

Parent's Guide to Electroencephalograms (EEG) for Children with Autism



These materials are the product of on-going activities of the Autism Speaks Autism Treatment Network, a funded program of Autism Speaks. It is supported by cooperative agreement UA3 MC 11054 through the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Research Program to the Massachusetts General Hospital. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the MCHB, HRSA, HHS, or Autism Speaks.”

My Autism Guide
SIGN UP



Information
based on
your needs

guide.autismspeaks.org

Table of Contents

Introduction	p.2
Why Does My Child’s Diagnosis Matter?	p.3
The EEG Procedure – What to Expect	p.4
Words to Know	p.4
What is an EEG?	p.4
General Suggestions	p.5
What are the Steps of an EEG?	p.5
Tests That May Be Done After Being Hooked Up	p.6
Sleep-Deprived and Overnight EEGs	p.6
Frequently Asked Questions	p.7
Understanding Sensory Issues and How to Help Your Child Cope	p.8
Touch	p.8
Sound	p.8
Smell	p.9
Helping Your Child Calm His or Her Body	p.9
Using Visual Supports to Help Your Child	p.10
What are Visual Supports and How Can They Help?	p.10
Creating and Using a Teaching Story	p.12
Sample Teaching Story	p.13
Helping Your Child During the EEG Set-Up Process	p.15
Challenging Behavior	p.16
Resources	p.17
Acknowledgments	p.17

Appendixes

Appendix A: Pre-EEG Parent Questionnaire	p.18
Appendix B: Sample Distraction Items	p.22
Appendix C: Pictures of Sample EEG Materials	p.23

Introduction: This tool kit was written for parents and caregivers of children with autism spectrum disorder (ASD) who need to have an EEG (electroencephalogram) performed. It gives information about ASD, describes an EEG and what the EEG involves, ways to help your child prepare for the procedure and how to help your child stay safe and calm during the EEG.

We hope this tool kit will:

- Help you talk with your child's doctors and providers about what each person involved in the EEG can expect
- Help lower parent and child anxiety about obtaining EEGs
- Help the EEG process go faster
- Help you feel more confident about helping your child complete an important medical procedure

There are some resources at the end of this tool kit that you might find helpful. We have also included a questionnaire that you can fill out before your child's EEG and share with his or her health care providers.

A separate tool kit was written for the providers who will work with your child during the EEG. You might get some information about the EEG from the hospital or clinic where your child is having the procedure. You can also share the tool kit developed by Autism Speaks with your child's EEG team. You can download the EEG Tool Kit for Providers here: <http://www.autismspeaks.org/family-services/tool-kits>.



Why Does My Child's Diagnosis Matter?

This tool kit was written especially for parents of children with autism spectrum disorder (ASD). Even though every child with ASD is different, there are some common traits that are important to think about when the child needs to have an EEG.

Communication Difficulties

- Children with ASD might not understand why they need to have an EEG or what is going to happen to them during the procedure, even if you have tried to explain it to them.
- They may take things literally or “word for word.” For example, if a nurse tells your child it will take 60 minutes to set up for the EEG and it ends up taking 70 minutes, your child might get upset.
- Some children might want to understand everything that is going on. Providers who work with these children will need to explain each step instead of giving them a summary at the start of the procedure.

Trouble with Social Interaction

- An EEG usually means meeting new people. A child with ASD might be nervous about this and not know how to express his or her feelings appropriately.
- Lots of children with ASD do not show as many facial expressions as other children, so it can be harder for people to know how they are feeling. However, this does not mean that people with ASD have less intense feelings.
- Your child may have trouble reading nonverbal social cues, like facial expressions or body language. He or she may need to be told what other people are thinking or feeling.

Likes Routine or Things that are Familiar

- Some children might be used to going to the doctor. They might have had either good or bad things happen at the doctor's office. For other children, going to a hospital or clinic might be new for them. A child with ASD may be upset by the new location and all of the things that go along with the visit. He or she might have trouble spending time in a waiting room, meeting new people or sitting still for a long time.

Sensory Differences

- Many individuals with ASD are sensitive to sensory input. They may have strong positive or negative reactions to sounds, smells, sights, tastes, textures or human touch. The EEG involves many different types of sensory input that might be new to the child.

*You will learn more about each of these areas
and how to help your child as you read through the tool kit*

The EEG Procedure – What to Expect

Words to Know:

EEG (electroencephalogram): An electrical measurement of brain activity that is read by a Neurologist or Epileptologist

Seizure: Uncontrolled, abnormal brain activity. Seizures can present as problems such as shaking or stiffening of limbs, staring and unresponsiveness, eyes being “stuck” in one position or losing bladder or bowel control.

Epilepsy: Recurrent, unprovoked seizures. Epilepsy is also sometimes called “seizure disorder.”

Neurologist: A medical doctor specially trained to diagnose and treat brain, nerve and muscle problems

Epileptologist: A neurologist with extra training to diagnose and treat epilepsy

EEG technician: A specialist who is trained to perform an EEG

Electrodes: Small, round discs with wires attached to them that are put on the scalp during the EEG

Epileptiform discharges: Brain activity that indicates that epilepsy or seizures may be present

This section talks about the steps of the actual EEG so you can:

- Be prepared for what you and your child will need to do
- Understand how to help your child do well
- Know ahead of time if your child will need some extra help with some steps during the EEG

After we list the basic steps, we will go through them more closely and share ways to make things easier for you and your child.

