



Complex Child E-Magazine

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Avoiding Erroneous Munchausen Syndrome by Proxy Allegations by Anonymous

To most parents, the idea of intentionally making their children sick is a foreign one. To most parents who have seriously ill children, the idea is all the more horrifying.

Unfortunately, there does exist a tiny subset of the population who deals with a serious mental illness called Munchausen Syndrome by Proxy, a disorder in which a caregiver--most often a mother--actively makes her child sick in order to gain attention. More recently, the condition has also been called Medical Child Abuse. Caregivers with this condition are often extremely good at covering their tracks, and many times, if not stopped, will continue until their children are very severely harmed, or worse.

Victims of Munchausen By Proxy Syndrome

There are four victims of this condition. The caregiver, who clearly is struggling with severe mental illness, is one. The child obviously is another. The doctors who are deceived into testing and treating the child, often in very invasive ways, are the third victims.

Lastly, the victim most people don't consider is the parent out there with a legitimately sick child, especially a child who might have a confounding or uncommon condition. It's the parent who ends up under scrutiny by the medical establishment--and in extreme cases the authorities--when her child's diagnosis is not immediately obvious. While this is often an overreaction on the part of the health care workers, one has to be careful not to place too much blame on them for being overcautious, considering those very health care workers may have been drawn into harming a child in the past due to a parent with this condition. When the stakes are so high, it's understandable that they occasionally make the wrong call.

Many families who have children with Mitochondrial diseases or other unknown multi-system conditions unfortunately have fielded suspicion at one time or another. While the number is not a lot by any stretch, it is a significant enough number to be worth addressing.

Mitochondrial diseases include complex, uncommon, and often confusing sets of conditions. Often families have gone through years of testing, frightening symptoms,

compounding questions, and many baffled doctors before they finally arrive at a diagnosis. The much sought-after diagnosis rarely provides answers, but instead creates even more questions and uncertainty than ever for parents.

Unfortunately, these are the very reasons families dealing with Mito and similar conditions have found themselves under scrutiny at times. A child who gets progressively sicker, with little explanation as to why, tends to send up warning flags in health care facilities. Unless the child's doctor is particularly knowledgeable in the metabolic field, it is not uncommon for Mito to go unrecognized for a very long time. Even after diagnosis, it is not unheard of for some families to find themselves the target of investigation. The unusual nature of the disease, the unfortunate frequency of inaccurately informed physicians, and the emotional toll the disease can take on a family can all play into a health care worker's concerns and lead to an allegation.

Protecting Yourself

There are, however, ways to protect your family from this scenario, simple steps that are good sense for any family dealing with a child who has complex medical issues. They not only serve the purpose of protecting the family from well-meaning but devastating allegations, but they can also serve to help in the long term care and treatment of your child.

- ☐ Never attend your child's appointments alone. If it's at all possible, take the other parent, a grandparent, an aunt/uncle, or even a good friend.
- ☐ If it's simply impossible to bring someone else to an appointment, take turns with the child's other parent. Share the caregiver role equally with both parents. This single step can go a very long way in assuring a physician that the child has a stable and healthy home life.
- ☐ If it's possible, encourage your child to talk to the doctor rather than answering the question for him/her.
- ☐ Request copies of clinic reports (you are entitled to see them) and double check them for accuracy. One small error can compound over time and become a major problem down the road. If you notice errors, request they are corrected.
- ☐ Don't make major decisions alone. Always involve the child's other parent if possible, or other family members if not.
- ☐ When your child is hospitalized, do not be the only person staying with him or her. Even if it's only for short visits or breaks, have other family members or friends come and stay with the child. If at all possible swap overnights with the other parent. Again, demonstrating that the child has a healthy and supportive family life will help allay any concerns on the end of the health care workers, and will serve to protect you should a false allegation come forward.
- ☐ If your child has a central line, IV, or feeding tube, allow nurses to provide all care and administer all medications while in the hospital.

These are basic steps that are not only helpful in protecting your family from a very real concern, but they are good positive steps you can take in caring for your child. Having multiple people involved in providing care and making decisions about your child's health care is a good thing regardless of the reasons. Nobody should have to travel this road alone, or make these sorts of decisions independently.

Handling Mistaken Allegations

While a false allegation is every parent's worst nightmare, remember that in spite of the occasional horror story, the vast majority of the time, innocent parents are indeed recognized as such and investigations are dropped. Remember the health care workers are not the enemy, nor are the authorities who are bound by law to investigate. They are simply doing what they need to do to ensure no child is needlessly harmed.

Unfortunately, in a system such as ours, the cost of ensuring the safety of all children means that many parents are falsely accused and put through the torture of an investigation at the worst possible time. Recognizing the risk exists, and taking steps to protect your family should significantly reduce the chances of dealing with such a situation, and will serve to protect your family should the worst play out and you find yourself under investigation at some point.