

# a Parent's Guide to Pediatric Epilepsy Surgery



## >> Frequently Asked Questions

This guide is for parents and families thinking about pediatric epilepsy surgery at the Comprehensive Epilepsy Center of Children's Medical Center Dallas.

We know that the decisions involved in surgery are not easy ones for you to make, but we hope that this guide will help make the journey a little easier.

Whether or not your child goes all the way to surgery, we want you to be as informed as possible.

Our team of highly qualified doctors and nurses is here to support you throughout this journey and to make sure that your child has the best care possible.

### Steps of the Pediatric Epilepsy Surgery Journey



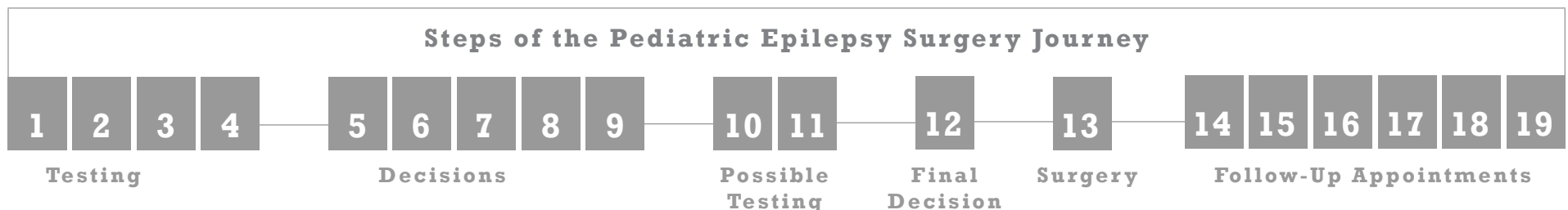
## *Why are some tests inpatient stays and other tests are outpatient stays?*

Some tests that we do require your child to stay at the hospital overnight or for a few days. These tests are called inpatient tests. The extra time is needed to help us learn more about your child's seizures. Inpatient stays may also be needed for tests that require extra care and attention by doctors and nurses. Inpatient tests include:

- Video EEG
- Wada test
- Ictal SPECT

Other tests only take a few hours and can be done as an outpatient. Outpatient tests include:

- EEG
- fMRI
- MRI
- PET



## *Why does my child need to see a Neuropsychologist?*

Neuropsychological Testing is a way to learn more about a child's thinking skills and behavior. The testing also tells us if some parts of your child's brain aren't working as well as they could be. These areas may be the areas that are causing seizures. Neuropsychological Testing includes:

- Parent interviews about development and school performance
- Parent ratings of behavior
- Tests completed by the child

These tests tell us more about a child's:

- Intelligence (also known as IQ)
- Language, memory, and attention
- Visual-spatial skills, problem-solving speed, and hand speed

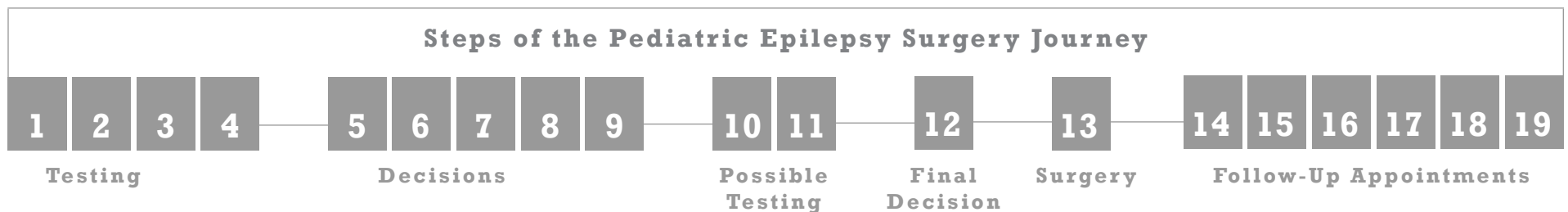
### Steps of the Pediatric Epilepsy Surgery Journey



*How do you know if surgery could help a child?*

Epilepsy surgery can help children who have:

- Partial seizures
- Epilepsy that can not be controlled after trying two or more antiepileptic medicines (intractable epilepsy)
- Seizures coming from an area of the brain that can be safely removed



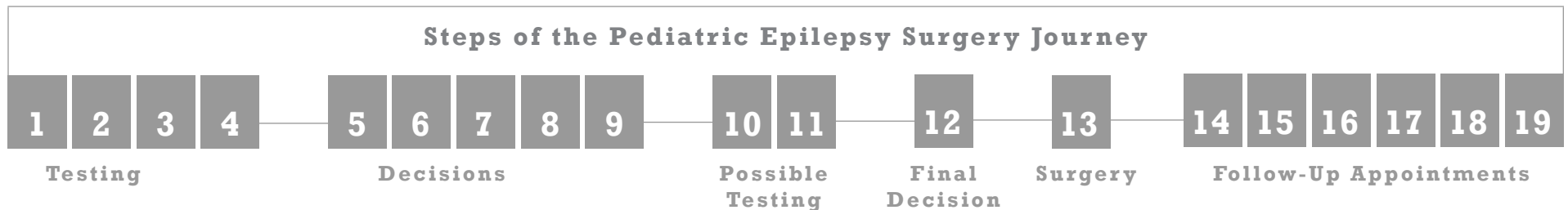
***What if I wait several years before saying "yes" to surgery?***

Most of the time, surgery will still help your child even if you choose to wait several years.

However, uncontrolled epilepsy can affect a child's health and development. Postponing surgery increases the risk that the seizures may cause physical injury or developmental delays.

The Epilepsy Team will only recommend surgery if we think that it would help your child.

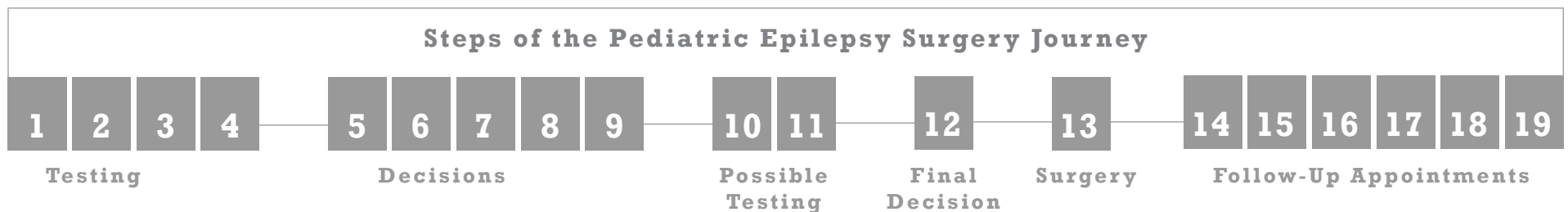
Many parents of past surgery patients have said that they wished they had done the surgery earlier.



***If surgery isn't done and medicines haven't worked,  
what other treatment options are available?***

The Neurologist might suggest that your child try other treatments, such as:

- Ketogenic Diet
- Vagus Nerve Stimulation
- Combinations of antiepileptic medicines
- Experimental trials of new antiepileptic medicines

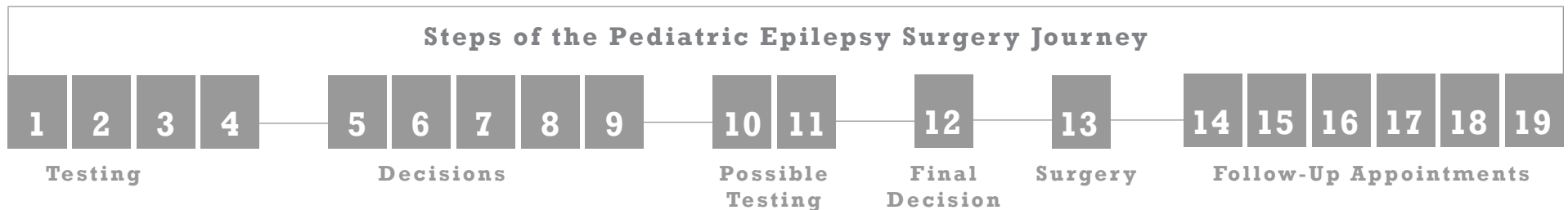


***Does surgery ever make a child's epilepsy worse?***

There are risks to any brain surgery.