What is an EEG?

An EEG is a procedure or test that measures brain activity. This is done by attaching small electrodes to the child’s scalp. The electrodes usually look like small discs and are put on one by one. A special type of glue holds the electrodes onto the child’s scalp. Thin wires connect the electrodes to a box that can record the child’s brain wave activity.

There are two typical ways of doing an EEG. In one, the child wears a cap that is made out of cloth or clear plastic. The electrodes are attached to certain places on the cap.

In the other type of EEG, the electrodes are attached to your child’s scalp with a special kind of glue. Our tool kit talks about this method since it is used more often. You can find out from your child’s clinic which method they use and what they can tell you about the procedure.

An EEG might feel sort of like a head massage to some children. If your child asks what the EEG will feel like, be honest and positive. The EEG does not hurt, but your child will need to sit still for up to an hour while the electrodes are placed on his or her scalp.

Even though the EEG is not painful and does not hurt, children (and parents) can feel anxious or uneasy during the procedure. This might be because of the way the child reacts to different sounds, smells and textures. We hope the information in this tool kit will help you and your child feel more prepared and less anxious.

Remember – your child’s hospital or clinic might have a slightly different way of performing an EEG.

Things might be different depending on the kind of EEG your child has. It is always a good idea to talk ahead of time with your child’s doctor or clinic staff to ask questions about what to expect. The steps below are just a starting point!

Getting prepared for the EEG is easier if the child has short hair and a clean scalp.

Things that might help:

- Take your child to get a haircut shortly before the EEG. This makes it easier for the technicians to put the electrodes on. For children with longer hair, a haircut is not required but might make the EEG a little easier
- Wash your child's hair the night before the EEG. Do not use any gels, oils, creams, conditioners or hair sprays on their hair
- Take out any braids or other hairstyles

Talk to your child's doctor before the EEG about your child's medications. Make sure you know if he or she should take the medication(s) or do something different.



General Suggestions

Ask ahead of time whether your child will be able to get up and move around once he or she is hooked up to the monitor. If not, be sure your child uses the bathroom before getting started.

Remember to keep track of your own feelings. Remind yourself that the EEG is not hurting your child (even if your child is upset).

Use positive language when talking with your child. Try not to talk about how hard it is for them:

- Instead of saying, **"I know, this whole thing is terrible,"** you can say, **"You are doing a great job. You're being very brave!"**

What are the Steps of an EEG?

1. The first step might mean waiting! You might have to wait for a little while for someone from the team to get there. Be ready for your child to have to wait in the room.
2. Someone might spend some time asking you questions about your child's medical history or his or her current behavior. It is a good idea to bring along books or toys that will keep your child busy during this time.
3. Someone might want to listen to your child's heart or look inside his or her eyes, ears and mouth.

(It is usually easiest if your child is sitting or lying down for the next several steps. If your child is smaller, he or she might be able to sit in your lap if that helps him or her stay calm.)

4. The technician will use a flexible measuring tape to measure your child's head. This is so the technician knows where to put the electrodes.
5. The technician will use a marker to make dots on your child's head that show where the electrodes will be.
6. The technician uses a cotton swab dipped into a special product that helps get your child's scalp ready for the electrodes. This product is grainy and might feel a little scratchy on your child's head, but it does not hurt.
7. The electrode is attached to your child's head and a small piece of gauze is placed over it to hold it in place. The gauze is dipped in a liquid that hardens and holds the electrode on. This liquid might smell like turpentine or nail polish remover. It does not burn or hurt your child's head.

8. Sometimes the technician might blow some cold air through a tube to help the gauze dry faster. The air hose makes a noise that sounds like a tiny vacuum cleaner.
9. The technician repeats steps 6-8 for as many electrodes as your child needs. You can ask the technician how many electrodes she will be using. She might also put some electrodes on your child's forehead and some patches or stickers on your child's chest.
10. Once all of the electrodes are on, the technician might wrap your child's entire head with gauze (this wrap may go under your child's chin to keep the wrap from falling off).

There are pictures of the EEG materials in Appendix C at the end of this tool kit.

Tests That May Be Done After Being Hooked Up:

The technician may ask your child to do some activities that will cause brain activity that will help identify any seizures. Here are some things your child might need to do:

- Look at a light that flashes quickly and then open and close his or her eyes
- Blow into a pinwheel for 3 minutes
- Fall asleep while the electrodes are on (see below for more information about this)

Sleep-Deprived and Overnight EEGs

To help get information about your child's brain activity while he or she is sleeping, you might be asked to change your child's sleep schedule. This might make it easier for him or her to fall asleep during their EEG. Use your best judgment about what will help your child be sleepy for the EEG.

- Try putting young children to sleep 1-2 hours later than usual and waking them up two hours earlier than usual.
- Older children or adolescents might need to be kept up most of the night. You might try a movie marathon night of high-interest movies he or she has not seen.
- Remember, do not let your child fall asleep in the car on the way to the EEG visit. You might want to bring another person to help keep your child awake during a long drive. Changing a child's sleep schedule and not letting him or her nap is usually enough to help him or her fall asleep during the EEG.

