

Helping Your Child Manage Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

Fact Sheet for Parents and Guardians

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a complex illness that can be challenging for parents and children. Following are some tips to help you in dealing with your child's illness.



Be an Advocate for Your Child

Take an active role in managing your child's illness and encourage him or her to do the same. This can allow you to make the best possible choices for his or her health.

- Learn as much as you can about ME/CFS and how it affects your child.
- Talk with your child's healthcare provider about your questions and concerns.
- Speak with school staff, such as teachers, guidance counselors, and school nurses, about concerns you have with your child in school.
- Work closely with teachers, counselors, and other school staff to develop an action plan and find resources to help your child succeed in school.
- Educate others involved in your child's life about ME/CFS, such as school staff, other family members, and your child's peers. When people know more about this illness, they may be better able to help and accommodate your child. This is particularly important at your child's school.

Be Familiar with School Resources

ME/CFS can affect an adolescent's or younger child's experience at school. Fatigue, pain, and concentration or memory problems can make it hard for a child to complete homework assignments. It may also be difficult for them to participate in the classroom or attend school on a regular basis. With some planning, teachers and parents can help students with ME/CFS to have a successful school experience.

Evaluation is an important part of identifying the needs of a student with ME/CFS. It can guide the development of programs to help them succeed in school. It is important to know that:

- Receiving a ME/CFS diagnosis will not immediately qualify a child for services. A child will need to be further evaluated and identified as needing services at school.
- Evaluations will need to be conducted by a team from the school. This team will assess the student through in-class observations, tests, interviews, and conversations with teachers and parents.
- Parents will need to give consent before a student undergoes an evaluation.

Additional services could include an Individualized Education Plan (IEP) or a 504 Plan. A 504 plan lists your child's disability and how the school can help. An IEP is a legal document that tells the school what it must do to help meet your child's needs. These programs are developed with help from administrators, teachers, and parents.

More information on IEPs can be found at the Center for Parent Information and Resources (CPIR) website (<http://www.parentcenterhub.org/repository/iep-overview/>) and information on 504 plans is available on the U.S. Department of Education website (<https://www2.ed.gov/about/offices/list/ocr/504faq.html>). It is important to work with your child's school to understand and explore these plans.

Participate in Family and Social Activities

Having a chance to socialize is just as important for your child as having a chance to succeed in school. With limited social involvement inside and outside of school, students with ME/CFS may feel isolated from their friends and peers. It can be challenging for families to be involved in social events or family activities. However, these activities are essential for the well-being of the child and family.

It is important to talk to your child's school about opportunities for your child to interact with peers. For example, the school could allow your child to participate in after-school activities or attend lunch periods. Some families may find it helpful to connect with support groups to talk with other families who have a child with ME/CFS.

For more information about ME/CFS, visit www.cdc.gov/me-cfs

- Contact -

Centers for Disease Control and Prevention

1600 Clifton Road, Atlanta, GA, 30333

Phone: 800-CDC-INFO (800-232-4636)

TTY: 888-232-6348

24 Hours/Every Day

Email: cdcinfo@cdc.gov