Static Encephalopathy

A Basis Explanation for Parents

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Q. My child has been diagnosed with static encephalopathy. What does this mean?

A. Static encephalopathy (SE) means that a child's brain is not working normally because of some kind of injury, damage, defect, or illness, and this interferes in some way with normal function, development, or learning.

“Static” means permanent or unchanging. The brain abnormality in SE is permanent or unchanging in the sense that it does not get worse. It is not progressive or degenerative. Unfortunately, it usually does not get better or improve much either. This does NOT mean that the child will not get better. Many do. But most children with static encephalopathy will always have some degree of learning or developmental problems because they always have some degree of abnormal brain function.

“Encephalo” means brain; “opathy” means damage of some sort. In static encephalopathy, the child's developmental problem is caused by an abnormality in the brain, not in the muscles, bones, nerves, eyes, ears, etc. The brain controls everything we do. When there is damage in one part of the brain, whatever that part of the brain should control will not work properly. How well a damaged brain can control development depends on how much of the brain is damaged and how severe the damage is.

Q. What are the symptoms of static encephalopathy? What kind of problems can I expect my child to have?

A. Every child with static encephalopathy is unique - different from anyone else. The symptoms or problems your child has will depend on what area of the brain is affected and how severe it is.

If the damage is in the part of the brain that controls muscle movements, the child may be slow in sitting, walking, etc. His movements may be stiff or “spastic”, or they may be jerky (athetoid or ataxic.) This kind of static encephalopathy is often called “cerebral palsy”. (Cerebral also means brain; palsy means paralyzed movements.)

If the damage is in the part of the brain that controls speech and language, your child might be delayed in learning to talk or to understand what you say.

If the damage is in the parts of the brain that controls learning, the child may be slow to learn new things or have a hard time remembering new things from day to day. Actually, learning is controlled by many areas of the brain and also by the connections made between different areas of the brain. If the damage is mild or limited to certain areas, your child might have a learning disability or simply be a slow learner. If the damage is more generalized or more severe, your child’s learning may be slow enough to be called “mental retardation.” Remember, retarded only means “slow”. Retarded children learn, but they learn slowly.

If the damage is in multiple areas of the brain, your child may have several problems, such as both cerebral palsy and speech delay, learning problems, or mental retardation, or other symptoms, depending on where the brain damage is.

Sometimes the damage will cause abnormal electrical activity in the brain, causing seizures. Some children with static encephalopathy do have seizures, but many do not. If your child does not have seizures now, there is a good chance he or she never will. But if you are worried, be sure to ask your doctor. (Some people have seizures but do not have static encephalopathy. There are many causes of seizures, and static encephalopathy is only one of them.)

If the damage is in the part of the brain that controls vision or hearing, your child may appear to be partially blind or deaf, even if his or her eyes and ears are normal. In this case, the eyes “see” and the ears “hear”, but the brain does not make sense of it because the part of the brain that interprets what the eyes see and the ears hear is not working properly. Blindness caused by brain damage or dysfunction is called “cortical blindness”.

Q. Is static encephalopathy the same as cerebral palsy?

A. Sometimes yes and sometimes no. Some children with static encephalopathy have damage in the part of the brain that controls muscle movements. Their movements may be stiff, slow, or jerky, and the child’s development of motor movements, such as sitting, standing, and walking may be slow. This is cerebral palsy. Cerebral palsy is one form of static encephalopathy. (There are different forms of cerebral palsy depending on which part of the motor-controlling part of the brain is affected. The most common type is spastic in which muscle movements are stiff. Other types include athetoid (jerky movements), and ataxic (poor balance), and hypotonic (floppy muscles.)

Some children have damage to other parts of the brain but not to the part that controls muscle movements. Their muscles move normally, but they have other problems with development or learning, such as speech delay, learning disabilities, or mental retardation. These kinds of static encephalopathy are not cerebral palsy because there is no problem with muscle movements.

