision was made. Part of me was terrified. During the week prior to Jacob's departure, with all his clothes scattered in piles on his bed and across the floor, I packed for my seven-year-old son's coming adventure.

To observers, I did all the things necessary to ensure his readiness for overnight camp. There were T-shirts and shorts, long-sleeved tops and pants, bathing suits and pyjamas in his duffel bag.

It was a typical precamp scene, one that many people were enacting at the same time during the last few weeks of June. But this scenario was different from that of our neighbours. In addition to his blue bag stuffed with clothes and bedding, I methodically packed a second bag with syringes, feeding tubes and various medications that Jake needs every four hours around the clock.

Jacob has Pelizaeus-Merzbacher disease (PMD), a neurodegenerative disorder that prevents him from walking, talking or sitting by himself. He is fed by a tube surgically implanted into his stomach. Although his physical abilities are severely limited, he understands what is said to and around him and he has an incredible sense of humour.

When asked by friends if I was worried about sending Jacob away for three weeks, I emphatically told them that he would be well cared for and I was confident this would be a great experience for him. I ignored the queasiness in the pit of my stomach that surfaced every time. Was sending my disabled child, whose needs are complex and constant, to camp the action of a responsible parent?

Jacob, my child with huge green eyes that sparkle when he smiles, has an ability to make people fall in love with him. There is something intangible that draws people to him and makes them want to be near him, help him and laugh with him.

Jacob's people-magnet skill was first observed as an infant while he was in the hospital for a prolonged stay following his birth. The nurses would argue over who would be fortunate enough to have him on their charge list for the day. Our morning would begin with the lucky winner entering his room with a smile, ready to start his daily routine of medication administration.

Jacob's charm was in overdrive when he joined a weekend activity group led by teenaged girls at a nearby high school. Jacob's princesses, as his sisters referred to them, flocked to him and playfully fought over who would spend time with him each week.

Belle, Jacob's favourite princess, convinced me to send Jacob to a camp for children with special needs. She selected two other princesses to accompany them. The three girls were breathless with excitement as they unveiled their plan – Belle would be with him during the day and the other two

would be responsible for his overnight care.

We arrived at camp in the evening, two minutes before a thunderstorm. As the car slowed to a stop, my heart was beating quickly and my breath was shallow. It was really happening – he was going to stay at camp without me for several weeks.

An hour later, Jacob was sleeping soundly in what was affectionately labelled “Jacob’s Palace,” his room with handmade signs and pictures taped on the walls.

Unlike my son, I was not relaxed. Not at all. I was unpacking his medical paraphernalia and anxiously trying to share as much information as possible regarding his care with the camp nurse, a woman exhausted from a long first day of camp. The refrigerator, necessary for Jacob’s food and medications, was not in the prearranged spot. We were unable to locate electrical sockets in his room to plug in his nebulizer, a device needed to administer one of his medications.

After some running around on the part of the counsellors, things started coming together. With a few final reassurances from the camp directors that he would be safe, I reluctantly left my little boy in the able care of his doting princesses.

Daily reports from Belle were consistently positive: “Jacob had fun boating today.” “Your son is dangerously cute and had an awesome time on the trampoline.” And my favourite: “He’s my best friend in the whole world!”

Not content to rely solely on Belle’s updates, I visited Jacob partway through his camp session. As I walked across the lawn to the building where Jacob was, several counsellors came up to me and gushed about how much they love my son and how much fun they have playing with him.

Jacob was wheeled to me flanked by five caring counsellors and his new friend, Nosson, the nine-year-old son of the camp director who was always at Jacob’s side. As soon as I saw Jake, his huge gap-toothed smile was all the convincing I needed to know that he was in his element.

We toured the camp and met his princesses, whose number had grown exponentially. Jacob looked tanned, healthy and ecstatic. I was so proud of my little guy, and all the tension I had inside my gut evaporated.

He was excited to see me, as evidenced by the wet, sloppy kisses he kept giving me, but he was not ready to come home. As I was leaving, I asked if he wanted to come with me, to which he quickly replied, in his way, “No!” When I asked if he wanted to stay with his princesses, he didn’t hesitate and immediately nodded his head “Yes.” After a few more hugs and kisses, I drove away with a sense of calm that had eluded me since the night we brought him to camp.

This month, as the school year winds down, Jacob’s clothes and medications are once again ready to be packed. Remembering his beaming smile and high-pitched squeal when I visited him last summer, I have no doubt that I am doing the right thing for him. I know that Jacob will, once again, have the time of his life. What more can I want for my son?

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[Vincent Clement](#) 6/22/2010 10:35:21 AM

Sick & Tired: Summer camps for children with special needs are not like your typical summer camp.

The camp my son attends has a 1:1 staff/camper ratio, on-site nurse that dispenses medication (most camps require medications to be in blister packs), generators to run fridges, and so on. The kitchen uses fresh ingredients and caters to dietary needs as required.

Staff are trained in CPR and non-violent physical crisis intervention. They sleep in rooms that are just outside the campers rooms. Some staff used to be campers.

You can't live your life in fear, thinking "what if" all the time. All these kids want is a chance to enjoy what 'normal' kids take for granted. They want to experience life. Our son can't wait to go to camp.

[Visitor Health Insurance](#) 6/22/2010 10:06:51 AM

True that at the age of 7 ..it's very early to send him alone. But it is also true that this will defo help him increase his independence and I expect this could have been his best days!

[Ccdd](#) 6/22/2010 8:39:29 AM

The first thing I noticed about summer camp when I was 8 was the smell of the trees and the shield. This is a good thing for everyone to experience.