If your child needs to have a sleep-deprived EEG, do not let him or her eat or drink foods that have caffeine the day before the EEG. This means no chocolate, soda, or energy drinks.

There are other kinds of EEGs including hospital overnight EEGs and ambulatory EEGs where the child wears the EEG at home. The electrodes will stay on overnight or longer for an ambulatory EEG. Find out how to dress and undress your child with the electrodes on. You might need to bring a button-up shirt to change your child into before the electrodes are put on. For staying overnight in the hospital, bring everything you would use at home during a typical night. This might include:

- Any special items your child likes to use for eating, using the bathroom or sleeping. You can also call the hospital or clinic ahead of time to see what they have available for families. This could be especially important if your child uses a ventilator or monitor while sleeping.
- Pajamas (Your child may change into these before any electrodes are put on, so you do not have to take clothing off afterwards.)
- Diapers, milk or formula and bottles
- Any special toys or objects your child sleeps with or likes. These might be a favorite stuffed animal or blanket. You can bring these for a daytime EEG too!
- Favorite bedtime stories
- All of your child's medications

When the EEG is completed, the technician will use a product that helps dissolve the glue to remove electrodes from your child's head. This product does not burn or hurt, but it might feel strange on your child's head. Most parents want to wash their child's hair after this step because it can be greasy. Sometimes it might take two or three shampoos to get it all out.

FREQUENTLY ASKED QUESTIONS

Why does my child need an EEG?

Your child's doctor is recommending an EEG because he or she wants to know more about your child's brain activity. Your child might have unusual brain activity that affects him or her even if you have never seen your child have a seizure. An EEG is a non-invasive way to get this information. An EEG can give doctors very important information about whether a child is having seizures. This helps doctors figure out what type of medical care is best for your child.

How long will the EEG take?

Setting up the EEG can take up to an hour if things go smoothly. Your provider will decide how long your child needs to keep the electrodes on. It might be a few hours or it could be overnight.

Does the EEG hurt?

No. It might be uncomfortable, but it does not hurt.

Can we visit the hospital ahead of time to see the rooms and equipment?

Ask the person who schedules your child's EEG about this. If you are allowed to visit, talk about the best way to do this. You might want to go when it is less busy. It might be easier for your child to visit when it is quiet. See if you can take pictures of your child visiting the clinic. Try taking pictures of your child waiting in an exam room, sitting on a hospital bed and saying hello to people there. Then when you get home you can look at the pictures together and talk about them.

It would be easier if they would sedate my child since I know he won't be able to handle this. Why won't the doctors do that?

Your child's doctor or EEG technician can explain whether sedation is an option for your child. Many clinics like to try completing the EEG without sedation. This is because sedation can have unpleasant side effects like vomiting. Also, you might be surprised at how well your child handles the EEG with some planning and working together with your child's doctors.

Can I stay with my child while the EEG is happening?

Yes. You should be able to be with your child during the EEG. Find out what kind of supervision your child needs once he or she is hooked up for the EEG.

What can I bring for my child to do while the EEG is happening?

Bringing in favorite items or activities from home is a great way to help distract your child and keep him or her comfortable! Find out if there are rules about what you can bring. The best items are those that keep your child quiet and need little movement, as movement can interfere with the EEG activity. Think about bringing favorite snacks, toys, books, devices like iPads or portable DVD players.

Understanding Sensory Issues and How to Help Your Child Cope

Some children have trouble with some types of touch, smell or sounds. Think about how your child reacts to touch, smell and sounds. Do you think he or she will be worried, try to leave the room or be aggressive during the EEG? If you know your child has sensory issues, make sure to tell the doctors and staff who are doing the EEG. They can talk to you about how to make things easier for your child.

Most of the ideas below use something called desensitization. Desensitization means helping someone be less sensitive to something he or she does not like. We do this by practicing small steps over and over again until the person gets used to the steps and does not get as upset. You might need to practice the steps a couple of times a day to help your child really get used to them. Your child might need help learning to handle how different things feel, sound and smell.

Touch

People are going to need to touch your child's head quite a bit for the EEG. They will have to measure it, make marks on the scalp with a pen, put on all the electrodes and wrap your child's head with gauze. There are some ways to help your child be more relaxed. Try to spend more time touching your child's head to get him or her used to how it feels. Fun ways to do this are:

- For younger children, sing songs like "Head, Shoulders, Knees and Toes" where your child (or you) gets to touch his or her head or "Itsy-Bitsy Spider" and use your fingers to "crawl" the spider up to your child's head.
- Take turns brushing people's hair (for example, a doll's hair, your hair and then your child's hair).
- Put barrettes or small hair clips in your child's hair or have him or her wear a headband.
- Play dress-up with outfits that have hats. You can use any kind of hat – we just want your child to get used to having something on his or her head! If your child really likes Angry Birds, try putting Angry Bird stickers on the hat before he or she wears it. If your child really likes trains, he or she might like wearing a train conductor's cap.
- Play with or braid your child's hair.

***If your child really does not like anything touching his or her head, you might need to start with smaller steps, like having him or her put a hat on another person in the family or on a stuffed animal. Some children may need extra motivation to practice and get through these steps. You can reward your child with stickers, a bite of a favorite food or extra television time.