Sometimes static encephalopathy causes a child to be slow in learning to sit or crawl or walk, but when they finally do learn to do these things, the movements are normal. This is not cerebral palsy. Cerebral palsy means the movements are actually abnormal, not just delayed. In a young child who is slow to develop, it can be difficult to tell for sure if the problem is CP, some other static encephalopathy, or something else completely. The doctor will often wait and watch to see how the child progresses before making a diagnosis.

Q. How does the doctor diagnose static encephalopathy?

A. Static encephalopathy is a clinical diagnosis. This means that there is no specific test or X-ray that can give an absolute “yes” or “no” diagnosis. The doctor has to put together all of the information he gets form the child's history (what has happened so far), the physical exam and any lab tests or X-rays. He has to be sure that the child is not getting worse or regressing over time. If he is, the problem is not “static”, it is degenerative. Then the doctor would test for a different kind of disease process. Using the physical exam and lab tests, the doctor has to be sure that the problem is in the brain (encephalo) and not in the muscles or nerves, eyes or ears. He also has to observe the child’s progress over time, either by repeated visits, or by a good report from the family, to be sure that the problem is “static” or permanent. Some encephalopathies, or brain injuries, are only temporary, and get well or resolve after a few weeks or months, and these are not “static encephalopathies”. (Some examples are brain swelling or injury from an illness like meningitis or poisoning, or a concussion from a fall, or a
Q. What lab tests should the doctor do?

A. This depends on what information he gets from the history (parent report of the child's medical background), and what he finds on physical exam. There are no absolute rules about what tests "must" be done. The doctor usually has a pretty good idea of what is wrong after he gets the history and does an exam. The tests he orders are chosen to help him confirm or rule out (disprove) whatever diagnosis he suspects. For example, if he suspects seizures, he will order an EEG (brain wave test). But if there is nothing about the child to make the doctor suspect seizures, he will probably not order an EEG.

Here is a list of some common medical tests that might be done on a child with developmental problems, and an explanation of what the test can and cannot tell us.

1. **EEG (electroencephalogram or brain wave test).** The EEG measures the brain's electrical activity. The test can usually tell if the child's brain electrical activity is normal for his age or not. There are several kinds of abnormalities that can show up. Seizures can be seen on an EEG if the child has a seizure while the EEG is being done. However, most children who are known to have a seizure disorder do not actually have a seizure while they are hooked up to the EEG machine. More often, the EEG will show abnormal patterns that could cause a seizure to start, or abnormal patterns that suggest the child just recently had a seizure. Then the doctor has to put this information together with the child's history to make the diagnosis of seizure disorder or epilepsy.

   The EEG can also be abnormal if the child is very ill (e.g., meningitis, coma, etc.) or if there is some abnormal structure in the brain (e.g., a cyst or tumor). The EEG does NOT tell you what the abnormality is. It just tells you that the brain waves are not normal, and the doctor has to figure out the rest.

   Sometimes the EEG will be normal even if the brain is not. The EEG picks up brain electrical activity through tiny wires "glued" to the scalp with paste. The electrical activity of the brain has to penetrate or go through the skull bone and skin before it gets to the wires. Activity deep down in the brain may simply not penetrate out that far. So the EEG usually picks up activity out near the surface of the brain. If the surface of the brain is normal, the EEG will be normal, even if deeper areas are not. This is one reason why a child with known seizures or other problems can sometimes have a normal EEG.

   In summary, an abnormal EEG usually means there is a problem, but does not always tell you what the problem is; a normal EEG does not guarantee a normal brain.

2. **CT or MRI Scans.** A CT (computerized tomography) is a computerized X-ray picture of the brain. An MRI (magnetic resonance imaging) is a picture of the brain made with magnetic energy. Both CT and MRI scans give detailed pictures of the brain structure (what the brain looks like). They do not tell us how the brain functions (how it is working). These scans can show things like cysts or tumors, abnormal formation or defects of the brain, or areas of the brain that are too small or too large, or scars from some injury, bleeding, or other damage.

