

Parent to Parent



Learning to Transition

Since the birth of my twins, at 23 weeks gestation, I have had to learn to transition... transition into parenthood, transition into losing a child, transition to caring for a child with special needs...and it keeps going. Transitioning means: leaving what you have come to know as your "norm" and going to a place that is unfamiliar, different, sometimes exciting but most often scary. I accepted that each transition has had a lesson that made moving through the transition just a bit more manageable.

Transitioning from hospital to home: Few people like being in the hospital. For a fragile child, however, the hospital had a level of security. People and machines that were ensuring appropriate care. As we left, there was fear of losing the extra eyes that watched my child and assured me all was okay; it was leaving the machines that showed me hourly that my child was breathing and functioning appropriately; it was being a parent - in our case, for the first time - with machines and tubes we now took home and had to monitor ourselves. It was scary. *Lesson:* Ask a lot of questions, be comfortable in what you know and don't be ashamed to ask about what you do not understand.

Transitioning into in-home nursing care: My home went from being a sanctuary to having many "strangers" - i.e., nurses for day or night shift with different nurses on different days, therapists for all aspects of care - in and out on a regular basis. Things were no longer in their place, things were missing or broken, and there was no longer peace. I set schedules, parameters and still I felt invaded, yet grateful, since the presence of people abated some of the fear developed from leaving the hospital. *Lesson:* Set ground rules, establish clear expectations on both sides, and make sure that you address any issue early to avoid letting it fester.

Transitioning into early intervention: Now, added to the nurses were therapists. Their goal was to teach us ways to integrate little things into our daily routine that would encourage development. *Lesson:* Make sure the therapists understand your family life. Be comfortable saying what is realistic with your routine and that you understand the purpose and intent of the activity.

Transitioning from early intervention into preschool: The comfort I had with knowing my child was home was now shattered with a new routine based in a school setting. The separation was both normal and terrifying. I now had to learn a new "system" in the school and learn how to let go of what I had just learned how to manage. Therapies

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were now done in school and were no longer integrated into the family routine. I was less involved in many ways and was feeling left out. *Lesson:* Use the team meetings with the teachers and therapists to fully understand their goals and be sure to share what you see and do at home, ask for ways to duplicate what they do to help observe the development, and be able to share your perspective on improvements or lack of. Keep communication open!

Transitioning from preschool to elementary school: When my child attended preschool, the teachers and therapists regularly shared a great deal of information on how she was doing. The preschool staff seemed to have an implicit understanding that parents are worried, protective, and need some coddling or support through letting go and letting the child grow up. When Mari transitioned to elementary school the philosophy changed. Kids are growing up and need to develop independence - and so do the parents. Regular communication continued, but not the minute-by-minute schedule of what was done, just an overview. *Lesson:* Be sure the Individual Education Plan (IEP) goals align with your developmental expectations for your child. In some areas, you may consider other sources of therapy outside of school, which may still be covered by health insurance, at clinics or by pediatric therapists in your community. School-based therapies often focus on development necessary for doing school work and interacting in school. We added supplemental therapies to focus on general development, such as dressing, walking independently, etc.

No matter what the transition, the challenge, the accomplishment, there is always a lesson. Figuring out what that lesson is and using it to make the next transition more manageable is the biggest lesson of all.

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