

section

3

Talking With Your Pediatrician

Talking With Your Pediatrician

As your child grows, you will watch as he or she achieves many developmental milestones. It's important to talk with your child's pediatrician if you believe that your child's development may be delayed.

For example, you may notice that your child is not walking or speaking as expected or that he or she has difficulty focusing.

Your pediatrician can observe your child and help determine whether medical problems are impacting your child's development and whether further evaluation is necessary.



You Play an Important Role in Your Child's Care

It is unlikely that anyone else knows your child as well as you do. Your pediatrician will need your help in understanding your child's strengths and challenges. Your physician may ask you a series of questions or provide a questionnaire for you to complete.

You can also help your child by collecting information from all caregivers and educators who spend time with your child to gain a complete understanding of his or her performance in a wide array of functions. If any of this information or insight worries you, share your concerns with your pediatrician or care provider.

You are your child's most important advocate.

Visit ctf.org/education to download or request brochures that you can share with your child's pediatrician, teachers, and other caregivers.

evaluations

Evaluations to Help Understand Your Child

There are many useful evaluations available to help your pediatrician and health care team understand your child's abilities. This section will outline the evaluations commonly used to assess the development of cognitive, motor, and language skills in children with neurofibromatosis type 1 (NF1). If you have any questions about these evaluations, or about your child's eligibility to take them, talk with your pediatrician or child care provider; he or she can direct you to resources that are available in your area to answer your questions.

Developmental Evaluation

Pediatricians conduct developmental evaluations for all children during an exam, even during well visits. In this evaluation, the pediatrician reviews your child's progress in reaching expected developmental milestones. The pediatrician uses standard measurements that compare your child's acquisition of developmental milestones according to a specific age range. The pediatrician observes a broad spectrum of skills that are expected to develop, including your child's fine-motor abilities, language, and ability to perform age-specific independent functions.



milestones



Print this page!

evaluations

Surveillance

During all visits, the pediatrician should provide developmental surveillance, an important technique used to observe and collect information about your child. This is the first step toward deciding whether further evaluation is necessary and to rule out any other medical problems that may be impacting development. During surveillance, your pediatrician will ask you a series of questions. He or she may also give you questionnaires to complete at home or in the office before the visit.

Here are a few example questions:

- How is your child doing in school?
- Does your child have problems with learning?
- Are you concerned about any behavioral problems at home or school or when your child is playing with friends?
- Is your child having problems completing class work or homework?

The pediatrician may collect additional input from your child's other caregivers, such as your child's teachers at school. It's important to share your concerns with your child's other health care providers and caregivers. If there are any problems, the pediatrician can recommend that further assessment be conducted.

Use this space to write down concerns to share with your pediatrician.

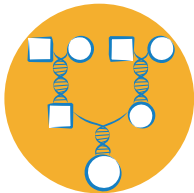


evaluations

Assessment for Learning and Behavioral Problems

A more in-depth assessment can be performed by one of your child's primary care providers, which may include your pediatrician or nurse practitioner. Specialist providers, including developmental pediatricians, neurologists, psychologists/neuropsychologists, and others, can provide more extensive evaluation of your child's development, including the identification of behavioral or learning problems.

A comprehensive assessment may include



a detailed family
and mental
health history



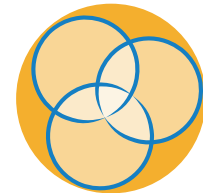
observations
and/or
interviews



a physical
exam



a behavioral
rating scale



an evaluation
for coexisting
conditions

Psychoeducational Evaluations

A psychoeducational evaluation is a school-based assessment that focuses on your child's ability to perform in relationship to the academic curriculum by age and grade. This evaluation may vary from school to school, but it is typically designed to assess for the presence of a learning disability that interferes with the child's functioning within the academic setting. A psychologist will perform this evaluation. Results from this evaluation will help you and the members of your child's educational team determine an appropriate academic path for your child.

