

## WORKING WITH THE SCHOOL SYSTEM WITH AN ILL CHILD

School is where a child spends the better part of his or her day for at least 13 years. While common illnesses require little to no explanation, describing how your child may be struggling with gastro issues is a definite challenge. While most find a conversation with the teacher is necessary, they may come away from it feeling they've not been understood. For a parent feeling the need to explain a private and poorly understood medical problem to a teacher with 30-40 students, it can seem an overwhelming task.

Many kids with motility issues suffer in silence due to the nature of their condition. Parents may follow suit in an attempt to protect their child's need for discretion and normality. But when frequent absences or trips to the nurse's office or bathroom warrant an explanation, a parent must learn about the school system's provisions so the child's schooling can continue. Handling the conversation with school staff respectfully and courteously may require a fair amount of effort if the child has been questioned directly in a way that has caused embarrassment.

Unfortunately, some teachers are not completely aware of the school district's arrangement for ill children, if they've never had a chronically ill child in their classroom. Some teachers may conclude that because the student doesn't appear ill, the condition is exaggerated or made up altogether. Working beyond the teacher can help reach a better level of understanding of what's best for the child and his/her education. Working backwards, working with the district office staff first instead of the teacher directly, can help a parent understand the multiple modes of assistance available and how to proceed with the teacher or pursue higher methods of help. If a child has performed poorly in school due to ill health and state test scores are low, at minimum, tutoring or one-on-one help may be accessible as a provision through the public school district.

In the area we live in (terms and provisions may vary by school district or state), we were offered one of three plans to keep our daughter's schooling in place while she went through several hospitalizations and setbacks over three school years. Fortunately, each and every teacher she had was wonderful to work even though not one understood or had even heard of my child's rare condition. I didn't need them to understand it really, only to cooperate and support my child in our desire to keep her in school.

Our daughter reached such a level of poor health that a home-hospital program was suggested. This recommendation came from the school district's registered nurse (not the LVN in the office on campus, the RN at the district office who floats to all schools in the district). For such an arrangement, the child's treating physician must give the order in writing. In our case, our daughter's doctor was strongly opposed to this idea. The doctor felt what was best was that she should power through setbacks and maintain a normal routine of attending school. I was stuck somewhere in the middle, seeing both sides of the district RN and the doctor and the pros and cons to each of the opposing sides.

We opted for a compromise: a plan called a 504. A 504 plan meeting is attended by several district employees - the teacher, principal, district registered nurse, and possibly district psychologist or counselor. This plan provides a written set of instructions to be outlined in behalf of the child so he/she is protected and accommodated. Frequent absences being a problem and nasty notices that may accompany them will stop and the time and stress involved in keeping up or making up school work can be adjusted so the student can work at his/her own pace during health challenges.



Prior to our 504 meeting, staff involved prepared us for the upcoming meeting and asked for our personal input in the plan's instructions. They also were courteous enough to ask what our daughter wanted - did she have any requests? Ask your child what would make him/her more comfortable at school. Does he/she want to stay in school? Would more support at school help to motivate him/her to complete school assignments? Managing the overwhelming school work piling up can be the biggest hurdle of all.

In our daughter's situation, her 504 provided for several things: permission to use the bathroom in the nurse's office (cleaner and more private); permission to leave the classroom at any time for bathroom trips; excessive absences excused; extra time to make up missing assignments or to complete assignments with frequent absences; access to snacks or medicine (in the office), if needed to improve the student's symptoms and to remain at school; being excused from physical education class, if unable to participate. This plan required some medical records but not a doctor's order. The district nurse did request written proof of our daughter's diagnosis.

For kids in a private school or on a home-school program, the arrangements for help and support may be available through a less formal approach. Quite possibly, the private or home-school programs may be preferred due to increased flexibility, smaller classes and a more personal support system.

After three rough years in the last half of our daughter's elementary school period, we opted for a home-school program. We chose this mainly because of the flexibility of time when school work could be completed. Ultimately, we control the time she does homework and make adjustments on down days, hospital stays, surgeries, doctor appointments, etc. When she needs a day off, she takes it. If we want to plan a day of something fun (or educational), we do so. Having the choice and the control has lessened the stress in our home of the regimented school routine. We have never looked back even after my daughter made huge strides with her health. Now, we are glad to have the opportunity to have more time as a family and balance that with the same school curriculum she completes at her own pace that we plan together.

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