CFS Toolkit for Health Care Professionals: Managing Activity

A DIFFERENT DEFINITION OF EXERCISE

Advising patients who have chronic fatigue syndrome to engage in aerobic exercise and “go for the burn” or “release those endorphins” can be detrimental. Most CFS patients cannot tolerate traditional exercise routines aimed at optimizing aerobic capacity. Instead of helping patients, such vigorous exercise can cause postexertional malaise, a hallmark of CFS that is defined as exacerbation of fatigue and other symptoms following physical or mental exertion. Even worse, this kind of exercise can precipitate a full-scale relapse that lasts for days or weeks.

A different way of defining exercise and managing activity is needed for CFS patients and their health care team.

AVOIDING TWO EXTREMES

The objective of exercise and activity management is to find a balance that allows patients to avoid postexertional malaise and prevent deconditioning so they can achieve better function and improved quality of life.

Some people with CFS inappropriately avoid all activity because personal experience has demonstrated a link between exertion and symptom severity. An even greater number of people engage in an endless “push-crash” cycle in which they do too much, crash, rest, start to feel a little better and do too much once again, perpetuating the cycle.

It is important that emphasis be placed on avoiding these two extremes and balancing activity. Appropriate rest is an important element of CFS management, and patients must learn to stop activity before illness and fatigue are worsened. In the early stages of resumed activity, patients should avoid becoming tired with physical activity.

THE IDEAL CLINICAL TEAM

The ideal clinical team is comprised of a caring and listening provider and an informed but receptive patient. Working with other health professionals like physical therapists, rehabilitation specialists, exercise therapists or occupational therapists can be especially beneficial when such allied professionals are available.

Such a multidisciplinary health care team can tailor an exercise and activity program that meets the needs of the individual patient. The team can assist in identifying goals and setting realistic expectations. Including the CFS patient as a full partner in developing this highly individualized activity plan is important so patients can eventually learn to manage the plan on their own.

Although a therapeutic team approach is ideal, primary care practitioners who “team up” with their patients can provide very effective care.

DIET AND NUTRITION

Good diet and nutrition can contribute to a successful activity management plan. Many CFS patients do not have the energy to prepare nutritious meals, leading to a poor diet that can

contribute to fatigue. Additionally, decreased activity levels that are common in people with CFS mean patients typically expend less energy in a day. Unless caloric consumption is adjusted, weight gain can occur, further exacerbating fatigue and other symptoms.

- Encourage a well-balanced diet to prevent nutritional deficiencies and weight fluctuation and to reduce diet-related fatigue.
- Advise patients who have sensitivities to various foods or chemicals to avoid or reduce their exposure. Sensitivities to refined sugar, caffeine, alcohol and tobacco appear to be common in CFS patients.
- Educate patients that nutritional supplements cannot take the place of good diet and nutrition.

GRADED ACTIVITY AND EXERCISE

A principle element of graded activity is to start slowly and increase slowly, gradually increasing both the level of activity and the duration.

- Teach CFS patients that all exercise needs to be followed by a rest period at a 1:3 ratio, resting 3 minutes for each minute of exercise. Some patients can exercise for remarkably short periods, just 2-5 minutes, without risking a relapse.
- Advise deconditioned patients to limit themselves to the basic activities of daily living until they have stabilized. Several daily sessions of brief, low-impact activity can then be added, such as a few minutes of stretching, strength exercises or light activity like walking or cycling. These sessions are increased by 1-5 minutes a week as tolerance develops.
- Advise patients to return to the most recent manageable level of activity if they report that exercise is worsening symptoms. Daily exercise may be divided into two or more sessions to avoid symptom flare-ups; some patients, however, cannot exercise daily early in the course of their rehabilitation.

ENERGY MANAGEMENT PROGRAMS

Two energy management programs—pacing and envelope theory—may be useful for CFS patients. These are often part of cognitive behavioral therapy (CBT), but they can be prescribed as stand-alone interventions.

Activity pacing involves moderating activity to minimize the push-crash cycle. Patients are advised to do specific activities, such as household tasks, in small, manageable chunks with rest breaks, rather than in a single energy-depleting effort. Activity should be spread evenly throughout the day, and it should not exacerbate fatigue or other symptoms. Once patients are stabilized, activity is incrementally increased.

Envelope theory instructs patients to view their available energy as if it were a bank account. If they overexert themselves, it is like being overdrawn at the bank and they have to pay it back by resting more the next day. As time passes, patients learn how much energy they can expend without experiencing the characteristic postexertional malaise.

STRENGTH AND CONDITIONING

A strengthening and conditioning program can reduce pain, improve strength and flexibility, and enhance stamina and function in CFS patients.

- Encourage patients to start with simple stretching and strengthening exercise, using only

body weight for resistance. Gradually add wall push-ups, modified chair dips and toe raises to the routine. Increase repetitions gradually. Patients can begin with a set of 2-4 repetitions and build to a maximum of 8.

- Add resistance exercise as strength improves. Exercise bands or light weights are both good options.
- Add a focus on strengthening core abdominal muscles to relieve back pain and improve overall circulation.
- Advise patients who don't tolerate an upright position to try swimming or a recumbent bicycle.

SEVERELY ILL PATIENTS

A subset of people with CFS are so severely ill that they are largely housebound or bedbound. They require special attention, including a modified approach to exercise. Hand stretches and picking up and grasping objects may be all that can be managed at first. Gradually increasing activity to the point patients can handle essential activities of daily living—getting up, personal hygiene and dressing—is the next step.

Focusing on improving flexibility and minimizing the impact of deconditioning so patients can increase function enough to manage basic activities is the goal with severely ill patients.