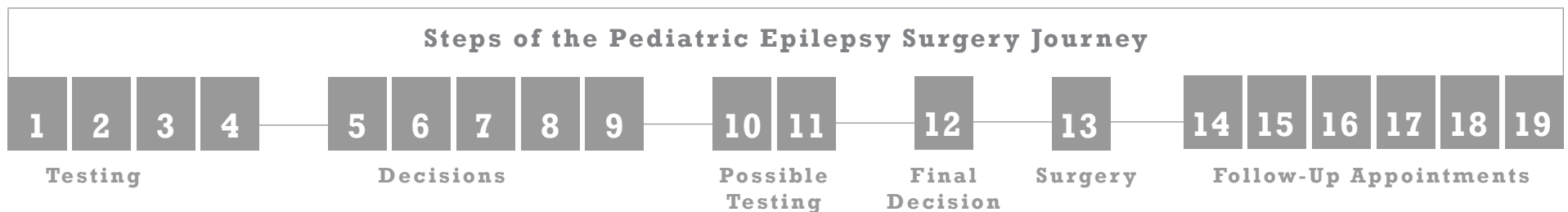
However, even if surgery does not stop a child's seizures, it usually reduces them.

Most families feel that their child's life was improved by the surgery.



*How old are your epilepsy surgery patients?*

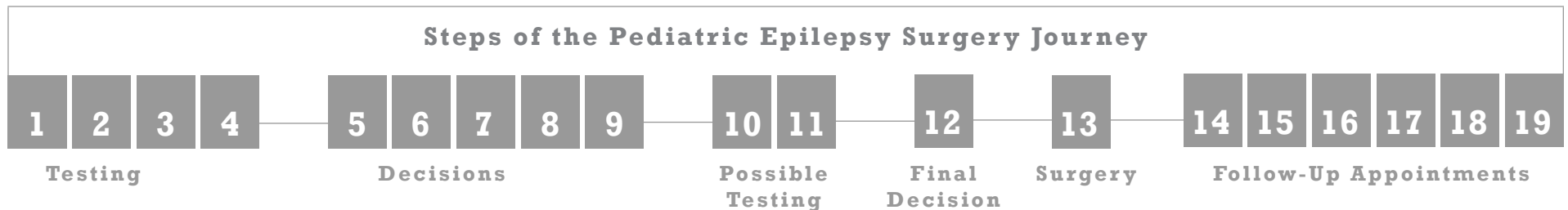
Our epilepsy surgery patients are anywhere from six months old to nineteen years old.





***Does insurance cover the cost of surgery?***

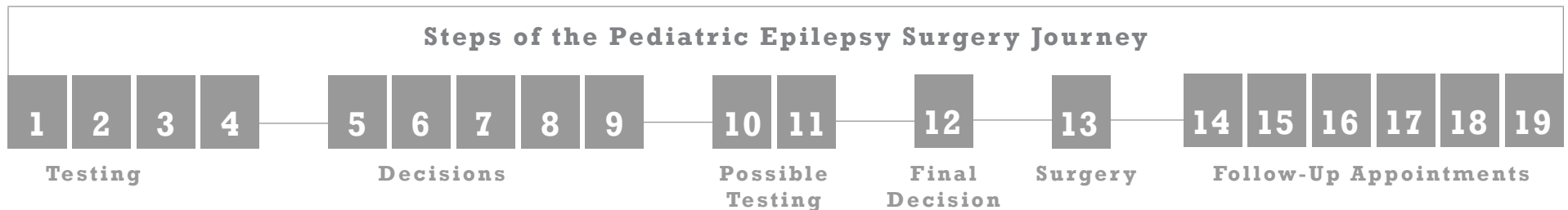
Yes. Epilepsy surgery is covered by most insurance companies.