Sound

If technicians need to use an air hose to help the electrodes stay on, your child will feel a burst of cold air on his or her head. He or she might also hear a sound like a very small vacuum cleaner. If your child is very sensitive to sounds like a vacuum cleaner or a hairdryer, try to find out if the EEG will use an air hose. If it will, you can use desensitization steps in the days or weeks before the EEG. If your child is very sensitive to noises, you might need to start with small steps:

- There are lots of different toys that vibrate (and make a humming sound) or make other noises. As a first step, your child might just be able to have the vibrating toy next to him or her. Then, he or she could touch it with one finger, hold it for two seconds, hold it for five seconds, etc. It is okay to use rewards like stickers, a favorite treat to eat or hugs after your child tries each step.
- If your child is not as sensitive, you can dry your hair while your child is close by (or in a nearby room). You can also use electric mixers or blenders with your child in the room.
- During the EEG, you might ask the technician to let your child push the button on the air hose to learn how it works before it is used on his or her head.
- See if your child can use soft ear plugs to reduce the noise.

Smell

The technicians use a strong smelling liquid during the EEG called collodion. The collodion helps harden the gauze that holds the electrodes to your child's head. Collodion smells sort of like turpentine or nail polish remover. If your child is very sensitive to the way things smell, he or she might need to practice being around this smell without getting upset. You can do this at home by putting some nail polish remover on a cotton ball and leaving it out near the child so he or she can smell it for several minutes at a time. On the day of the EEG, you can ask the technician if your child can smell the collodion before it is used with the gauze (if you think this would help your child adjust to the smell).

Helping Your Child Calm His or Her Body

Some children can get anxious or worked up during EEGs, even though it does not physically hurt. You can remind them to take deep breaths and maybe take some yourself. Deep breathing usually works best when someone takes a long breath through his nose, holds it for one or two seconds, and lets it out through their mouth. A good way to describe this to children is to tell them to "smell a flower, hold it, and blow out a candle."

For many children, sucking on something can calm them down. You might try pacifiers, rubber necklaces, or lollipops depending on how old your child is and what he or she likes.

Two other things that can help some children feel calmer are:

- movements like rocking or swinging (although this should not be done once the electrodes are on as the movement can interfere with EEG activity).
- deep pressure activities, like someone squeezing or massaging them or using a weighted blanket, weighted vest, or compression vest.

If you have a few days or weeks before your EEG, try rocking or swinging your child in a blanket once or twice a day to see if it helps him or her calm down. You can also try squeezing their arms, legs, or feet while you sing songs. If these activities seem to make your child more active or upset, they probably will not be good things to try the day of the EEG.

Later in the tool kit we will talk about how to use a teaching story to help children get ready for the EEG. You can practice some of the strategies above while you go through the story with your child so he or she can become familiar with the process and how it might feel.

If your child works with an occupational therapist (OT) or physical therapist (PT), the therapists might have specific ideas about how to help your child calm down when he or she is upset. They might also have other ideas for desensitization activities that use your child's specific interests.

The Day of the EEG:

Children who over-respond usually do best in situations that are quiet, calm and predictable. There are a couple of things to try once your child is in the room where the EEG is happening:

- If your child is sensitive to bright lights, ask the technician if you can dim the lights or turn them off (as long as the technician can still see).
- Ask people in the room to use quiet voices when speaking.
- Bring earplugs if this will help your child block out some of the noises in the room.
- If you think your child will enjoy listening to music or watching a movie, using headphones may be a good option. Ear bud headphones will work better than ones that go over your child's head because of the electrodes attached to his or her head.

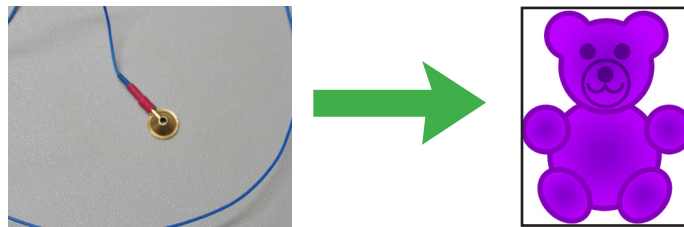
If your child calms down when being rocked or getting deep pressure, ask if you can take a break after each electrode to do these activities for a few seconds. This might keep your child from getting overwhelmed.

Using Visual Supports to Help Your Child

What are Visual Supports and How Can They Help?

Many children and people with ASD like to know what is going to happen next. To help them, you can use visual supports. Visual supports are things like pictures, schedules and objects that give extra structure and help people know what to expect.

Children who do not understand much language might need a very simple visual support, like a "first-then" card. This is a card that has two pictures on it – one picture that is usually something less fun (like having an electrode put on) and then one picture of something more fun (like a treat or a fun activity). You can use the visual support and simple language to explain to the child what is going to happen. For example, if you are calling the electrodes "buttons," you can point to each picture and say, "First button, then gummy bear."



First

Then

Some children might need a treat after each electrode to help them stay motivated and calm. Other children might be able to have three electrodes put on before they get their treat. It is okay for children to eat treats or chew gum while the electrodes are being put on, but they will not be able to do this once the technician is ready to start collecting data. The jaw movements of chewing can interfere with the brain waves your child's team is trying to collect.

