

# Rant: parents of chronically ill children

Original article by: [Michael Tam](#)

*Warning: the following is a rant of my personal opinions on the issue.*

This article for inspired by a [comment received](#) by a family member of a chronically ill child. The comment is representative of many "difficult parents". In this article, I will dissect it and give you an alternative way of thinking.

I'm not a doctor but a grandmother of a baby that was born with Christmas Tree Anomaly. As a result she has short gut syndrome. She was admitted to hospital for dehydration after a gastro virus made her vomit. They were hydrating her very well but as always before they seem to overdo it and now she is in ICU because her sodium and potassium levels shot up. So when your calculating the IVs, please consider that this is a person's life you are messing with. This is a 15 month old beautiful baby girl that is spending her 2nd Christmas in the hospital all because her levels were not being watched properly and they did not account for what was already in her body when they smacked another IV drip up there. Doctors, listen to your patients and their parents. They may know more than you think they do and maybe more than you do. After all, this baby is the little girl that will be sneaking up on Christmas morning to peek at presents that someone loves so dearly. And one day it may be your loved one.

On the face of it, this seems fair enough. A child suffers an adverse outcome and the family is angry at the doctor. However, is it? My analysis is that this comment contains many uninformed if not unfair criticisms engineered to belittle and dominate the doctor.

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The impudation of course is that we don't consider a baby to be a precious human being in our work. This is of course untrue and parents who suggest otherwise should be corrected immediately.

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I do not, of course, know of the actual scenario but I am almost certain that the above again is not true. The child has a short bowel syndrome with acute gastroenteritis. Fluid calculations are always difficult for these children. Unfortunately, the medical profession suffers from the "burden of perfection", with patients (and family) not understanding that a certain proportion of poor outcomes is normal with the current level of knowledge and technology.

This child is spending her time in hospital not because she was overhydrated as is claimed. It is almost always safer to err on the side of overhydration. She is in hospital as she has a congenital abnormality. The fact that she is alive at all at two years of age is a triumph of the advance of medical science in the last several decades. Though family may lose the "big picture", you should not, and you should try to educate the family if possible.

*Doctors, listen to your patients and their parents. They may know more than you think they do and maybe more than you do.*

You should always listen to the parents of a sick child. Often, they will know more than you *about their child*; having lived intimately with the child for months or years. However, never lose your objectivity. The parents, unless they are medically trained, would almost certainly **not** know more than you. Your duty is to the patient, that is, the sick child, not to the whims of the parent. Where

the parent significantly disagrees with the course of treatment, your duty would be to speak with the parent, try to understand their point of view, educate and insist on the best course of action.

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The form of this comment and argument is what is known as "[appeal to emotion](#)" which is a [logical fallacy](#). Although it is *understandable* it does not hold any truth. Take it as you will, but this form of logical armour is required to protect you from emotional manipulation from both patients and family members. A quotation from "[Dune Messiah](#)" by [Frank Herbert](#):

### **Reason is the first victim of strong emotion...**

Your duty and professional obligation to your patient is best served by reason and objectivity. Emotional conflicts and feelings of guilt can be subtle. Try to be mindful of your feelings and reframe the situation. What is the parents' agenda? What is yours?

Be logical and objective. Remember the arrow of time travels in only one direction. *Would* (not *could*) you have done anything different?

If there is one thing to learn, it is that you must engage with the parents of ill children. You must keep them involved in the care giving process. If they understand what is being done, as well as the limitations and are given realistic expectations, then we shouldn't receive the above comments. They are a symptoms that communication with the family could have been better.