### *What are the risks of epilepsy surgery?*

The risks of any brain surgery include:

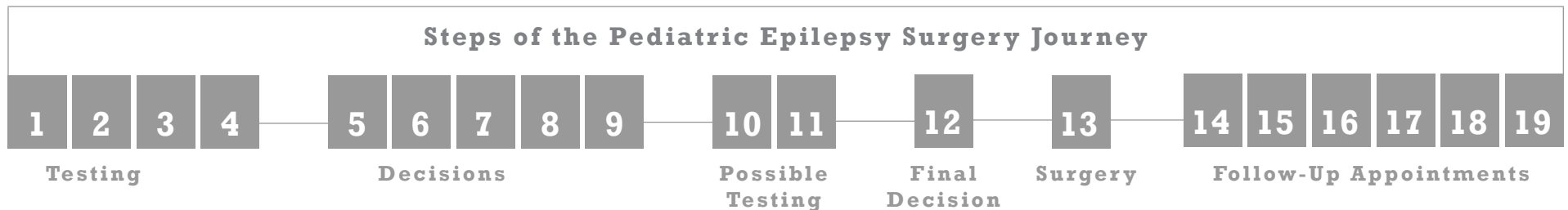
- Swelling
- Infection
- Stroke
- Bleeding
- Need for a second surgery to put in a shunt to relieve pressure
- Paralysis
- Death



***How experienced are your surgeons?***

All of our pediatric Neurosurgeons have been highly trained to give them the skills needed to safely do surgery on your child.

For more information on your child's Neurosurgeon, please see the online Neurosurgery Directory of Children's Medical Center Dallas.



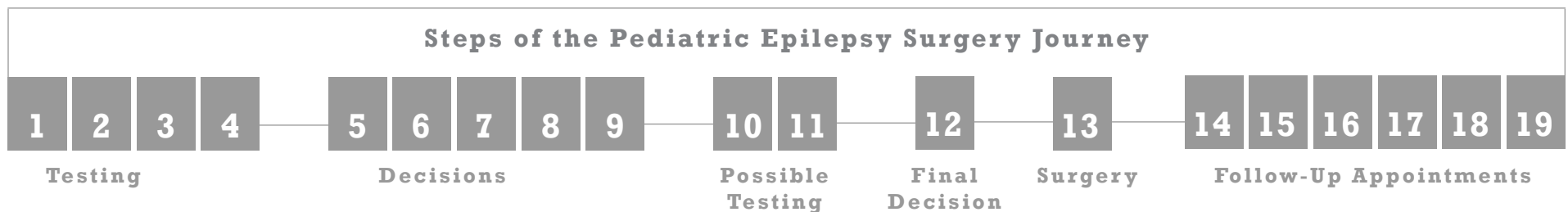
## *How long does the surgery take? So it's not a day surgery?*

No, epilepsy surgery is not a day surgery.

Our Neurosurgeons do several different types of epilepsy surgery. Some take much longer than others.

In general, the surgery usually lasts four to seven hours.

However, the pre-operative preparation and recovery time after surgery are also important. Your child will have to stay at the hospital for at least a few days after surgery. Some children need to stay longer.



### *What will the scar look like?*

The scar will look like a sideways "U" or a "question mark."

Over time, you won't even be able to see the scar as your child's hair grows.

Below are a few examples of what the scar might look like. Please ask the Neurosurgeon what your child's scar will look like.



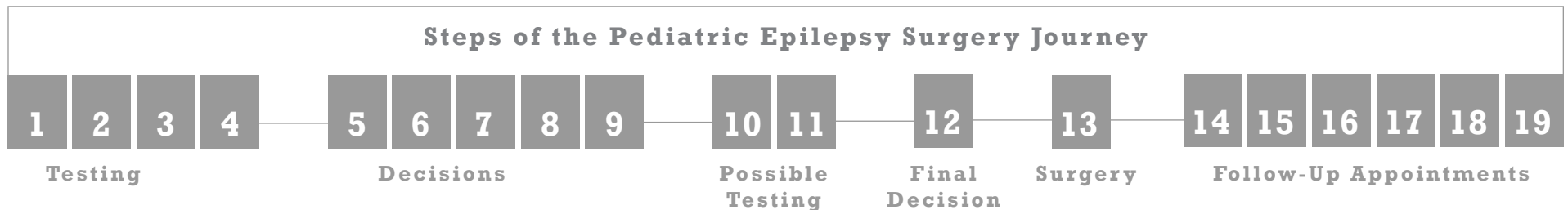
#### Steps of the Pediatric Epilepsy Surgery Journey



***How much of the brain is taken out?***

This is different for each child.