   If the CT or MRI is abnormal, it can give a clue about brain function. For example, if one side of the brain is much smaller than the other, or if there is a large cyst in the brain, we can guess that the child will have trouble doing the things which that part of the brain should control.

   Some abnormalities may show up on the scan which do not affect function. They are in a part of the brain that does not interfere with body control. So it is possible to have an "abnormal" scan even if the child is normal. Usually we don't call these scans "abnormal" but rather "variations of normal".

   It is also possible to have a normal scan in a child with very abnormal development or muscle movement or learning. This is because the scans only give a picture of what the brain looks like but not how it works. It does not tell us if the brain chemicals or electricity or cells are normal. In summary, CT or MRI scans can help with the diagnosis, but they usually do not give us the whole answer.

3. **Blood and urine tests.** The doctor will sometimes do a variety of blood and urine tests to check for abnormal chemicals in the body which could interfere with brain function. Most of these chemical (or metabolic) problems are rare, but a few can be treated with medication or diet. If the child seems healthy in every way except for slow development, the doctor may not do these metabolic tests because most metabolic diseases cause other problems as well. But if the child has other symptoms such as unexplained seizures, unusually slow growth, fevers and vomiting or dehydration for no apparent reason, or an unusual smell to the body or urine, or if slow development runs in the family, then the doctor may test for metabolic errors.

4. **Genetic Testing.** If the child has an unusual physical appearance or if developmental problems run in the family, the doctor may do genetic testing. For the child, this means getting blood drawn and sent to the lab. The most common test is a chromosome analysis. The chromosomes in the body cells are long strings of genetic material (genes) that can be seen with a microscope. Sometimes these strings can be broken or have pieces missing or extra pieces added. The missing or extra genes can cause slow development and some physical variations such as unusual ears or skin creases on the hands or eyes. Such physical variations are not abnormalities and do not interfere with how the ear or hand or eye work, but they are clues to the doctor that the slow development may have a genetic cause.

   Not all physical variations such as unusual hand creases are signs of genetic problems. Some are normal variations and run in the family. About 4% of normal people have these variations and don’t even know it. After all, they are normal variations most of the time.

   If an abnormal chromosome is found, it may or may not be the cause of the slow development. Some people have changes in their chromosomes that do not affect development. So it the doctor finds an abnormal chromosome, how can he tell if it is the cause of the slow development or not? Usually this is a matter of association. If there are other people who have had the same chromosome abnormality and the same developmental delays and physical features, we assume
that the chromosome abnormality is the cause. Down Syndrome is a good example. All children with Down Syndrome have an extra chromosome (#21), and all have very similar physical features and slow development. If the chromosome abnormality is unusual, it may be hard to say for sure whether it is the cause of the delays or not.

If a chromosome abnormality is found, the doctor may also order a chromosome test on both parents. In some cases, one of the parents can have the same abnormal chromosome but NOT be developmentally delayed. If this is the case, then the parent is a “carrier”. He or she carries the abnormal chromosome but does not have any symptoms from it. However, if he or she has another child, that child has a chance of getting the abnormal chromosome and the physical and developmental problems. The way this all works can get very complicated. If this situation has occurred with you and your child, it is very important to get good genetic counseling so you understand the chances for your future children and your grandchildren.

Another genetic test that is sometimes done is DNA analysis. DNA is the actual biochemical that makes up the chromosomes. This is much more complicated and is available for only a limited number of diseases. However, in the future, DNA testing will probably be used much more.

One last thing about genetics testing: there are some genetic problems that we don’t have a test for yet. We know they must be genetic because of the way they run in families, but we can’t “prove it” in the lab. If physical problems or slow development runs in a family, even with the normal tests, the doctor still might counsel the parents that it could happen again with their next pregnancy. We just can’t be sure. Hopefully, genetic technology will improve enough to answer more of these questions soon. The research continues.

