



The Rights and Needs of Young Persons with ME/CFS

By Jenn Waterman

Believe in the child. Do not doubt the reality of the illness. When so many falter, question, and lose faith, it is all the more important that you show unfailing support.

Understand the child. Learn about the illness and what to expect from it. Be patient with frustrating cognitive, concentration, and memory difficulties - understand that they confuse and frustrate the young patient even more.

Listen to the child. Listen to what his or her limitations may be and how he or she feels. Do not push children with ME/CFS. Listen to what they want and need.

Do not belittle. ME/CFS is more than "just" tired. Do not belittle the condition. In doing so you belittle young patients and what they feel. They know how they feel.

Be patient. ME/CFS can last for months and years. It is not the fault of the child that he or she is "still" sick. Constant reminders and innuendoes of failure hurt. No one "wants" to stay sick.

Be encouraging and help the child to see the positive when things get rough. Hold children with ME/CFS up as they learn to navigate the rocky road ahead.

Be fair. The child with ME/CFS is the same child that you knew before. Let children with ME/CFS be as normal as possible; do not treat them as "different." Encourage normalcy.

Be flexible. ME/CFS is unpredictable; plans cannot be carved in stone. Do not make the child feel guilty for cancellations - missing out is hard for him or her. Continue to include young ME/CFS patients in events whenever possible.

See the child as a whole person despite the illness. Learn to look past physical limitations. Children with ME/CFS are no less interesting or interested people. Interact and do not allow isolation.

Help others to understand as well. Reach out to friends, family members, schools, etc. and explain. Keep the child in touch with the world - he or she does not want to feel strange and different.

Be open. ME/CFS is not a shameful secret.

Do not accuse or persecute. The child should not be made to feel defensive for having an illness and should not have to explain him or herself.

Support the child every step of the way.