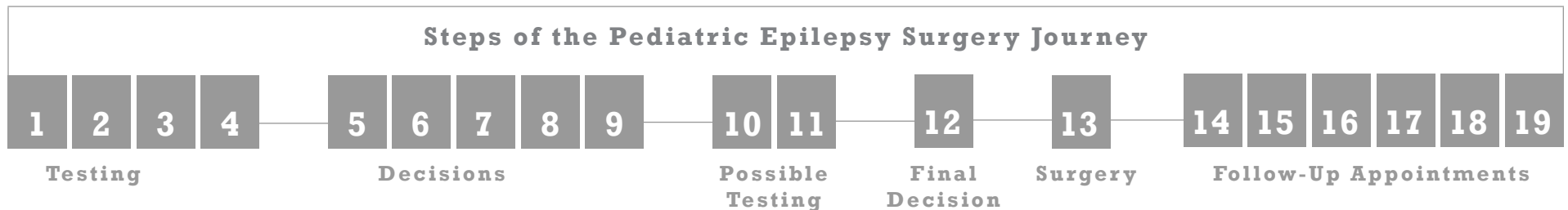
The Neurosurgeon will explain your child's surgery to you before the surgery.



***Will my child be awake during the surgery?***

No. Your child will not be awake during the surgery.

Our highly skilled Anesthesiologists will safely put your child to sleep so that he or she does not feel anything.



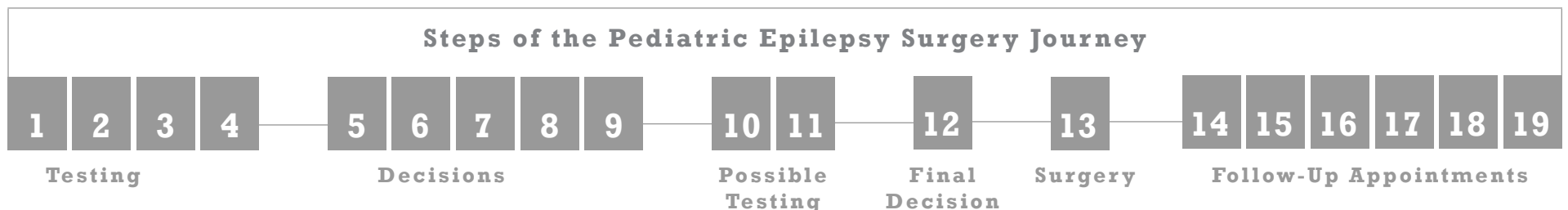
## *Will my child need blood during surgery?*

Some children need blood during surgery.

Blood that matches your child's blood-type is always kept in the Operating Room in case it is needed.

If you are not comfortable with your child receiving donated blood from our blood bank, please talk to your child's Neurosurgeon about a Directed Donor form.

Directed Donors are family members with a blood type that matches your child's blood. These family members can donate blood at an outside clinic several days before surgery. This blood will then be available in the Operating Room for your child.

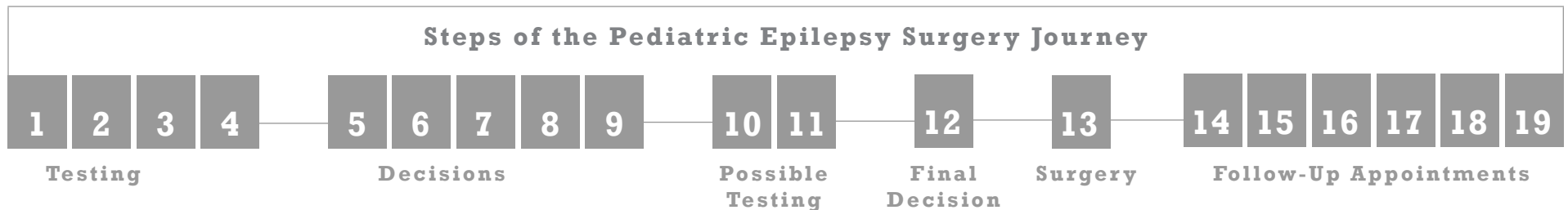




*Will my child need a feeding tube?*

Children very rarely need a feeding tube.