One final word about genetic testing: Even if an abnormality is found, there is usually not a medical treatment that can fix the problem. At the time of this writing, there is not a way to change the genes of human patients. The value of doing genetic testing is, first of all, to know the diagnosis, if possible, and secondly, for genetic counseling about the risks for the problem to occur again if the parents, patient, or other family members have more children.

5. **Vision and Hearing** should be tested to be sure the child can see and hear. A child who cannot see or hear well may have slow development even with a normal brain. Many vision or hearing problems can be corrected well enough that development is normal. When they cannot be corrected, special methods of teaching and therapy can help these children live more normal lives.

6. **Muscle and Nerve Tests.** If the doctor suspects that the cause of the slow development is in the muscles or nerves rather than the brain, he can order several tests. Muscle enzymes are chemicals in the blood stream that come from muscles. If the amount of these enzymes in a blood test is abnormal, it can be a sign of muscle disease, such as muscular dystrophy. An **EMG** (electromyogram) measures the electrical activity in the muscles. **Nerve conduction velocities** is a measure of how fast the nerves carry messages from the brain to the muscle. Finally, a nerve or muscle biopsy may be done. A tiny piece of muscle or nerve is surgically removed, usually from the leg. It can be examined under the microscope and chemical tests can be done to see if the nerve and muscle show signs of any disease.

If the problem is in the muscles or nerves, this is NOT a static encephalopathy, because it is not in the brain. When a child has slow development, it may be hard to tell at first if the problem is in the brain, or elsewhere, such as the muscles or nerves. This is why doctors may do tests on muscles or nerves, even if the diagnosis later turns out to be static encephalopathy.

One last note about testing: Sometimes the doctor will not recommend any tests, or will recommend some but not others. There are potential risks for all tests, even for something as simple as drawing blood. The doctor will weigh the risks against the likelihood that the test will be helpful in diagnosing the child’s problem. Sometimes the risk of doing the test is greater than the potential benefit, and then it is better not to do it. Sometimes the doctor may not recommend any tests because the likely cause of the disability is obvious from the history or physical exam. In this case, even through the tests might “prove” the cause, it is of no benefit to the child to put him through the tests. Whether or not to do lab tests is a very individual decision, and it is between the doctor and the child’s family to decide what to do.

**Q. What causes static encephalopathy?**

**A.** Anything that can damage or injure the brain can cause a static encephalopathy. Obvious causes are things like a severe head injury or a major birth defect of the brain. Bleeding into the brain, either before or after birth can cause it. Serious infections like meningitis or encephalitis can cause some damage. Severe lack of oxygen is another possible cause.

Sometimes a child had some illness or accident that we think might have caused an encephalopathy, but we can’t be sure. For example, if a child had a difficult labor and delivery or was extremely premature, he is considered “at risk”. There is a chance that the brain could have been damaged, but most of these children seem to be developing normally. For those who do have an encephalopathy, we may suspect that the prematurity or birth problems were the cause, but we can’t be sure. Some research indicates that difficulty during labor is a sign that the baby already has an abnormal brain rather than being the cause of it.

Unfortunately, most of the time we simply do not know the cause of static encephalopathies, even after all the tests have been done. This is because the brain is the most complicated part of the body, and even with all the tests and technology we have, we simply do not completely understand everything about the brain. It is very difficult when a child has brain damage and we cannot figure out why. Parents want and need to know what has happened to their child, but even with the best medical evaluation available, we don’t always know. Sometimes the best we can do is to say what is not the cause rather than what is. It is important for parents to understand that most of the things they worry about did NOT cause the damage. For example, having the cord around the neck at birth, a forceps delivery, smoking, drinking coffee or a little alcohol, taking prescription medication, exercising, etc. during pregnancy do not seem to cause damage to the baby. It is important for parents to discuss any such worries with their doctor. Usually the doctor can put your worries to rest so you can spend your energy on other things that do matter and make a difference for your child.
**Q. How is static encephalopathy treated?**