It's important that you understand your child's educational rights and ask for additional testing as needed.

evaluations

Different assessment procedures, or a combination of procedures, are used to examine the following individual areas of performance and concern:

Cognitive skills



IQ testing

Achievement



academic skills

Communication skills



verbal and
nonverbal

Behavioral
development



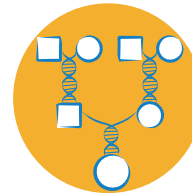
rating scales and
observations

Psychosocial
development



psychological and
social adjustment

Family history



developmental
history

Although cognitive deficits may impact your child's educational success, these challenges are part of the broader medical concerns associated with NF.

evaluations

Neuropsychological Assessment

A neuropsychological assessment is a specialized, comprehensive evaluation performed by a neuropsychologist that provides information on how the brain is affecting behavior and learning. The results provide information on your child's strengths and weaknesses in the areas of reasoning, memory, and problem solving. This form of evaluation utilizes direct testing of your child's learning and cognitive skills as well as symptom questionnaires provided by parents and teachers, behavioral observations, and in-depth clinical interviews.

In a neuropsychological assessment, the individual areas of performance and concern include

- verbal and nonverbal reasoning (intelligence)
- attention
- executive functions, including short-term and working memory, flexibility, impulse control, self-starting, strategic planning, and organization
- visual and verbal memory
- visual-motor and spatial abilities
- language and communication
- social-emotional development

You are an expert in your
child's individual needs.



evaluations

Evaluation Interpretation and Follow-up

After receiving the results from your child's evaluations, review them as a whole and ask for clarity if needed.

Use this information to

- maximize your child's strengths to address his or her difficulties by sharing this information with school and family members
- be an *active* member/participant of the your child's academic team. Participate in the development of accommodations and interventions for your child to address his or her needs
- talk to your child, and help him or her to understand why certain tasks may come easily and why some things may be more difficult

When a newly instituted education plan is in place, follow up with members of your child's educational team in about three months to see how your child is performing on the new plan.

interventions

Advocate for Your Child

All evaluations are useful, but not all may be deemed necessary by your child's school when considering your child's academic performance and developmental level. That is why it's important to become an expert in your child's individual needs. Talk to your child's school about your child's problems and then decide, as a team, on a plan of action for meeting his or her needs.

After the Results: Types of Intervention

The primary goal of obtaining any of the evaluations described above is to help your child's health care and educational team develop a custom plan to help your child with his or her individual needs. Different types of interventions are available and recommended for different situations.

Depending upon your child's results, he or she may benefit from either or both of the following types of interventions:



Home-based intervention

Behavior programs, some using technology, that help address cognitive and psychological/behavioral difficulties within the home.



School-based interventions

Special education plans such as a Section 504 Plan or an Individualized Education Program (IEP) may be recommended to assist with academic and social problems within the school setting. These school-based interventions will be discussed in more detail in section 11.

interventions

What Is Early Intervention?

Early intervention (EI) is a home-based intervention program for children younger than school age. Although a child is often referred to EI by his or her pediatrician, a parent or caregiver can also ask for an evaluation for EI services. Most states offer evaluations and services free of charge.

Early intervention programs are designed to address delays in early motor, language, and behavioral development.

Early intervention can include



speech
therapy



occupational
therapy



physical
therapy



behavioral
interventions

It is important to set up at-home prevention strategies, too, which can be as simple as talking to, playing with, and smiling at your child often.

You may also consider setting up a special play time that incorporates fine-motor activity skills, such as



playing with
Play-Doh®



painting



drawing



assembling or
building items

It's important that you do not wait for a problem to occur
start an intervention early!



interventions

“I am beautiful.

I am not my disease. I am powerful...I am a fighter!”

—Candice Patterson, who lives with NF

All of this information may seem a bit overwhelming, but it can be helpful to think positively, focus on one or two challenges at a time, and remember that change takes time.

Here are a few tips for starting your EI:

- Recognize that you can only work on things that are within your control
- Do not try to work on all of your child’s deficits at once—tackle one challenge at a time
- To help you decide which challenges to tackle first, pinpoint those challenges that affect your child and family the most
- Try interventions that others have found useful
- Try strategies that maximize improvement with low effort
- Look for available tools and technologies that can help



Together you will make it through.

notes



activity to share with your child

3



Print this
page for
your child!

ask a question

Sparx knows that it's important to talk to your doctor. In the bubble at the left, write a question that you would like to ask your doctor, and at the right, ask your parent or guardian to write in your doctor's answer.

