

YOUR CHILD'S DIAGNOSIS

For parents of children with special health care needs, we often find ourselves in situations which require more strength, instant in-depth knowledge and ending patience we never knew we had.

No one can say how things will be for you and your child. No one can tell you *exactly* what it is going to be like. Many people will try, and some (hopefully those on your health care team) will come close.

This next section is dedicated to all those moments when you will need to make decisions that only you as parents can make. It is designed to help you through some of the tough moments you may encounter with your child. The under-lying, probably most important piece of information we can give to you: Take your time, slow things down as much as you can, and listen to your inner voice.

Janet Morel, author of *Playing the Hand that's Dealt to You*, states:

“Above all else, I want to encourage you on your journey through this challenging life. Maintaining a positive outlook is essential to maintaining your sanity. That is just as important as any of the tips or ideas you may find useful. In fact, I would go so far as to say it is the most important part of living a happy and successful life, especially while playing the special hand that life has dealt you.” *

*Play the Hand that's Dealt to you: A guide for Parent of Children With Special Needs:
Morel, Janet Canmore Press 2002.

HANDLING THE SHOCK OF DIAGNOSIS

Tools for Parents of Children with Special Needs

Do you remember how you immediately felt after you were told what type of disability or special need your child has? Where were you? How were you told? How did you react? Consider the following questions that many parents ask after their child has been diagnosed as having a disability or special need. If you need help with your journal or writing down your feelings, these questions may help you with this process.

- What is the cause of your child's special need or disability?
- Could this disability have been prevented?
- Did something go wrong during the pregnancy or delivery to cause this problem?
- What did we do wrong to deserve this?
- Can this disability be "cured"? Will my child grow out of it?
- Why did this have to happen to us?
- How severely delayed will my child be?
- Is it safe to have another child?
- Does the genetic background of one parent contribute more to the disability than that of the other?
- I cannot help but feel sorry for my child. Is this wrong?
- If our child with this special need lives at home, how will it affect our other children?
- How can we explain the disability to our other children, to relatives, friends and neighbors?
- How can I deal with others reactions to my child's disability?
- Should we belong to some organization? Are there parent organizations that address our concerns?
- Will we ever be able to have a normal life again?
- What will happen if we precede our child in death? Who will care for him?

These are all excellent questions. We encourage you to talk with members of your health care team for help in answering these or any other questions that you have about your child's diagnosis.

Taken in part from: James J. Messina, Ph.D. & Constance M. Messina, Ph.D. Web site: www.coping.org

STEPS TO TAKE AFTER YOUR CHILD HAS BEEN DIAGNOSED

What should you do after your child has been diagnosed as having a disability or special need?

Here are a few suggestions:

Accept your child has special needs that you may need assistance in addressing. Sources for assistance may include:

1. Family, friends and neighbors who care about you and your children.
2. Doctors, nurses, dentists, psychologists, therapists, ministers and other health care workers knowledgeable in the field of children and disability.
3. Programs and schools (for help in receiving special education or training relating to your child's disability.)
4. Disability related organizations (i.e.: Muscular Dystrophy Association)
5. Support Groups.

Accept your child as your child is:

1. Resist the temptation to pressure or expect normal development in your child who has development challenges.
2. Avoid the impulse to fix your child. Instead, help your child in ways your child can develop.
3. Never miss an opportunity to praise your child.
4. Set goals and celebrate each accomplishment, no matter how small it is.
5. Give them as many opportunities as you can for developmental progress.
6. Find your child's strengths and strong points and build on them.

Other Tips:

1. Be there when your child needs you.
2. Learn to have patience – Don't take your frustrations out on your child.
3. Tailor the discipline you provide your child to your child's special need. Example: don't have a child who has a writing disability write the reasons why his/her behavior should change). Learn to be consistent.
4. Be honest (don't tell your child there is nothing wrong; don't promise a quick cure).
5. Take a positive approach.
6. Have faith and trust in the people who are trying to help your child.
7. Don't give up!!

QUESTIONS & MORE QUESTIONS

1. Sometimes a doctor or other member of your health care team may mention a possible diagnosis for your child's condition. Be sure you understand whether a diagnosis is **suspected** or is actually **given** (confirmed).
2. Write down your questions. Bring these with you to your next appointment. If your questions can't wait, call! Don't hesitate! Yes, you've heard it before: there's no such thing as a stupid question.
3. If you don't understand the terms or language (words) any member of your team is using, ask them to explain until you gain the understanding that you need.
4. There may be more than one acceptable medical treatment option for your child's condition. Ask what the options are and what can be expected from each option. If the decision you need to make is not life or death, ask for more time before you say yes or no to the treatment option if you need to.
5. Never hesitate to ask for a second opinion. A good practitioner (physician, nurse, and therapist) welcomes all opinions for the care of their patient.
6. Sometimes, however, "too many" opinions can add to the confusion when encountering a new diagnosis. Be patient with yourself. Learning about your child's needs and about what you need as a parent takes time. It is ok to request more time to consider a diagnosis or a new plan of treatment.
7. Make a list of people you want your child's medical reports sent to (usually requires filling out a Consent to Release Medical Information form) and be sure to include yourself.
8. When receiving a referral to another doctor or specialist, ask about the purpose of the referral. Make sure you understand completely what will be involved for you and your child.
9. You may have other needs that are non-medical in nature: for example—the need to receive financial support information or personal counseling. This is something that your Continuity of Care team member will be more than happy to arrange for you.

QUESTION LOG

QUESTION:

ANSWER:

**Example: What do you mean when
You say cognitive delay?**

Cognitive delay means compared to other children similar in age to your child, his or her ability to understand certain things, is delayed, or, behind. This does not mean that your child has mental retardation. We will keep a close eye on your child's education, emotional and intellectual progress as time goes on.

QUESTION LOG
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QUESTION:

ANSWER:

DIAGNOSIS TRACKING RECORD

Diagnosis:
Definition:
Doctor(s) who diagnosed:
Date diagnosed:

Diagnosis:
Definition:
Doctor(s) who diagnosed:
Date diagnosed:

Diagnosis:
Definition:
Doctor(s) who diagnosed:
Date diagnosed:

Diagnosis:
Definition:
Doctor(s) who diagnosed:
Date diagnosed:

Some words of inspiration by an unknown author about the beauty and the strength that can be gained from sharing difficult experiences with others:

*If you have learned to walk
A little more sure-footedly than I,
Be patient with my stumbling then
And know that only as I do my best and try
May I attain the goal
For which we both are striving,
If through experience, your soul
Has gained heights which I
As yet in dim-lit vision see,
Hold out your hand and point the way,
Lest from its straightness I should stray,
And walk a mile with me*

-Author Unknown