Infants or toddlers may need one in rare cases.

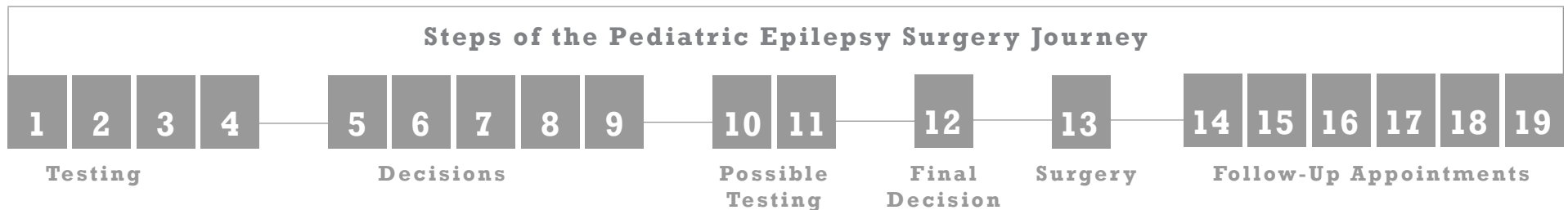


***What is the recovery time after surgery?***

Some children recover quickly and can go home after just a few days.

Other children may need to stay in the hospital for about a week.

Please talk to your child's Neurosurgeon about what to expect for your child's type of epilepsy surgery.

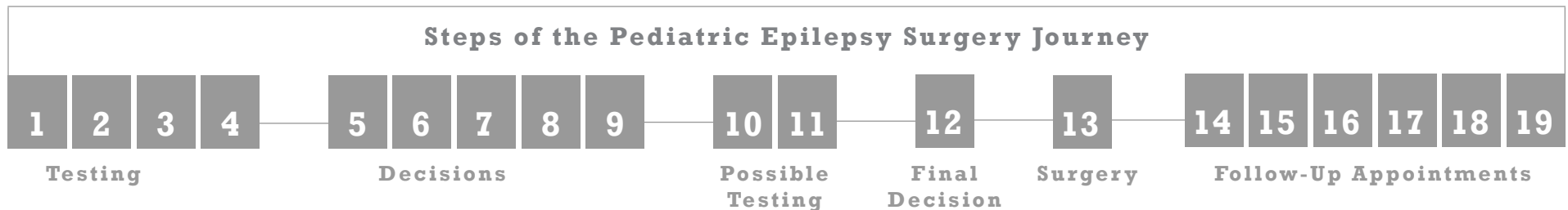


## *Will my child's seizures stop immediately after surgery?*

Many of our patients have not had a single seizure again after waking up from the surgery.

Some children have seizures during the first few weeks while the brain is healing and then become seizure-free.

Some children continue to have seizures after the surgery. However, the seizures are usually milder or less frequent than before the surgery.

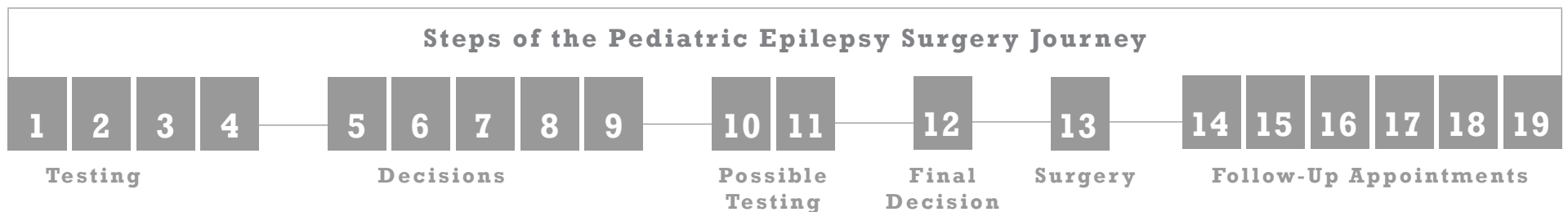


### *Realistically, what kind of results can I expect from surgery?*

Before the surgery, the Neurologist and the Neurosurgeon will give you an idea of what your child can expect from his or her surgery.