**A.** Since static encephalopathy can cause different problems for each child, there is no one treatment that is right for everyone. And since the brain damage is permanent, there is no treatment that can be considered a "cure." At the time of this writing, there is currently no way to "fix" damaged human brain. Therefore, each child should be treated as an individual, using medication, therapy and other treatments chosen according to each child’s individual needs. The goal of treatment is to make the child as independent and as functional as he or she can be. Some common forms of treatment are outlined below.

- **Medication:** If the child’s encephalopathy causes seizures, medication can usually prevent or control them. Some children may have problems with a short attention span or hyperactivity as part of their static encephalopathy. (Note: most attention and hyperactivity problems are not caused by static encephalopathy, but sometimes they are. Do not assume your child automatically has static encephalopathy just because he or she has attention problems or hyperactive behavior.) Carefully managed medication may help improve these behaviors in some children. In some children with spasticity, medication can help relax tight muscles. All drugs must be carefully chosen and managed by the child’s physician to try to achieve the best result with the fewest side effects.

- **Therapy:** If the encephalopathy causes delayed motor or speech development, a therapy program often helps the child improve in these skills. A physical therapist helps the child with gross motor skills such as sitting, standing, walking, and climbing. An occupational therapist helps with fine motor skills such as holding a pencil, coloring, cutting, and writing. The occupational therapist also works on activities of daily living such as feeding, grooming, toiletting, dressing, etc. The speech therapist can help the child understand language, say sounds and words, or communicate in other ways. Speech or occupational therapists may also help with feeding problems.

- **Teachers:** Children learn by experience – by getting into things to see how they feel, taste, smell and work. A child with brain damage may not be able to get into things as easily, or his brain may not make sense out of the things he sees, hears, and touches. So learning comes slower. Early Childhood special education teachers give these children a wide variety of experiences so they have the best possible chance to learn about the world and prepare for elementary school. Once the child enters elementary school, special education programs can help him or her learn to the best of his or her ability. Special education programs should be individualized to meet the unique needs of each child.

- **Special Equipment:** Depending on the child’s problem, his therapist or doctor may recommend braces, splints, special chairs for positioning, computers, etc. Each piece of equipment must be individually chosen for a child’s particular need. The goal of the equipment is to help the child be as independent as possible. But the child’s brain has to be ready for the particular skill which the equipment is designed to help, or it won’t work. For example, if a child’s brain is not ready to walk, no special shoes or braces or walkers will make him walk. If his brain is ready, the equipment can give him a little extra balance or stability to get him going. If you have questions about equipment choices for your child, ask a qualified therapist or doctor before you spend money on it.

- **Surgery:** Surgery is an extremely individualized treatment for some children. Only a qualified surgeon, sometimes with a diagnostic team helping him or her, can determine whether surgery is appropriate for a particular child. For some children, surgery to loosen up tight muscles or joints can help the child move better. If the child has problems hearing because of fluid in his ears, surgery to put tiny tubes in the eardrums can help. If the child has crossed eyes (strabismus), surgery can straighten them most of the time. It is important to understand that just because one child benefited form a particular surgical procedure, this does not mean that all children will.

- **Vision and Hearing:** Besides the surgery above, some children need other help to see and hear better. Glasses or contact lenses, hearing aids and auditory amplifiers, sometimes help children with static encephalopathy learn better if they have correctable vision or hearing problems. Glasses, hearing aids, etc. do not help if the eyes and ears are normal but the brain cannot make sense out of what it sees and hears. These things help only if the problem is in the eye or ear. They cannot help if the problem is in the brain. This is why a child with "cortical blindness" is not usually given glasses.