** You probably will not want to use treats like candy if your child is lying down while the electrodes are being put on because of the risk of choking.

Another way you can use visual supports is to make a schedule of steps of the EEG so your child can follow along. This schedule is a little different from the teaching story we talk about later because it uses less language. The number of steps depends on how much detail you think your child needs. An example of a very short visual schedule might look like this:

Drive to hospital



Wait in room



Put buttons on head



Take a nap



Wash hair



Have a treat



You can help your child follow along so he or she knows what step was just completed and what step is coming up next. Give your child something to look forward to after the EEG like going to a favorite restaurant or picking out a new toy for good motivation.

Remember to praise your child after every step!

Creating and Using a Teaching Story

A teaching story is a type of story that can help children understand a certain situation and what to expect in advance. It can also remind the child of how to act in a situation. A teaching story usually includes:

- Some personal information about your child. You might include a coping strategy you know works for your child.
- Information about what to expect. For a story about the EEG, this will probably include the way things look, feel and smell.
- Concrete and positive language (“I will try to sit still” instead of “I will try not to move around”).
- Pictures and photos can be used and may be helpful for many children.

One thing to think about is how specific you should be in the teaching story. Some children do best when the story includes a lot of details. For other children, using lots of details can be risky because if something during the actual EEG is different than what you wrote, the child might get upset. You can try to avoid this by using words like “might” or “may”. You are the best person to judge how detailed your story should be for your child.

For example, instead of writing “I will sit in my mom’s lap the entire time,” you could write “I might sit in my mom’s lap or on a bed.”



Carol Gray created a specific kind of teaching story called Social Stories™. For more information, go to www.thegraycenter.org/social-stories.

We wrote a sample teaching story on the next page that describes the EEG. Remember that a teaching story usually works best when it is written specifically for each child. Here are some other websites that have EEG teaching stories:

http://www.maxishare.com/included/docs/eeg_book_printable.pdf

http://www.oneplaceforspecialneeds.com/main/library_eeg_test.html

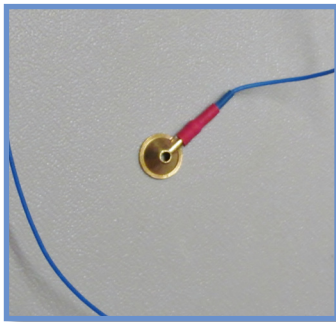
You can also try doing an online search using terms like “preparing for an EEG” or “helping children with autism have an EEG.” Remember that some results you find might not be specific to children with autism.

Sample Teaching Story

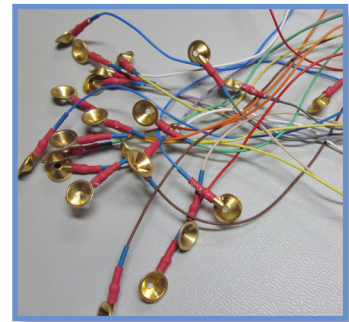
I am going to have something called an EEG test. An EEG test helps doctors learn about how my brain works. I will go to the hospital or a special clinic to have the EEG and might spend the night there. My mom or dad will be with me while the EEG happens. The EEG might feel weird or funny but it will not hurt. I can talk with my mom or dad before the EEG happens. They will help me figure out how to stay calm. I can bring favorite books, games or toys with me to the hospital.

I will start in the waiting room. My mom or dad will talk with people while I wait. I can read a book or play a game. We will go to a small room where I will stay with my mom or dad during my EEG. I will meet people who will help me with the EEG. I will meet someone called an EEG technician. I can ask anyone questions about what is going to happen if I forget. I will try to follow the directions. I will try to sit calmly during the EEG and play with the toys my mom or dad brought. This will help the EEG go faster.

The technician will bring out some supplies for the EEG. I will know about some of these things. Some things might be new. One of the new things is called an electrode. It looks like a little metal circle with a wire attached to it:



There might be lots of electrodes all together with different colored wires:



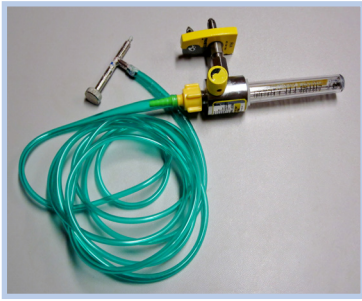
The technician will put a tape measure around my head and make little dots on my head with a pen. She makes these dots to know where to put the electrodes on my head. The technician might have to lean close to me while she makes the dots. She will be careful and will not hurt me.



Next, the technician will take a cotton swab and dip it into a paste that helps clean my head. When she touches my head with the cotton swab, it might feel scratchy or weird. Then she will put the electrode in that same spot. The electrode has a little bit of glue on it that will come off my head with shampoo when the EEG is over.

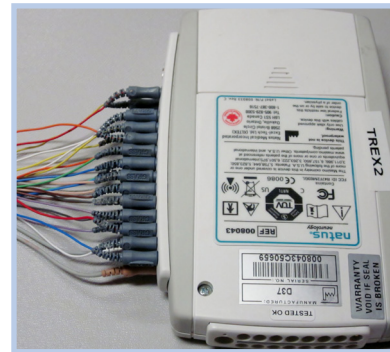
To help the electrode stay on, the technician will use a little piece of gauze dipped in a liquid that smells funny. I might not like the smell but I will keep trying to sit calmly. The technician will put the gauze over the electrode.





