Child Neurology FOUNDATION

Child Neurologist New Visit Toolkit

What your new neurologist needs to know

DIRECTIONS: We encourage you to fill out this form prior to your first visit with a neurologist or when visiting a new neurologist. We recommend you print this form out and bring it to the visit with you as well as keep an electronic or paper copy for yourself. It will be a valuable resource to track your child's journey and ensure the best quality of care.

SECTIONS ON THIS FORM INCLUDE:

- New Visit Highlights
- Testing & Treatment Summary
- Medication Summary
- Symptoms Summary
- Service Summary
- Seizure Summary
- Prenatal/Birth History

Please note, you may not have all this information, and that is OK. Simply provide what information you can.

Giving your neurologist essential information helps them effectively diagnose and treat your child. Often there are symptoms you do not realize are significant and may be related to your child's condition. We hope this tool helps you and your neurologist collaborate successfully during your visit.

Additional items to bring to your visit

IF YOU HAVE ANY OF THE FOLLOWING ITEMS, THEY MAY BE HELPFUL.

1. A copy of visit notes from your last medical visit related to this condition.
2. Videos of any relevant seizures, movements, behaviors etc.
3. Bring a copy of related test results (labs, genetic tests, imaging etc), if you have electronic copies bring those as well.
4. Copy of most recent neuropsychologist/academic assessment.

Tips and tricks for your visit

1. **Bring a notebook and pen** so you can take notes
2. When describing symptoms, **be as specific as possible** and don't exaggerate or downplay symptoms.
3. If your child is able, **encourage them to share their concerns and questions during the visit**. This will help your child feel involved in the process and gives them skills to advocate for themselves.
4. **Invite another adult** to help take notes, offer support, and care for the child so you can focus on the conversation with the doctor.
5. **Don't be afraid to ask a question** if you are confused by what the doctor is saying. You may want to repeat answers back to ensure you've captured everything.
6. Be sure to ask when/if you should **schedule your next visit.**
7. If you are having tests done, if they can't give you results immediately, **ask when you should expect to get the results**, and ensure you authorize sharing results with other members of your child's care team.
8. Before you leave, **make sure you discussed your top concerns and got answers to your top 3 questions**. If the doctor does not have time to answer them during the visit, ask if a nurse can help, or if you should schedule a follow up visit or phone call.
9. **Doctors prefer summaries over specifics**, if they need more details they will ask, so having your information organized can help make answering those questions easier. Consider putting everything into a binder and group visit summaries, test results, treatment summary and medication history in separate sections. If possible, keep in chronological order, with the most resent information first.

New Visit Highlights

Visit Date: _____ Child's Name: _____ Child's Age: _____

Current Diagnosis(es):

OVERVIEW

What is your primary goal for this visit? (a diagnosis, treatment plan, aim to be on less meds, aim to get better seizure control, etc.)

What are your top 3 concerns you want to discuss today?

1. _____

2. _____

3. _____

What are the top 3 questions you want to ask your doctor today?

1. _____

2. _____

3. _____

Please provide a brief history of your child's neurologic condition. When did you first notice symptoms, what were they and how have the symptoms or condition evolved over time?

Testing & Treatment Summary

TESTING

Provide information on the testing related to the neurologic condition that has been done to date.
Examples of tests include EEG, MRI, CT Scan (CAT Scan), PET Scan, SPECT Scan, Spinal Tap, Epilepsy Panel Genetic Test, Whole Exome Test, Whole Genome Test, Chromosomal Microarray RNA Test, and Blood Draw.

If possible, bring actual images/doctor reports from most recent test. If you have originals, try to bring copies you can leave with the doctor.

Type of Test	Date of most recent test:	Did the test show irregularities?
		Yes ○ No ○ Unsure ☐
Please provide information on any irregular test result:		
Type of Test	Date of most recent test:	Did the test show irregularities?
		Yes ○ No ○ Unsure ○
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Type of Test	Date of most recent test:	Did the test show irregularities?
		Yes ○ No ○ Unsure ○
Please provide information on any irregular test result:		

Treatment Summary

Has your child had any emergency room or hospital visits in the past year? Yes ○ No ○ Don't Know ○

If yes, please describe reason for visit, duration of visit, outcomes and frequency of visits if more than once.

Has your child had any surgeries? (Include implanted devices) Yes ○ No ○ Don't Know ○

If yes, please describe.

Has your child tried diet modifications to manage their condition? (i.e.: Keto diet) Yes ○ No ○ Don't Know ○

If yes, please describe.

Medication Summary

Please list daily and rescue medications used to treat your child's condition(s). Non-prescription medications can be listed on the next page. Past prescription and all non-prescription medications can be listed on the next few pages.

