



Informed Consent

by Steve Dolling

Steve Dolling brightened many a dreary day for subscribers of the ACOR nblast listserv with stories of house repairs (in his underwear), hospital parking woes, sailing with a bread-loving Portuguese Water Dog named Scupper, and daily life fighting NB. Spencer (May 12, 1995 - May 21, 2008) said it best when he explained, "Aside from having cancer, you can see I have a pretty good life." The Dollings are now aboard the Blackdragon sailing where ever they fancy.

<http://www.sailblogs.com/member/blackdragon/>

By now you are used to the familiar style. Deep sense of drama that sucks you along for a page and a bit followed by a quirky twist that tickles the funny bone. This isn't one of those, and if that is what you are hoping for, you are likely to be disappointed. Of course there is no way you are going to believe me here at the beginning. You've been fooled before. Fair warning. I had to advise you of the risk before we begin. It's your choice whether or not you care to read on.

Informed consent. It's the foundation of all the non-emergency treatment and diagnostic procedures that they do at the hospital. Whether it was created as the outcome of some enlightened medical care philosophy or it was thrust into the healthcare realm by an overly-zealous legal system doesn't really matter. Inherently, you have the right to choose. Nobody can do anything to your child without your OK. The decisions belong to you.

So how does it all start for the typical cancer family? Some hideous sequence of events brings you to Children's hospital. The first things they need to do are tests. Lots and lots of tests. "Yes we would like to do an ultrasound, x-ray, CT scan, bone scan, more blood tests, and an MIBG to accurately diagnose and stage your child's disease." Yes you get to choose whether or not to subject your child.

Inevitably follows some definitive diagnosis and a treatment protocol. The reams of chemotherapeutic agents all have side effects. "This one causes baldness, that one causes high frequency hearing loss, this one can affect the kidneys, that one can affect the heart, nausea is a common side effect, etc. etc." You listen with a sense of bewilderment and some amusement. You have a choice but don't even bother to ask about the alternative. You already knew the first time you heard them say the word "cancer".

Depending on what you're up against, surgery might be part of the game. A general anesthesia alone sounds like a bad risk. Once the surgeons fully detail all the potential complications of what might happen when your kid's particular tumor is removed, you sometimes wonder about the benefit of being informed. It doesn't leave you with a sense of comfort, but at least you have the choice.

Then there is the bone marrow or stem cell transplant. Now that meeting is a happy one. Let's contemplate the potential major organ failures: kidney, liver, lungs, bone marrow, and very occasionally, the heart. "Oh and of course there is some risk to the brain but generally not unless the other organs go first. Oh yes and of course there is infection. Your options are bacterial, fungal and viral. They are all potentially lethal, but we do our best." Strangely enough, they don't even mention hair loss as an adverse side effect on this one. Remind me again of the options please, I have a choice to make.

These are all the impossible choices. Not that it is impossible to choose one way or the other. It just feels impossible to believe you are in the situation to begin with. Impossible to believe that you might eventually reach a point where you might want to consider option B.

But it's not all high-drama. Every day there are a bunch of informed medical decisions to be made. Would he like this medicine in liquid form or can he take a pill? Gravol now or should we wait and try to space it between the ondansetron doses? Platelets are low today, but not real low, we could hold off until tomorrow to transfuse if you can come back to the clinic then? He's losing weight; we should consider an NG tube. And on and on and on.

These are all the meaningless choices. Not meaningless in the sense that they are unimportant. Do a good job on all the day-to-day stuff and it can have a big impact in your child's comfort and your peace of mind. Make all the wrong choices though, and it won't likely have any effect on the final outcome. In that sense, they're all meaningless.

So of all the impossible and meaningless choices that you get to make, is control just an illusion? Isn't it just one great train ride you are on and at some point you pass a switch in the track that determines your final destination?

That might be true. But there is one other choice you get to make that does have a lot of meaning. It may or may not affect the destination, but it certainly does affect the ride. It's not even an obvious choice because nobody will ever present it to you. You don't have to sign the consent form. You don't even have to announce your decision.

You get to choose how miserable you want to be.

OK. Life sucks. Your kid has cancer. But every day you get to choose if you want to be pessimistic or optimistic. You get to choose whether you want to be a victim or your kid's biggest champion. You get to choose if you want to endure the day or have some fun and make the best of it whatever it brings you. You get to choose what example you want to set for your kid. And you get to choose whether you want to teach your kid that he has a choice of whether or not to be miserable.

It's a choice that you actually get to make a dozen times a day in different circumstances. And you don't always have to make the "happy" choice. Sometimes it feels really good to just have a bad moment and tear the head off the incompetent idiot who appears not to have the skills to issue your parking pass.

Once you realize that you actually do have control over just about everything in your life except perhaps the impossible choices and impossible outcomes, it makes the journey a whole lot easier.

You might still be lumbering down the railroad, but if you believe you're flying the space shuttle, you might actually have a better chance of reaching escape velocity. And it's a whole lot more fun to eat astronaut food.

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