She might use a little air hose to help dry the liquid on the gauze. The air hose may be loud and sound like a tiny vacuum cleaner. It blows out cold air on my head. I can ask to use small earphones if the sound of the air hose bothers me. After the gauze is dry, my first electrode is done! The technician will put on more electrodes like this in different places on my head. She might also put some electrodes on the front of my head and things that look like stickers on my chest. This is so doctors can see how my heart is beating.

Once all the electrodes are on my head, the technician will use more gauze and wrap my head up like a mummy. This is so all the electrodes stay where they are supposed to. The wires from the electrodes go into a box that keeps track of my brain waves.



My mom and dad will be proud of me for sitting still while all the electrodes were put on! After I have my mummy hat, I might need to look at a flashing light or blow into a pinwheel.

I also might take a nap or spend the night in the hospital. This is so doctors can see the different waves my brain makes when I sleep. Once the EEG is over, the gauze squares will come off. We will use a special liquid to help get the gauze squares off my head. The liquid might feel slimy or greasy but does not burn or hurt. I might need to wash my hair a couple of times to get rid of all the liquid. After that I will be all done with my EEG!



Helping Your Child During The EEG Set-Up Process

There are lots of things you can do during the actual EEG to help things go more smoothly. One of the best tools you and the EEG technicians can use is distraction. Several ideas are given here, but feel free to think about your child's special interests or favorite activities and use them too!

Putting on the EEG electrodes is usually easiest if the child does not move around very much. Some children might do better if they are lying down (so they do not move their head as much). Others might do best sitting in their parent's lap. Talk to your EEG technician about what setup you think will work best for your child. Remember that the technicians need to be able to reach all parts of your child's head.

One of the most helpful things you can do is to find a toy or activity that quietly distracts your child while the EEG technician is putting on the electrodes:

- You can plan ahead by having a special video to watch or some new toys and activities for your child to look at the day of the EEG.
- Toys or activities that require your child to use his or her hands are especially good choices. He or she will be less likely to try and pull the electrodes off if his or her hands are busy doing something else.
- Many children enjoy playing on their parents' phones or devices such as iPads. These devices can be good distractions since they involve your child looking at and touching something.
- If your child has a favorite DVD or video, he or she can watch that. Some hospitals or clinics may have televisions and DVD players in your child's room or have a video library to choose from. Letting your child use headphones may also be helpful if it will help drown out the sound of the air hose.

Children may also enjoy items called "fidgets" that they can explore with their hands. There is a list of sample fidgets (and pictures) in Appendix B at the end of this tool kit. Also, check with your child's EEG technician to see if there are any toys or electronics at the clinic or hospital that your child can use.

Other examples of good distractions:

- Reading a favorite book
- Singing songs (ones where the child can imitate hand movements like Itsy-Bitsy Spider or Wheels on the Bus are good choices)
- Playing games like tic-tac-toe
- Coloring, doing mazes in a book or doing word searches
- Talking about a favorite topic or special interest

My child is verbal and very smart. What strategies should I use?

Smart children with good language skills can still use lots of the strategies above like distraction activities and visual supports such as a schedule. They may also like having some time to ask the technician questions about the EEG before it starts or seeing the room where their brain waves are recorded. Giving choices to children with ASD can be another way to help them feel more in control. For the EEG, this might mean letting them choose the color of the electrode wire that goes on their head next or where on their head it should go (i.e., the back of the head or the forehead).

If you find a toy or object that your child really enjoys, try to limit how much time he or she gets to play with it before the EEG. Even if you might want to let him or her play with it all the time, it will be a more powerful distracter during the EEG if your child has not seen it for several days.

Challenging Behavior

Most children have challenging behavior at some point, even if they do not have ASD. These behaviors may include screaming, kicking, hitting, biting, not wanting to do something or trying to run away. Many children with ASD have a hard time understanding and expressing their emotions. This means they might “show” their feelings through behavior, especially when they are anxious. Lots of children with ASD have challenging behavior when they are anxious because they do not know how to say what they are feeling.

Many children have a hard time when they need to have a medical procedure like an EEG. Two of the best ways to help prevent challenging behavior are to:

- Prepare your child ahead of time (maybe by using some of the desensitization suggestions in this tool kit).
- Let the clinic staff know how they can work with your child. You can fill out the Pre-EEG Procedure Questionnaire at the end of this tool kit and share it with your child’s EEG staff to help them understand your child better.

If your child does have challenging behavior during the EEG, try to focus on what you would like him or her to do (“Lift your chin up”) instead of what he or she should stop doing (“Don’t move your head”). Remember that it might help your child calm down if you stay calm.

RESOURCES

The Autism Speaks Family Services Department offers resources, tool kits, and support to help manage the day-to-day challenges of living with autism www.autismspeaks.org/family-services. If you are interested in speaking with a member of the Autism Speaks Family Services Team contact the Autism Response Team (ART) at 888-AUTISM2 (288-4762), or by email at familyservices@autismspeaks.org.

ART en español: 888-772-9050.

