



Complex Child E-Magazine

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Keys to Organization: Maintaining Communication, Time and Sanity by Jennifer A. Peterson

Once my husband and I had become confident in our ability to care for our son's medical and neurologic needs, a thought hit me out of the blue. It was one of those moments of sheer panic. The drive to become organized started in earnest when I wondered what my husband would do if something were to happen to me. *Are we prepared?*

I had information about all of my son's providers scattered around the dining room and among some of his medical records. My husband could figure out the main pieces, but there were still the nuances and schedules that only I really knew about. Then the real panic struck: *how would people know everything that goes with securing our son's daily care?*

I drew insight from my background in the sciences and law, along with various personal strengths. My most successful times were while doing work behind the scenes as a secretary and paralegal. Lists, calendars and reference guides continue to be invaluable resources at my disposal. With a family background in nursing, familiarity with medical terminology came easy. Above all, I had an interest in the structure of organizations and hierarchies--how everything came together to work as one giant machine. Employment with my hometown's municipal building and later in the legal profession furthered my understanding of these systems.

Tools of the Trade

As parents of children with special needs, we do not want other families to feel as though they need to recreate the wheel. Every time we see a new parent on a medical forum asking for guidance, it is hard not to relive those first feelings of helplessness, wondering where to start.

Here are my tips:

Between appointments, school and therapy sessions, the traditional wall calendar will eventually go by the wayside. Having a paper or electronic day planner is one of the first things I would highly recommend. If possible, take it everywhere you go.

If your child has multiple medications to be administered several times daily, doses can be made up ahead of time. The Lock-n'-Lock brand is a great example of a medication storage device that is handy and comes in different sizes. Be sure to check with your doctor or pharmacist to see if this is permissible and refrigerate pre-made doses, if necessary.

Compile a medical history at-a-glance form and keep multiple copies of it everywhere, in all vehicles, activity bags, purses, backpacks, at school and to relatives' houses you frequent. Try to update it once a month or as often as necessary. See accompanying article on this subject at <http://articles.complexchild.com/July2009/00135.html>

Another very helpful item we adopted is having a "go" bag, which was an idea from a previous article on this website. I took it a step further and collected some of my older clothes and went to the dollar store for toiletries. You never know when an unplanned trip to the nearest children's hospital is in order. Our preparation has proven successful when our son's GJ tube unexpectedly broke and had to be replaced.

I'll give another plug for Wrightslaw materials in the context of documenting and organizing everything. Get into the habit of requesting copies of medical records on an annual basis. It is worth the effort when you are coordinating both medical care and obtaining proper educational services for your child. Having a reputation of being on top of things is seen as a relief by teachers and medical staff. That way, everyone has more time to get down to the topic at hand instead of figuring out who never received a specific document. On the other hand, it comes in handy when you must prove your case during a dispute with the school or to explain why you are refusing a duplicate medical test.

The Everyday

Being on top of everything in our house lasts a day or two at best. Trying to keep organized *and* care for young children is hard enough even with typical children without special health concerns. The usual telephone call has me covering the receiver every now and then when I hear the sound of "*Mommy!!*" Better yet, it's always fun to clean up a biological mess one-handed for fear of having to hang up and spend forever on hold again. With our luck, the time when everything is caught up is when a funding source or service provider randomly decides to throw us a curveball. Ironically, this happened while drafting this current article, no less.

Admittedly, my weakness is in getting paperwork properly filed away at home. There are probably quite a few readers out there who also have big piles of paper stacked somewhere. Be assured that there are very successful parent advocates out there who have the same filing style!

Conclusion

Planning ahead during downtime helps when a crisis is at hand and there is no time to wonder if you packed the charger for your child's medical equipment. Unsettling as it may seem to imagine disruption of the status quo, try to reevaluate your family's situation if the following were to suddenly become an issue:

- Unplanned long-distance travel
- Change in employment
- Having to move
- Power outage
- Birth of a child
- Change in family members living together

What services could your child or family become eligible for? What if there are gaps in insurance coverage? Do you have a backup supply for medical equipment, medicine or bottled water for mixing formula?

Currently, coordination of social services, medical staff, educational programming and finances usually falls to one immediate family member. Maybe one day this burden will be relieved--even if somewhat--by either a professional or through technologic advances. For now, though, as parent and primary caregiver, this is my chosen profession.