

What Children with CFIDS Need and What Adults Can Do to Help Meet Those Needs

presentation by

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What Children with CFIDS Need

I asked several dozen children with CFIDS what they most needed from others. These are their responses:

1. *Believe us.*

- Believe that we are sick, even though we look fine.
- Trust that we *want* to be responsible, hardworking students, but we can't.
- Trust us when we say we are having brain fog and can't do things. Trust that we are not school phobics, just trying to gain something.

1. *Try to understand us.*

- Learn the basics about the illness we are battling.
 - This is a real illness that effects real body systems.
 - Our symptoms waxing and wane.
- Give us space to grieve.

1. *Accept us.*

- Be patient with us.
- Accept that we will often be sick.
- Accept that we can't plan ahead or make long-term commitments.
- Accept that we may have relapses.

1. *Encourage us.* Many of us don't have access to the normal avenues of affirmation and recognition.

- Affirm us.
 - Let us know when we are doing a good job at something.
 - Let us know that our perseverance and courage are important to you.
- Send us cards, letters, or notes
- Make us laugh
- Pray for us and with us

1. *Stay with us for the long haul*

- Have patience with us.
- Put up with us when we are crabby and discouraged.
- Carry hope for us.

What Adults Can Do to Help Meet Those Needs

1. Trust the YPWC.

- Trust that what the YPWC reports is true. It is better to err on the side of believing the one or two children who are not accurately reporting symptoms than not to trust the hundred who are.
- Respect their ability to articulate what they are experiencing.

1. Encourage the YPWC.

- Inspire courage to grow in the YPWC by affirming all the characteristics you see developing (perseverance, inner strength, patience with peers who don't understand, strength to endure pain, etc.)
- Praise the YPWC for any accomplishment; anything done under the pain and debilitation most of them experience at their age is worthy of applause.

1. Commit to support the YPWC for the long haul

- Be there through the long, dark days.
- Live with the roller-coaster of symptoms and emotions the YPWC experiences.
- Help the YPWC grieve the losses.
- Get counseling help for the YPWC as he or she processes the losses and developmental changes during the illness.

1. Guard the YPWC's self-esteem.

- Be willing to step in when peers or adults misunderstand the YPWC's illness and unintentionally (or intentionally) damage the YPWC's self-esteem.
- Help the YPWC have positive experiences, even through severe debilitation and pain.

1. Compensate for the YPWC's losses.

- Help the YPWC have as normal an experience of life as possible with a debilitating illness.
- Do "normal" things, even if that means you do them in abnormal ways.

1. Commit yourself to the YPWC's growth.

- Help the YPWC develop his or her mind, emotions, and spirit during the duration of the illness.
- Understand developmental changes that affect the illness.

1. Advocate for the YPWC.

- Be the child's voice to school and medical personnel, youth-group leaders, etc.
- Get the services the YPWC needs.
- Stand in the gap for the child by understanding the illness that he or she may be too young to understand.

Adapted from *Finding Strength in Weakness: Hope and Help for Families Battling Chronic Fatigue Syndrome* (Zondervan Publishing House, a subsidiary of HarperCollins), available from The CFIDS Association or your local bookstore.