ACKNOWLEDGMENTS

This tool kit was developed by the following individuals: Lindsay Washington, Ph.D., Rocky Mountain Human Services, Aurora, Colorado; Terry Katz, Ph.D., JFK Partners, Autism and Developmental Disabilities Clinic, University of Colorado School of Medicine & Child Development Unit, Children's Hospital Colorado; Reet Sidhu, M.D., Department of Neurology, Division of Child Neurology at the Columbia University College of Physicians and Surgeons, New York, New York; Ann M. Neumeyer, M.D., Child Neurology, Massachusetts General Hospital for Children, Boston, Massachusetts; Tim Benke, M.D., Ph.D., Departments of Pediatrics, Neurology, Pharmacology, Otolaryngology, and Neuroscience Program, University of Colorado School of Medicine/Children's Hospital Colorado, Aurora, Colorado; Patti LaVesser, Ph.D. OTR/L, JFK Partners and Department of Pediatrics, University of Colorado School of Medicine, Aurora, Colorado; Markelle Springsteen B.S., CCLS, Ambulatory Care, Children's Hospital Colorado, Aurora, Colorado.

In addition, we would like to acknowledge the following individuals for their invaluable support, encouragement, and feedback: Chelsey Stillman, PA-C, MPAS, Neuroscience Institute at Children's Hospital Colorado, Aurora, Colorado; Sy Turner, R. EEG T., CLTM, BS., Neurophysiology Lab and Epilepsy Monitoring Unit at Children's Hospital Colorado, Aurora, Colorado; Helly Goez, M.D., Division Director of Pediatric Neurology in the Department of Pediatrics, Stollery Children's Hospital, Edmonton, Alberta. Finally, we are extremely grateful for the suggestions and feedback we received from the parents, caregivers, and providers in our focus groups. These individuals graciously offered to discuss and reflect on their own experiences so this tool kit could be a resource for other families.

The tool kit was edited, designed, and produced by Autism Speaks Autism Treatment Network / Autism Intervention Research Network on Physical Health. We are grateful for review and suggestions by many, including by families associated with the Autism Speaks Autism Treatment Network. This publication may be distributed as is or, at no cost, may be individualized as an electronic file for your production and dissemination, so that it includes your organization and its most frequent referrals. For revision information, please contact atn@autismspeaks.org.

These materials are the product of on-going activities of the Autism Speaks Autism Treatment Network, a funded program of Autism Speaks. It is supported by cooperative agreement UA3 MC 11054 through the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Research Program to the Massachusetts General Hospital. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the MCHB, HRSA, HHS. Published August 2014.

Appendix A

Pre-EEG Parent Questionnaire

Please share this completed questionnaire with your child's EEG technician or clinic staff.

Your Child's Name: _____
Your Name: _____
Phone Number: _____

Child's Date of Birth: _____ Child's Age: _____
Child's Scheduled EEG Date: _____

Does your child have a specific diagnosis or diagnoses? Yes No
If yes, please list: _____

If your child has a diagnosis or disability, please describe how it affects him or her:

Is your child currently taking any medications? Yes No
If yes, what medications and what dosages? _____

Has your child ever had seizures? Yes No
If yes, what was the date of his or her last seizure? _____
Describe the frequency and types of seizures: _____

Does your child ever stop blinking and stare off into space for brief periods? Yes No
If yes, how long do the staring episodes usually last? _____
How often do they occur? _____
Is there anything you can do to get your child's attention during these episodes?

Does your child have any allergies? Yes No
If yes, please list: _____

Does your child wear a hearing aid? Yes No
If yes, please explain: _____

Does your child wear glasses or contact lenses? Yes No
If yes, please describe how well your child can see: _____

Does your child have any other physical challenges that the EEG team should be aware of?

Communication and Behavior:

Is your child able to communicate verbally (i.e., does your child use spoken language/words to communicate)? Yes No

If no, how does your child communicate with you or let you know what he/she wants?

Does your child use nonverbal communication like gestures or pictures? Yes No

Please check any of the following that your child uses:

Mayer Johnson Symbols Sign Language

Picture Exchange Communication System (PECS)

Sentence board

Gestures

Other communication device

Other: _____

Will you be bringing a communication system with you? Yes No

How much language does your child understand? _____

Are there any symbols/signs that we can have available to help with communication?

Are there any useful phrases or words that work best with your child to help him/her stay calm?

If you have talked about or practiced the steps of the EEG at home, are there certain words you have used that we can try to use during the actual procedure? (For example, if you have talked to your child about “stickers” being put on his or her head, the EEG technician might be able to use the same language when applying the electrodes.)

Behavior:

Please list any challenging behaviors you want the EEG team to know about:

How can you tell when your child is starting to get nervous or upset?

Please check if your child engages in any of these behaviors when upset:

- Trying to escape the situation or room
- Biting
- Hitting
- Kicking
- Screaming
- Crying
- Tensing up his/her body
- Throwing objects
- Getting very quiet
- Exhibiting self-injurious behavior
- Other: _____

When your child gets upset, what do you do? What would you like the staff to do if your child gets upset during the EEG?

Sensory:

Please list any specific sounds or sensations that your child is sensitive to:

Does your child like quiet settings? Yes No

Is your child more comfortable in a dimly lit room? Yes No

Is your child sensitive to having his/her head or hair touched? Yes No

Is your child more comfortable in a clutter-free environment? Yes No

Does your child like to be touched lightly or firmly? _____

Please provide any other information that may help the EEG team prepare for a successful EEG experience:

Previous Experiences:

Has your child had an EEG before and if so, how did it go?