CURRENT PRESCRIPTION MEDICATIONS:

Medications	Dosage*	Frequency	Do you believe this medication helps?	Any known side effects?	Do the side effects impact ability to take medication?	Does the child take the medication consistently as prescribed?	What symptom(s) does this medication address?
			Yes ○ No ○ Unsure ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	
			Yes ○ No ○ Unsure ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	
			Yes ○ No ○ Unsure ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	
			Yes ○ No ○ Unsure ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	
			Yes ○ No ○ Unsure ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	
			Yes ○ No ○ Unsure ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	
			Yes ○ No ○ Unsure ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	
			Yes ○ No ○ Unsure ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	
			Yes ○ No ○ Unsure ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	
			Yes ○ No ○ Unsure ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	
			Yes ○ No ○ Unsure ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	
			Yes ○ No ○ Unsure ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	
			Yes ○ No ○ Unsure ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	
			Yes ○ No ○ Unsure ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	
			Yes ○ No ○ Unsure ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	
			Yes ○ No ○ Unsure ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	
			Yes ○ No ○ Unsure ○	Yes ○ No ○	Yes ○ No ○	Yes ○ No ○	

**If multiple dosages used, list highest dosage.*

PREVIOUS PRESCRIPTION MEDICATIONS:

Medications	Dosage*	Frequency	Do you believe this medication helped?	Any known side effects?	Why did you stop this medicine?	Did the child take the medication consistently as prescribed?	What symptom(s) does this medication address?
			Yes No Unsure	Yes No		Yes No	
			Yes No Unsure	Yes No		Yes No	
			Yes No Unsure	Yes No		Yes No	
			Yes No Unsure	Yes No		Yes No	
			Yes No Unsure	Yes No		Yes No	
			Yes No Unsure	Yes No		Yes No	
			Yes No Unsure	Yes No		Yes No	
			Yes No Unsure	Yes No		Yes No	
			Yes No Unsure	Yes No		Yes No	
			Yes No Unsure	Yes No		Yes No	
			Yes No Unsure	Yes No		Yes No	
			Yes No Unsure	Yes No		Yes No	

**If multiple dosages used, list highest dosage.*

KNOWN ALLERGIES TO MEDICATIONS

Medication:	Reactions:

Medication Summary

CURRENT NON-PRESCRIPTION MEDICATIONS:

May include over the counter, dietary supplements, herbal medicine, etc.

Medications	Dosage*	Frequency	Do you believe this medication helps?	Any known side effects?	Do the side effects impact ability to take medication?	Does the child take the medication consistently as prescribed?	What symptom(s) does this medication address?
			Yes No Unsure	Yes No	Yes No	Yes No	
			Yes No Unsure	Yes No	Yes No	Yes No	
			Yes No Unsure	Yes No	Yes No	Yes No	
			Yes No Unsure	Yes No	Yes No	Yes No	
			Yes No Unsure	Yes No	Yes No	Yes No	
			Yes No Unsure	Yes No	Yes No	Yes No	
			Yes No Unsure	Yes No	Yes No	Yes No	
			Yes No Unsure	Yes No	Yes No	Yes No	

PREVIOUS NON-PRESCRIPTION MEDICATIONS:

Medications	Dosage*	Frequency	Do you believe this medication helped?	Any known side effects?	Why did you stop this medicine?	Did the child take the medication consistently as prescribed?	What symptom(s) does this medication address?
			Yes No Unsure	Yes No		Yes No	
			Yes No Unsure	Yes No		Yes No	
			Yes No Unsure	Yes No		Yes No	
			Yes No Unsure	Yes No		Yes No	
			Yes No Unsure	Yes No		Yes No	
			Yes No Unsure	Yes No		Yes No	
			Yes No Unsure	Yes No		Yes No	
			Yes No Unsure	Yes No		Yes No	

**If multiple dosages used, list highest dosage.*

SYMPTOMS OF NEUROLOGIC CONDITION

Symptoms	Is this a concern?		Has this recently changed?		Please describe reason for concern.
Growth and physical development	Yes ◯	No ◯	Yes ◯	No ◯	
Gross motor skills (i.e.: sitting, standing, crawling, walking)	Yes ◯	No ◯	Yes ◯	No ◯	
Fine motor skills (i.e.: holding a pencil, buttoning a coat)	Yes ◯	No ◯	Yes ◯	No ◯	
Short-lasting sudden movements (motor tics) or uttered sounds (vocal tics)	Yes ◯	No ◯	Yes ◯	No ◯	
Communication skills	Yes ◯	No ◯	Yes ◯	No ◯	
Hearing or vision	Yes ◯	No ◯	Yes ◯	No ◯	
Headaches	Yes ◯	No ◯	Yes ◯	No ◯	
Sleep or fatigue	Yes ◯	No ◯	Yes ◯	No ◯	
Mental Health	Yes ◯	No ◯	Yes ◯	No ◯	
Behaviors	Yes ◯	No ◯	Yes ◯	No ◯	
Academic development (reading, writing focus, etc.)	Yes ◯	No ◯	Yes ◯	No ◯	
Sexual health	Yes ◯	No ◯	Yes ◯	No ◯	
Other	Yes ◯	No ◯	Yes ◯	No ◯	

DOES YOUR CHILD CURRENTLY RECEIVE ANY SERVICES AT SCHOOL?

	Service
◯	504 Accommodations
◯	Individualized Education Plan (IEP)
◯	None
◯	N/A, not attending school
◯	Don't Know
◯	Other:

If yes, is it helping? Yes ◯ No ◯ Unsure ◯

Do you want to share anything else about how your child is doing academically and socially at school?

