CFIDS Association of America

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Ten Points on Organizing Care for Children with ME

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Children with myalgic encephalomyelitis (ME) suffer significant setbacks in social development and education due to their condition. Unfortunately, ME (as CFS is called in England and many other countries around the world) is not well understood by education professionals and parents.

Following are 10 points in the collaborative care management model for ME, guidelines that I developed with Dr. Nigel Hunt, a general practitioner who treats both adults and children with ME.

1. What is ME?
The general practitioner (GP) is the key health care professional in charge of the management of ME in childhood. Suspected viral triggers for the condition include non-polio enteroviruses, and certain types of physiotherapy and graded exercise can exacerbate illness in some cases, just as in poliomyelitis.

Chronic fatigue syndrome is a recent research-based name for the condition and there may be subgroups within this term. In practice, symptoms other than fatigue, such as pain and cognitive disturbance, may be the most disabling. The child can minimize symptoms by careful self-management of energy expended, combined with physical aids such as a wheelchair.

2. Attending school.
Unlike adults, a child is required to work while sick and the GP is instrumental in facilitating their education. "Suitable education" is a legal right, but school attendance or rigid lesson schedules can undermine the GP's management of the condition and cause repeated relapses. Despair at lack of achievement may also develop.

Parents should keep in mind that distance learning or appropriate home tuition sometimes achieves better academic results and aids recovery more effectively. A five-year study in the United Kingdom found that 51% of children on long-term sickness absence from school had ME.

3. Effect of isolation.
Social isolation may distress children who remain at home for long periods. For this reason, a 1996 Royal Colleges report recommended early return to school. However, as mentioned above, relapses were commonly reported. This problem can be resolved by GPs recommending that when well enough, a child visits school for social contact only. School staff may visit children at home. Also, school work may be completed by other methods that assist academic success. Children can benefit from contact with other ME sufferers, but they also need friends from outside the "ME world."

4. Setting a program.
The management model is designed to help GPs develop a joint medical and educational program for children with ME. This program should put health first, while still enabling children to achieve their own goals despite what may be a long illness. Keep in mind that children with ME have special educational needs by virtue of their cognitive dysfunction and potential for relapse.

On the financial side, be aware that there are options. Government money for children's education is given to the school, but can also be used for home schooling or other accommodations if the school is not meeting the child's needs.

5. Getting children involved in care.

The principle underlying the management model is that the child is regarded as the client, and is closely consulted in a non-threatening situation, with no pressure to follow established systems. Different children may have different priorities.

If a child "owns" such strategy decisions, tempered by the GP's advice on their feasibility, they are more likely to work, as motivation is high. Flexibility and adaptation of the plan may be necessary.

6. Role of patient organizations.

A myth about ME is that contact with patients' organizations delays recovery. This is now considered a simple artifact of research: patients who contact support organizations are gener- ally more ill in the first place.

In other illnesses, patients' organizations are recognised sources of information and support, and many are listed in "Supporting pupils with medical needs," a good-practice guide issued jointly by the British Department of Health and Department for Education and Employment.

7. Helping parents.

Parents may be distressed from coping with their child's debilitating and painful illness, and may appear overprotective as a result. They may have experienced misunderstandings by teachers and others whose recommendations have unwittingly resulted in further illness and may become overly aggressive as a result.

This is not abnormal behavior, and a little consideration goes a long way. ME-friendly GPs and letters supporting the child's needs are like gold dust to families dealing with a child who has the condition.

8. School phobia and anorexia nervosa.

These conditions are often confused with ME. A rule of thumb to avoid confusion with school phobia is that a phobic child is typically well when allowed to stay at home. Children with ME, by contrast, are typically ill on weekends after trying to cope with school during the week. They may even aggravate the situation by non-acceptance of their illness and attempting active leisure pursuits. Those with anorexia nervosa have a distorted image of their bodies and fear of gaining weight, attitudes not characteristic of ME.

9. Raising self-image.

The self-esteem of young people with ME is often low as they cannot lead the normal life of a healthy adolescent. There have been suicides, but caution is necessary in prescribing antidepressants because ME sufferers are unduly sensitive to medication.

Young Action Online, an Internet service also available in the U.K. by mail and telephone, offers free personal support. This network of medical and other professionals with experience of ME can advise GPs, colleagues and families. The network can be contacted via the web at www.jafc.demon.co.uk/yaonline/.

10. Where to get more information.

The full report on the collaborative care management model will have a "frequently asked questions" section, so your queries are valuable. Please address these to the Collaborative Care Management Team, PO Box 4347, Stock, Ingatestone, Essex CM4 9TE, or e-mail jane@jafc. demon.co.uk. For a copy of the preliminary report, send a large stamped, self-addressed envelope (with an international reply coupon for postage) to the same address. Let us know if you would like to take part in future projects.

Editor's Note: Jane Colby has a new book coming out titled Zoe's Win. The book, which tells the story of a young girl with CFIDS, includes a section for physicians and teachers as well as encouragement for young people with the condition. Watch next issue for order information.