- **Regular Medical and Dental Care and Nutrition:** Children with static encephalopathy need regular health care just like any other child. All children learn best when they are healthy. But for the child who already has a disability, an illness can make learning even harder. Sometimes children have so many specialists and therapists whom they see regularly that they do not go to a general pediatrician or family doctor. However, the general pediatrician or family doctor is one of the most important people to see for regular checkups, immunizations, and for coordination of all the other services that the child gets. All children should see a dentist in the second or third year of life and have regular checkups after that. This is especially true for children with static encephalopathy because many are very sensitive in the mouth, making tooth brushing difficult. Some are on medicines (such as Dilantin for seizures) that can affect gum growth.

- **Counseling:** Many children with static encephalopathy are very aware that they are somehow “different” from other children. This is especially true by school age. It can be very helpful for these children to have counseling or play therapy from a psychologist, counselor, or social worker who is experienced with young children with developmental differences. The counselor can help the child recognize his strengths and self worth and can also help him with social interactions with other children.

Counseling can also be helpful for other family members. No matter how much the family loves the child and is committed to him or her, the diagnosis of brain damage or developmental delays can be devastating. There is often much uncertainty about the future and a lot of change in their daily routines. There are doctors, therapists, appointments, tests, and medicines replacing comfortable daily family routines. Families may feel stress at work, in their marriage, with their other children, and with friends and relatives. Brothers and sisters of the disabled child may feel confused and afraid, and sometimes feel left out because the parent now spends so much time with the disabled child. A good counselor cannot change what has happened, but he or she can help parents, siblings, and relatives learn to understand the child’s problems, to put them in perspective with the rest of the family’s needs, and go on with life.

A good counselor can often prevent some problems from developing in the first place, or he or she can help a family resolve small problems before they become big.
wonder whether counseling could help you, discuss it with your doctor.

Q. Is my child handicapped?

A. Some children with static encephalopathy have only mild disabilities, and with therapy, special education, medication, etc., he or she may function normally in life. In this case, the child has a disability, but is not handicapped. He or she can overcome the disability to live a "normal" life. Other children may be more severely disabled and even with the best of treatment, may not live a "normal" life. They may not ever be independent, and may always need help from other people even for the most simple and basic things. These children are usually considered handicapped. The current definitions of the words are this: "disabled" means the person has an impairment (a medical problem, such as static encephalopathy) that affects how his body works. "Handicapped" means that the disability interferes enough with the person's function that he cannot live a "normal" life, even with special therapy, medication, etc.

The words "disabled" and "handicapped" are just words. They don't tell us very much about the person. Many truly handicapped people live meaningful and productive lives, even if they do not do things "normally", while many able-bodied people never live up to their potential, even though they have the ability. Do not let words predict how your child will live his life. You may use the words to help your child, but do not let them limit him. (What I mean by this is: If a child is diagnosed as handicapped, you may be able to get a special parking sticker, or some special services at school or elsewhere that you cannot get if the child is not "handicapped". In this case, the label, or the word, may be used to help your child. But it does not really tell us much else.) Don't let words throw you. Understand them, and use them, but put them in their place.

Static encephalopathy can be a very complicated subject, and the symptoms and implications can be different for every patient. It is not possible to answer all questions in one short (or long) article. This has been a very basic introduction to static encephalopathy. Use this information to begin your search to understand your child. Write down your questions as you think of them, and bring your question list with you to your doctors and therapists. Do some research. Read, and look up things on the Internet. But be careful. Just because it is on the net or in print does not mean it is true. People can publish anything they want to, and they can put anything they want on a website. Always look for reputable information from a reliable source. And if in doubt, ask your doctors or therapists. Getting a diagnosis of static encephalopathy is just the beginning. Now comes a lot of hard work, and each child's life will be different. There is a lot of help available. But you have to ask. Not every day. Some days, you just have to be yourself. But when you are ready, go for it!