IS YOUR CHILD WORKING WITH ANY OTHER SPECIALISTS TO TREAT THESE SYMPTOMS?

If yes, please provide information about the specialists.

Specialists may include Pediatrician, Psychologist, Psychiatrist, Occupational Therapist, Physical Therapist, Speech Therapist, Optometrist, Ophthalmologist, Sleep Specialist, Allergist, Registered Dietitian, Pulmonologist, Behavior Specialist, Educational Specialist, and Tutor.

Specialty and Name	Phone Number	Is this treatment working?
		Yes ◯ No ◯ Unsure ◯
		Yes ◯ No ◯ Unsure ◯
		Yes ◯ No ◯ Unsure ◯
		Yes ◯ No ◯ Unsure ◯
		Yes ◯ No ◯ Unsure ◯
		Yes ◯ No ◯ Unsure ◯
		Yes ◯ No ◯ Unsure ◯
		Yes ◯ No ◯ Unsure ◯
		Yes ◯ No ◯ Unsure ◯
		Yes ◯ No ◯ Unsure ◯

Seizure Summary

Does your child have seizures? Yes ◯ No ◯

Seizure types include: Generalized Seizures (tonic clonic, clonic, tonic, myoclonic, atonic, epileptic spasms, absence), Focal Seizures (focal with impaired awareness, focal aware and epileptic spasms), Infantile Spasms
Learn more about the seizure types here: childneurologyfoundation.org/disorder/epilepsy

Tip: If possible, provide a video of any seizure or suspected seizure. Also, if you have one, bring a copy of your child's seizure diary.

IF YES, PLEASE USE THE FORM BELOW TO DESCRIBE THE SEIZURES:

What is the primary seizure type your child currently has?

At what age did these seizures begin? _____ Years _____ Months

How often does your child have these seizures? ◯ Yearly ◯ Monthly ◯ Weekly ◯ Daily

How many minutes did the seizure usually last? _____ Minutes

Is there a known trigger? ◯ Yes ◯ No Is there a warning sign? ◯ Yes ◯ No

What time of day does your child have this seizure? ◯ Morning ◯ Midday ◯ Afternoon ◯ Evening ◯ During Sleep

Can you interrupt the seizure? ◯ Yes ◯ No

If yes, how? (touch, movement/waving arms, loud sound, calling name)

Is your child still having this type of seizure? ◯ Yes ◯ No ◯ Don't Know

If no, when did they stop?

IF YOUR CHILD HAS/HAD ADDITIONAL SEIZURE TYPES, PLEASE PROVIDE DETAILS AND PRINT OUT ADDITIONAL COPIES OF THIS PAGE IF NEEDED TO DESCRIBE ALL SEIZURE TYPES.

Additional Seizure Type:

At what age did these seizures begin? _____ Years _____ Months

How often does your child have these seizures? ◯ Yearly ◯ Monthly ◯ Weekly ◯ Daily

How many minutes did the seizure usually last? _____ Minutes

Is there a known trigger? ◯ Yes ◯ No Is there a warning sign? ◯ Yes ◯ No

What time of day does your child have this seizure? ◯ Morning ◯ Midday ◯ Afternoon ◯ Evening During Sleep

Can you interrupt the seizure? ◯ Yes ◯ No

If yes, how? (touch, movement/waving arms, loud sound, calling name)

Is your child still having this type of seizure? ◯ Yes ◯ No ◯ Don't Know

If no, when did they stop?

DOES YOUR CHILD HAVE A SEIZURE ACTION PLAN? ◯ Yes ◯ No ◯ Don't Know

If yes, ensure it has been reviewed recently and if not, talk to your doctor about creating one.

Learn more about Seizure Action Plans: *www.childneurologyfoundation.org/seizure-action-plan*

Prenatal/Birth History

PREGNANCY INFORMATION

Fertility treatments? ◯ Yes ◯ No ◯ Don't Know

Illness during pregnancy? ◯ Yes ◯ No ◯ Don't Know
(ie: gestational diabetes, high blood pressure, early bleeding, infections/illness, bedrest, pre-eclampsia, eclampsia, seizures)

Medications during pregnancy? ◯ Yes ◯ No ◯ Don't Know

Use of recreational drugs; including alcohol during pregnancy? ◯ Yes ◯ No ◯ Don't Know

DELIVERY INFORMATION

Type of birth ◯ Vaginal ◯ C-section ◯ Don't Know

If C-section, why?

Was the baby born at full term? ◯ Yes ◯ No ◯ Don't Know

If no, how many weeks early?

Birth weight: _____ lbs /kg _____ oz/gm ◯ Don't Know

Length: _____ in/cm ◯ Don't Know

Head circumference: _____ in/cm ◯ Don't Know

Apgar Score: _____ ◯ Don't Know

Did you child need to stay in the hospital after birth? ◯ Yes ◯ No ◯ Don't Know

If yes, why? (seizures, ventilator, or hemorrhage etc.)

If you answered "Don't Know" to the questions above, please explain.

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Child Neurology FOUNDATION

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