

**1. EXPECTATIONS** - Live the life you would have lived before the diagnosis. Just know that it will need some modification and maybe some (or lots) of 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** - Giving up hope means giving up dreams. Hope can help you to be productive in trying new things. And what have you got to lose? Hope leads you to find answers and new questions. Living with hope is a lot more interesting way to live. Find others to build hope with: join and build communities of like-minded people.

**3. TRANSFER EXPECTATION & HOPE TO YOUR CHILD** - Early on, kids need to see we believe in them. Then they will believe in themselves. Later this team — you and your child — will be an awesome force!

**4. TRANSFER EXPECTATION & HOPE TO THOSE AROUND YOU** - Often when families make a special request or do something that is different from what other caregivers and the public are used to, they are greeted with: "No one has ever asked for that before," or "It probably wouldn't work." Someone's got to be first, why not you? People are willing to say "yes" when they understand the complete picture. What you say, how you say it and when you say it can make change happen.

Sometimes you may not be able to change those circumstances or those views, and you may have to live with a lesser response or outcome than you wanted. When you can, however, work to convince people to give a new look to an old issue. Suggestions: 1) stay calm and don't appear agitated or impatient; 2) acknowledge the person for trying to help; (which may encourage him/her to actually help); and 3) if necessary, ask to speak to a supervisor. The people with more authority in an organization have more power to be more helpful; don't give up with the first "No."

**5. INFORMED DECISION-MAKING** - You do not have to know everything or everyone in order to manage your new situation well; now, via the Internet, we are only a click away from finding people, resources, and ideas to make life easier and hopefully better. Just recognize that opportunities exist everywhere for helpful connections to people in the know and to sources of information and help. Also, become familiar with the laws (ADA, 504, IDEA, HIPAA, etc.) and medical rights/information. The more you know, the better equipped you will be at making the right decision.

**6. LIMITATION** - You may think you are facing a limitation. Keep in mind, there are always little bumps along the road in addition to the big challenges. Limitation is a hard word for me to even type here. When I see that word I think of being stopped, giving in, or being "lesser than." But sometimes there are issues and problems that cannot bend or change, and at the moment you may feel as if you *are* being stopped. Facing a problem squarely in the eye might help get you where you want to be. A limit does not have to be a stop sign.

Once we had a conflict with a wheelchair vendor and he became quite mad. He refused to work on my son's chair any longer. This had never happened to us before. We were stymied because repairing Glen's wheelchair required high-tech skills. We had to find another technician who turned out to be even more skilled than the first one, and we got along fine. We would never have found the new vendor if we hadn't had a problem with the old one. That relationship had been a dead-end; we acknowledged that, realized that we could not change it, and moved on.

**7. 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 who are well are in school, have the chance to learn, get to play and stay away from the hospital. Teach your child early about his/her diagnosis; involve her/him in making treatment plans, ordering medications, and making appointments for well visits. This lesson is a lifesaver.

**8. EDUCATION** - Whether education takes place in a classroom or during a community or recreational activity, be with friends, and participate whenever possible. Book-learning AND life skills get you farther in life.

**9. EXPRESS YOUR OWN VOICE** - This topic is closely related to your skill in being an informed decision-maker. So many times it is families who have had to be "tree shakers" to get a sleepy or negligent system to respond. But we need to also make sure we give our children and youth the opportunity to learn how to lead and how to get what they need and want.

Promote opportunities where your child or youth signs his/her name for "assent" (e.g., IEPs, medical procedures, etc.). Youth need to know that nothing significant will happen to them in their medical care without a signature. Learning how to provide official consent is not only a commitment to be an informed decision-maker, but it helps kids express their needs, desires, and opinions. Teaching our kids to be involved in this way takes a bit of time, but is a great gift to them so that they can face challenges throughout their lives.

**10. HONESTY**- Life-threatening health issues can be more than a bummer - they can be staggering. People often feel initially devastated. After the "inhale and exhale," be prepared to answer some very tough questions. When my son asked me if he was going to die, I responded, "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 reporting that kids teased him about his large head (it was large because his body was so small), I had him look in the mirror. He agreed it was large; then we plotted what smart-a\*\* reply he could give from now on, "Yeah, it's large because it holds more brains."

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**FINAL THOUGHT...LIFE IS FOR LIVING!** 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 my son and I started putting life—not the diagnosis—on the front burner, life became more fun. During his last hospital admission, someone asked Glen whether he had a living will. "No, I have a will to live!"

**DID I HAVE THIS ALL PLANNED OUT?** As a former inclusive tech teacher I wanted my students to stretch and seek what life had to offer, and to learn how to problem-solve. As the mom of a son who was tech-dependent and had a progressive neuromuscular disease, I wanted him to take charge of his life and let him take on bits and pieces early.

From age 2 on, he carried his insurance card (photocopied) and presented it at clinics. At age 3 he chose which hand would have a blood gas procedure. At age 6, he co-signed, assenting for all medical treatments. At age 10, he made his own doctor appointments and called in prescription refills. He also was responsible for directing that his wheelchair batteries be plugged into the charger nightly, so his chair would be recharged by morning. And yes, when he forgot, it meant the next day his friends had to push his chair at school. (Going with dead batteries one day, made for a quick learning curve.) By age 13, he had his own check-book and paid for his co-pays. As he got weaker, he consented to treatments by directing others to use his signature stamp after he reviewed the paperwork. He emailed his monthly supply order and teleworked from home. Glen lived to be 30 (and had a few white hairs to prove it)!

Did I have this all planned out? NO. I listened 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 when needed, was his health surrogate.

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**HRTW Phase II Projects** are currently active in Arizona, Iowa, Maine, Mississippi, and Wisconsin.

*The opinions expressed herein do not necessarily reflect the policy or position nor imply official endorsement of the funding agency or working partnerships.*

