

# TRANSITION TOP 10 LIST!

- Patti Hackett -

1. **EXPECTATIONS** - Live the life you would have before the diagnosis, just know that it will need some modification and maybe equipment or medication. Seek to live life to the fullest. Surround yourself with positive believers. Find mentors for yourself and for your child.
2. **HOPE** - often families when they ask for something different are greeted with: No one has ever asked for that before -or- It probably wouldn't work. Well what have you got to lose while trying? It's a whole lot better than just sitting there. On your way you may find what you are looking for.
3. **TRANSFER EXPECTATION** and hope to your child - Early on they need to see you believe in them and they will believe in themselves. Later that team - you and your child - will be an awesome force!
4. **INFORMED DECISION MAKING** - The old saying, "The more you know, the more you get" is true. And now via the internet we are only a click away from finding people, resources and ideas to make life easier and hopefully better. You do not have to know everything or everyone, just know the connections to sources that do. Be familiar with the laws (ADA, 504, IEP.)
5. **LIMITATION** - may give you a right turn to a better resource - Boy I have a tough time even typing that word. But sometimes there are issues/problems that cannot bend or change, but if you look at it square in the eye the next turn after that may get you where you want to be. In this age of assistive technology, more things are possible. Once we made a wheelchair vendor quite mad, he refused to work on my son's chair. This had never happened before. We were stymied as his chair required high tech skills. Well the next vendor turned out to be even better than the former one and we would have never found the new one without the other experience. It was a dead-end—we acknowledged we could not change it and moved on.
6. **WELLNESS** - Whatever the health issue learn how to avoid or minimize periods of sickness. When we feel well we get to do more things in life. Kids are in school, they are learning, they get to play and not be in the hospital. Teach your child early about his diagnosis, have him involved in treatment plans, medication ordering, making appointments for well visits. This lesson is a life saver.
7. **EDUCATION** - Whether it is in a classroom or during a community/recreational activity be involved, be with friends and go the inclusive route whenever possible. Book learning and life skills get you farther in life.
8. **OWN VOICE** - This relates to informed decision making. So many times families have had to be the "tree shaker" to get the system to respond. But we need to make sure we give our children the opportunity to learn how to lead,

how to get what they need and want. Promote opportunities where your child signs his name for "assent" (IEPs, medical procedures, etc) They need to know that nothing important happens to them without a signature. Learning how to "consent" to be an informed decision maker takes time and to our kids it is something they will face throughout their lifetime.

9. **HONESTY** - Life threatening health issues can be a bummer. After the "inhale and exhale" be prepared to answer the tough questions. When my son asked me if he was going to die. . . "Yes, we all do. You most likely will die from pneumonia; that is why we work hard to keep you well." When he came home from school saying kids teased him about his large head (it was large cause his body is so small), I had him look in the mirror and agree it was large; then we plotted what smart a\*\* answer he could use, "Yeah it's large to hold more brains."
10. **FUTURE** - The MCHB Healthy & Ready to Work national initiative believes EVERYONE DESERVES A FUTURE. . . but you cannot have one if you do not dream it and plan for it. Life is for living. Stay on the wellness path and out of the system. When we started putting life on the front burner and not the diagnosis, life became more fun. During his last hospital admission my son was asked if he had a living will. "No I have a will to live!" Ironically this was the admission that he later had to choose to have a tracheotomy and be on the vent 24R.

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As a former inclusive tech teacher I wanted my students to stretch and seek what life had to offer, learn how to problem solve.

As a mom of a son who is tech dependent and has a progressive neuromuscular disease I wanted him to take charge of his life, by teaching him along the way and letting him take bits and pieces early. Since age 2 he carried his insurance card (photocopied) and presented it at clinics, age 3 he chose which hand would have a blood gas, age 6 cosigned/assent all medical treatments, age 10 made his own DOC appointments, age 13 had a check book and paid for his co-pays.

Now that he is approaching 30 (has a few white hairs to prove it!) he is facing other life/death issues. He now consents with a signature stamp, emails his monthly equipment order and teleworks from home. Did I have this all planned out? NO. I did listen to what he wanted, and together we figured out how to get as close to his dream as possible. I am a mom, a life coach and now when needed a health surrogate.

*"The future belongs to those who believe in the beauty of their dreams." E. Roosevelt*