

## Talk To Your Doctors | 和您的医生聊聊

by Michael Leetzow | November 14, 2018

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If your daughter (or son) is approaching 18 years old, there are a couple of matters that you must handle. While most people know that when our children turn 18 years of age, they are no longer ours, but they are their own person. For me, that meant working with my attorney to be appointed as my daughter's legal guardian – her guardian advocate here in Florida. Not difficult to do, **but imperative that it be done.**

当您的女儿(或儿子)快到 18 岁时,有几件事您必须要处理了。虽然大多数人都知道,当我们的孩子 18 岁时,他们就不再属于我们,而是属于他们自己。对我来说,这也意味着我要和我的律师一起工作,让我被指定为我女儿的法定监护人——她在佛罗里达州的监护人。做起来并不难, **但必须做。**

What no one told me was that you also need to talk to your child's doctors. And you need to do it before you have a medical emergency. Let me explain. My daughter had Rett Syndrome. She was 19 and usually very healthy. It took a lot to get her sick, but when she was, we usually ended up in the ICU. The culprit was usually pneumonia. The left lung most of the time – sometimes both. For 10 years we went to a children's hospital – that's where we were in the ICU no fewer than 4 times. That's where her rods were put in to straighten out her spine. So, the last time she was sick, I loaded her up and took her to the children's hospital. We checked in and went to a room to start the process of determining how bad it was.

但是没人告诉过我还需要和孩子的医生谈谈,特别是需要在有紧急医疗情况之前做这件事。让我解释一下。我女儿患有 Rett 综合征。她 19 岁,大多数时候很健康。她很不容易生病,但一旦生病往往就会住进 ICU。罪魁祸首通常是肺炎。大多数时候是左肺,有时两者都有。在过去的 10 年里,我们常去一家儿童医院,在那里我们住了不下 4 次 ICU。她也是在这家儿童医院做的手术植入了那根用来伸直脊椎的金属杆。所以,当最近一次她又生病的时候,我也是把她抱起来送到了儿童医院。我们办理了入院手续,进入了病房,然后开始检查看看病情怎么样。

Well, very shortly after arriving in the room, the nurse came in and told us we were being transferred to the regular big-people's hospital a couple of blocks over. I didn't understand. My daughter, although 19 + years old, was less than 4 feet tall and weighed only 49 pounds. She is a child and belongs at the children's hospital. She still watches the kids shows and videos! She can't be an adult.

不过,当我们刚进病房不久,护士就进来跟我们说要把我们转到几个街区外的综合性的普通成人医院去。我真的不明白。我的女儿尽管已经超过 19 岁,但她身高还不足 4 英尺(1.22 米),体重只有 49 磅(22.2 千克)。她还是一个孩子,应该去儿童医院。她还在看孩子们的电视节目!她不可能是成年人。

Even though I objected and stomped my feet (literally), and called for the person who made the decision to come talk to me, it was to no avail. I was told that she was 19 chronologically and she had to go to the other

hospital. They required an ambulance trip to the other hospital – 2 blocks away! We had issues when we got there. They didn't have equipment or supplies that were the correct size – they had to get them from the children's hospital from where we just came. No real kids' videos and no way to hook up her dvd player to the big tv so she could watch her videos as we did in the children's hospital. They wanted to perform tests more appropriate to adults and they lacked appropriate food/drink choices for someone with Rett.

我表示反对，跳着脚反对(确实在跳)，并让护士把做出这个决定的人叫过来跟他理论，但是毫无效果。我被告知，她年龄上已经 19 岁了，必须去别的医院。他们要求我们坐救护车到两个街区外的另一家医院去。而我们到那里时遇到了很多问题。医院没有尺寸合适的设备和器械，只能临时从我们刚被赶出来的儿童医院购买。医院没有真正的给孩子准备的视频节目，也没有办法像我们在儿童医院那样把她的 DVD 播放器连接到大电视上看她的视频。医院做的检查更适合成人，而且也没有适合 Rett 患者的食物和饮料供选择。

**Please, please, have this conversation with your doctors and the hospital in advance.** You do not want to be fighting for your child's life on one hand and fighting the hospital at the same time for the most appropriate place for treatment.

**请一定，一定，一定要提前和您的医生和医院谈谈。**您不会愿意在为孩子生命奋战的同时，又在为找寻最适合治疗的地方而跟医院奋战。

Many medical institutions are implementing transition programs to move the chronically ill children from the pediatric side to the adult side. If your child is approaching 18 years old, please check with your doctor and the hospital you use to make sure the transition happens more smoothly for you than it did for us. And call your lawyer while you are at it so you are able to make those decisions when you arrive at the correct hospital.

许多医疗机构正在实施过渡项目，将患有慢性病的儿童从儿科转移到成人科室。如果您的孩子快 18 岁了，请咨询您的医生和您常去的医院，以确保您的过渡过程比我们顺利。然后到满 18 岁的那一天，请打电话给您的律师，这样您就能做好决定，在需要时前往正确的医院。