We can not promise you that your child will be seizure-free after surgery.

We also can not promise that your child will never need antiepileptic medicines again.



## *Will my child's personality change after surgery?*

The goal of surgery is to remove the part of the brain causing your child's seizures without affecting other areas of the brain that control behavior and personality.

However, surgery can be a frightening and stressful experience for both children and their families.

Some children react by becoming anxious or depressed. Our child life specialists and social workers will visit you in the hospital to help you and your child during this difficult time.

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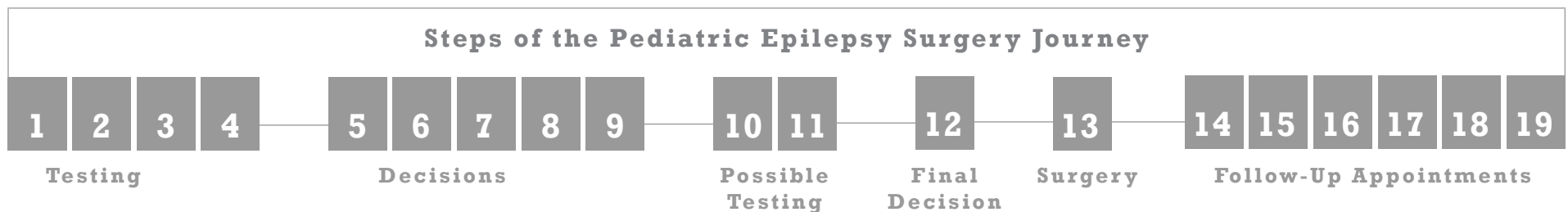


## *Why does my child still have to take medicines after surgery?*

Not all children become seizure-free after surgery. Some continue to need medicine for a short time while the brain heals from surgery. Others need medicine for the rest of their lives.

Even if a child continues to take medicine but has no seizures, we consider the surgery a success. With or without medicine, children whose seizures are under control have the chance to live a much fuller life than before surgery.

If your child has no seizures for the first two years after surgery, the Neurologist may talk about the possibility of slowly tapering antiepileptic medicine.



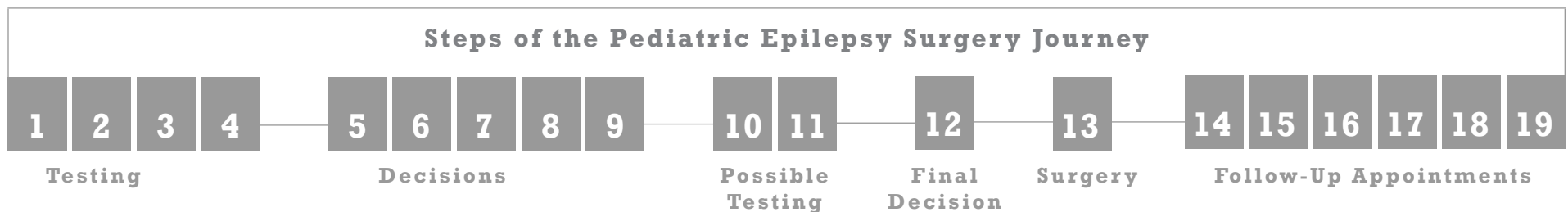
## *Will my child need therapy after surgery?*

Some children need therapy after surgery.

This therapy may include:

- Physical therapy
- Speech therapy
- Vision therapy

Therapy is especially important for hemispherectomy patients who may have more weakness on one side of the body after the surgery.



## *Why are there so many follow-up appointments after surgery?*

Our involvement in your child's care does not stop with the surgery. We want to make sure he or she makes a complete recovery.

If your child's seizures have improved, we may be able to slowly reduce or stop some of his or her medicine.

We will also need to repeat some of the testing done before surgery to see if there have been changes since the surgery.

