

The Munchausen Syndrome by Proxy Perpetrator Profile or Warning Signs (quite different from diagnostic signs)

Reactions from parents of chronically ill children appear in italics

The following profile list is compiled from several profiles available on the internet, including the FBI list.

Note how illogical and contradictory they can be.

- Primary caregiver, most often mother *[99% of those accused are female]. This describes 50% of the population and most caregivers. You can't profile on such a common characteristic. Fathers are often very involved in caregiving, if you ask.*
- Educated, middle to upper class. *Why would this be a bad thing? So why are more accusations against poor mothers? This group is more likely to appropriately consider doctors to be their hired consultants.*
- A highly attentive parent who is reluctant to leave her child's side and who herself seems to require constant attention. *This is entirely typical and appropriate for the parent of a sick child. Often they have to play the squeaky wheel. Children should NEVER be left alone in a hospital. Hospital personnel EXPECT parents to stay overnight and help care for the child. An overwhelmed and confused parent needs and deserves reassurance.*
- Friendly with medical staff and highly supportive and encouraging of staff. *Totally appropriate in this decade. Interestingly, many MSBP accusations are filed the day after the patient sues for malpractice.*
- Some medical background, most often nursing. *Most parents of sick children end up with an amazing level of medical knowledge. Nurses are more likely to be vocal advocates because they realize medicine is an inexact science.*
- Takes child to multiple physicians, moves frequently or transfers to another facility. *Seeking experts is completely normal and appropriate for the parent of a child with a difficult or undiagnosed condition. Many disease groups have documented an average of 6-10 physicians missing the diagnosis. Not all those missed diseases are rare! (celiac) Families move due to job changes more frequently than in the past. Insurance changes can necessitate a change in physicians.*
- Refuses to accept changes in diagnosis or lack of diagnosis. *If an adult was in pain or feels terrible and told there is no reason for it, they would refuse to accept this. Why should parents accept the lack of a diagnosis?*
- Demands specific medical procedures or medications. *In this day and age, it is quite common and appropriate for patients to research tests and treatments and request them. Pew Charitable Trust has research papers documenting this.*
- A parent who appears to be unusually calm in the face of serious difficulties. *Different parents have different coping styles and this should not be held against them. Project Delivery of Chronic Care sends medical residents to visit homebound, profoundly disabled children. The residents are usually completely astonished at how well and calmly many parents cope with situations that most people would consider intolerable.*
- A parent who is depressed or overwhelmed. *Again, a different coping style or a temporary stage. Most parents of chronically ill children get depressed at some point. Most are chronically overwhelmed. Getting help for the depression is a positive step and should NEVER be used against the parent. Often a parent will realize they are depressed and overwhelmed but be unable to take the time away from the child to care for their own health. Many fantasize about walking away. Remember the phrase, "It only takes a single child to raze a village."*
- A parent who is angry and demanding. *Again, a different coping style/personality style and sometimes appropriate or necessary to get the child help. Many parents get little sleep due to their child's illness. Women in particular may still be accused of being hysterical. In the old days, the favorite treatment for some childhood illnesses was Valium for the mother.*
- Marital problems, distant spouse. *One spouse may spend extra time at work due to financial stress or may have to stay home with siblings. Marital stress is common even with colic. With a chronic or mystery disease, if doctors disagree on treatments, so will the parents. Many fathers leave due to the chronic illness or death of a child. This should not be held against the remaining spouse who needs additional support. Spouses may naturally and subconsciously fall into roles that don't fit your paradigm, yet they may be*

perfectly functional in a dysfunctional situation. Parents may take turns falling apart or keeping it together – an unwritten rule prevents them both from coming unglued at the same time.

- *A parent who dramatizes small crises or seems to have new crises continually. As a way of getting your attention? Because life with a sick child IS full of crises? To laugh instead of crying? Is their Pissing and Moaning Quotient really that high or do they have many legitimate things to complain about? Parents of sick children get sick themselves easier, lose their keys and have minor traffic accidents more because they operate on overload every minute of every day. Complaining or talking about their stress is a good thing, but we no longer encourage parents to do it with their child's doctors.*

- *Welcomes tests, even if painful. Knowing is almost always preferable to not knowing, even with cancer or fatal diseases.*

- *Leaves out portions of medical history. Long, complicated histories need to be summarized. Dead ends or leads the parent doesn't put stock in may get left off.*

- *Child's symptoms don't fit known diseases. Medicine is full of mysteries and many people with rare diseases see dozens of doctors who don't recognize the pattern*

- *A child who has one or more medical problems that do not respond to treatment or that follow an unusual course that is persistent, puzzling and unexplained. INDEPENDENT medical experts who have a flair for medical mysteries should review the ENTIRE medical record AND see the child with their own eyes AND be allowed to talk freely to mom about the medical history and her theories.*

- *Physical or laboratory findings that are highly unusual, discrepant with history, or physically or clinically impossible. Children with metabolic diseases have 'impossible' lab results. Lab work should be carefully repeated and any odd results thoroughly researched before any action is taken. Video cameras should be used with EEGs and apnea monitors. Toxicology results can be due to a chemically similar substance (epicac and benadryl look the same on chromatography). A toxicology expert should be consulted.*

- *Child has multiple hospitalizations. Common in chronic illness.*

- *Child's symptoms improve when away from mother. Some diseases get better on their own or have a course that waxes and wanes unpredictably. A change in diet may fortuitously improve the symptoms in an allergy or metabolic situation. The change in symptoms is valid only if mother has trained the observer to watch for subtle changes. Children with rare diseases have become much sicker and even died when away from the mother. The CINA attorney should see the child and talk to the temporary caregivers frequently. Temporary caregivers MUST have the full medical information from the parents.*

- *A family history of similar parental or sibling illness, unexplained sibling illness/death. Many illnesses are genetic. Relatives may live for decades with mild symptoms. Patient associations should be consulted for possible genetic connections that are not yet published. For deaths many years ago, parents should be asked if they have a theory about the cause of death. A retrospective look at unexplained deaths is needed. Parents should be allowed to provide witnesses.*

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