What do you think would have made the EEG easier for you or your child?

Additional Information:

Would it help your child if the technician explained each step of the procedure to him or her?

Yes No

Would help your child if or she could explore the way the materials smell and feel? Yes No

Does your child enjoy making choices? Yes No

Would your child enjoy using a mirror to watch the setup process and see the equipment as it is applied? Yes No

How long can your child sit still if he or she has a favorite toy or object to play with?

How does your child react to new people?

How does your child react to being in a hospital setting?

Appendix B

Sample Distraction Items

Bubbles



Cause-and-effect toys



Hand-held oil and water toys



Glitter wands



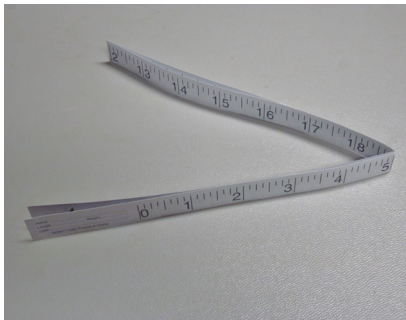
Books

(with flaps, musical buttons or hidden objects)

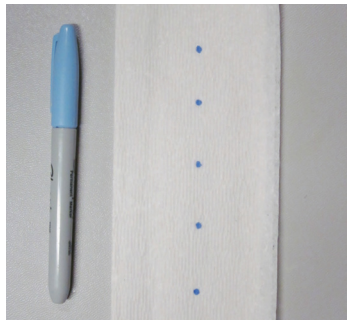


Appendix C

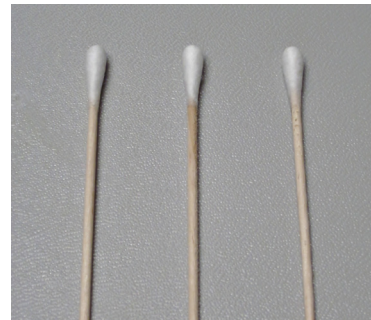
Pictures of Sample EEG Materials



Tape measure



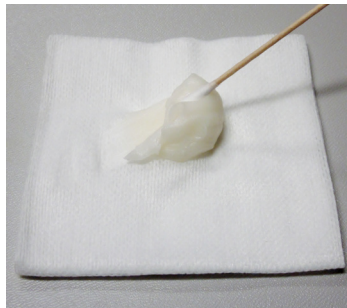
Pen and dots



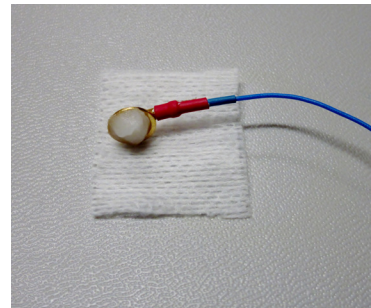
Cotton swabs



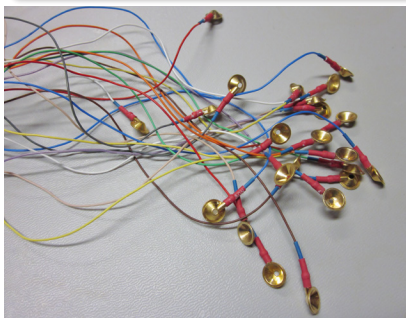
Cotton swab and prep



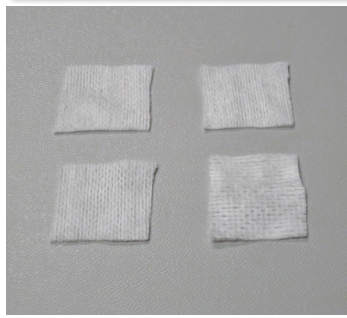
Cotton swab and glue



Electrode with glue



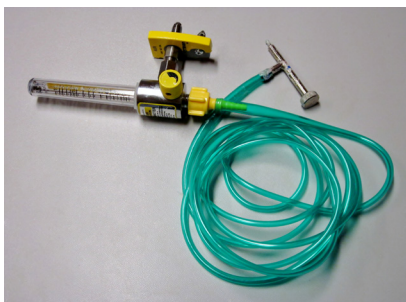
Electrodes



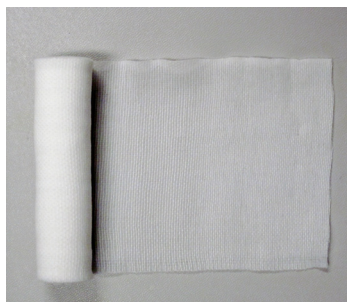
Gauze squares



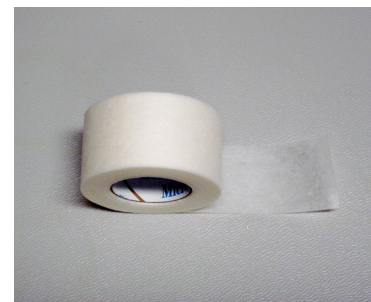
Collodion



Air Hose



Gauze



Tape