CFS Toolkit for Health Care Professionals: Managing Supportive Care

CFS MANAGEMENT GOALS

The objective of an effective management program for chronic fatigue syndrome is threefold: 1) to help patients develop effective coping strategies for living with a life-altering illness, 2) to relieve symptoms and 3) to teach patients to manage activity levels to avoid postexertional malaise on the one extreme and deconditioning on the other.

While symptom management is critical to CFS care, prescribing treatments to address individual symptoms without simultaneously addressing the emotional and psychosocial issues related to the CFS experience may not be effective. In fact, a patient's unresolved anger, guilt and anxiety may actually exacerbate symptoms, or interfere with pharmacologic therapies. That is why a discussion of CFS management guidelines begins with supportive care.

Health care practitioners should recognize that there appears to be considerable variability in CFS symptom expression, symptom severity and the efficacy of specific treatment protocols. There is no known cure, and a therapy that works for one CFS patient may be of little benefit to another. While this can make managing CFS challenging, there are treatment strategies that can not only help your patients, but contribute to a more rewarding doctor-patient relationship.

ADDRESSING THE PHYSICAL AND EMOTIONAL TOLL

Like other chronic illnesses, CFS can have a profound impact on daily life, requiring patients to make significant lifestyle changes and adapt to a series of new challenges. Common difficulties include problems coping with the variable and unpredictable symptoms; a decrease in stamina that interferes with activities of daily living; memory and concentration problems that seriously impact work or school performance; uncertain prognosis; loss of independence, livelihood and economic security; alterations in relationships with family and friends; and feelings of guilt, isolation and abandonment. Patients may also worry about bearing and raising children and the potential impact of decreased sexual activity on intimate relationships.

The overall treatment plan should acknowledge these challenges and the patient's emotional reaction to them. Educating patients about the link between stress and symptom exacerbation is key to establishing effective coping strategies and a positive approach to adapting to the illness.

THE BASICS OF SUPPORTIVE CARE

There are several components of supportive care that should be considered when creating an individualized care program for your CFS patient.

1. Validating the illness experience. Because CFS is an "invisible illness," patients often do not look sick. Public misconceptions about CFS being "all in your head" contribute to a social context that leaves many patients feeling misunderstood and isolated as they routinely face skepticism from others. Having to confront negative responses to their illness is a source of considerable anxiety for many patients.
Be particularly conscious of your attitude, and provide a supportive environment where patients can safely discuss their illness. Treating patients with respect and validating their illness may be

the single-most important therapy you can provide.

2. Professional counseling. Referral to a mental health professional may be indicated to help build effective coping skills. A supportive counselor can help patients cope with the prospects of long-term illness, as well as the anxiety, depression, grief, anger and guilt that frequently accompany any chronic illness. These issues can be addressed by a competent therapist using problem-solving techniques and standard psychotherapy and counseling methods. In some cases, combined medication and psychotherapy may be required.

Health care providers should be alert to family problems and institute appropriate care management. Consults with behavioral health providers may be necessary. You may want to encourage all family members to participate in behavioral therapy to address changes in family dynamics related to living with CFS.

3. Alternative therapies. Deep breathing and muscle relaxation techniques, massage and healing touch, and movement therapies like stretching, yoga and tai chi can be beneficial for some CFS patients in reducing anxiety and promoting a sense of well-being.

Patients should be encouraged to discuss all potential alternative therapies with a health professional since many CFS treatments that are heavily promoted on the Internet are unproven at best, and potentially dangerous at worst.

4. Cognitive behavioral therapy (CBT). The goal of CBT is to help patients cope with their illness and change perceptions and behaviors that can contribute to symptom expression. While CBT is frequently prescribed as a coping strategy, it can also improve fatigue and activity levels. Optimally, CBT can help your patients better adapt to the impact of CFS and improve their quality of life.

Some patients are resistant to this therapy because they mistakenly believe health practitioners who prescribe CBT believe CFS is purely a psychological illness. Educating patients about the role CBT can play in helping them learn to manage activity levels, stress and symptoms may help overcome this reluctance.

See the fact sheet on CBT in this toolkit for more information.

5. Support groups. Many people with CFS find it therapeutic to meet with other people who have this illness. A good CFS support group should provide a warm and caring environment where patients can share their experiences and tips for living with a chronic illness. Support groups can help fulfill their need for information, empathy and a sense of community as patients learn to cope and adapt to life with a chronic illness. Encourage patients to seek out support groups with a positive focus instead of “gripe sessions” that may add to their stress.

DISABILITY

By definition, all people with CFS are impaired. While many patients are able to adapt to their functional limitations, others suffer occupational disability. Depending on the level of impairment, CFS patients can lose their jobs, economic security and homes. Helping severely impaired patients accept and cope with the fact that they are no longer able to work and must rely on disability benefits can have therapeutic value.

Also of value in reducing patient anxiety is being a willing participant in the disability process. The health care professional is a major source of documentation in this process. Keeping good clinical notes and using simple assessment tools to track health status are important to the benefits process.