

A Team Approach to Treating CFS

Matching Best Medical Practices to Phases of Illness

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Chronic fatigue syndrome (CFS) involves multiple systems of the body and a complex array of symptoms. The chronic nature of the illness and the functional limitations it imposes affect people on a variety of levels—physical/behavioral, psychological and social/interactive.^{1,2,3} The complexity of these factors necessitates a multidisciplinary team approach to the treatment and management of CFS.^{1,4,5} Patients benefit not only from the involvement of a skilled physician, but from the participation of mental health professionals, social workers or case managers who can address the wide range of effects that chronic illness may have on patients' lives.¹

As a society, we tend to look at illness from an acute, pathology-driven framework. Viewing an illness such as CFS from an acute framework is rarely effective in a treatment context because the illness is chronic and patients cycle repeatedly through relapses and remissions.^{1,2,3} When patients experience yet another cycle, all the individuals involved—including the physician—can feel as if they're failing.

Patients with chronic fatigue syndrome are not a homogeneous group. The physical, emotional and social needs of a patient in the early phases of the CFS experience can be considerably different from the needs of a patient who has been ill for several years. Research supports our concept that individuals coping with CFS

progress through four distinct phases as they learn to deal with their illness.^{6,7,8,9,10,11}

Fennell's Four-Phase Model provides a helpful framework for understanding this critical process.^{1,2,3,11}

Patients may respond differently to various treatment modalities depending on which phase of illness they are in. Research has suggested that matching intervention to phase has a positive effect on treatment outcomes.^{12,13,14,15} The Four-Phase Model can help clinicians determine what may be expected over time and the best ways to intervene to improve the patient's quality of life at any given point. Matching medical interventions to phase of illness can potentially help both physicians and allied health professionals treat patients more effectively, saving time and resources. The goal of this approach is not pursuing the ever-elusive cure, but integration of the illness into the patient's life.

Recommended interventions for patients with CFS, corresponding to each phase of illness, are outlined below.

Phase 1: Crisis

Definition: The individual moves from onset of illness—which may be sudden or happen gradually—to an emergency period when the patient knows that something is seriously wrong.

Task: Contain the crisis; manage urgency and possible trauma.

Patients in Phase 1 usually have a strong sense of urgency and are sometimes traumatized by the illness experience, which can make



CFS patients can benefit from the involvement of a team of primary and allied health care providers in managing the physical, social and psychological effects of the illness. Viewing treatment in this expanded framework can help mitigate the cycle of frustration that often plagues both patients and their providers due to the chronic and debilitating nature of CFS.

implementing interventions difficult. The physician will need to focus on diagnosing and treating the physical symptoms of the illness, which requires treating the crisis itself. This is why it's particularly important for clinicians to construct a team to carry out effective treatment. A social worker or psychologist can assess and treat the trauma often associated with the Phase I crisis and coordinate with the physician in addressing it.^{1,16,17}

When a patient presents with an illness that might be CFS, a physician must rule out other illnesses in order to make or confirm a diagnosis of CFS. At the Fatigue Consultation Clinic in Salt Lake City, a comprehensive history, physical exam and relevant lab tests are all essential components of this process. At this facility, clinicians combine a complete medical evaluation with a personal/social history and psychological evaluation in order to understand how the illness evolved and validate a diagnosis of CFS, fibromyalgia (FM) or other illness. This list of diagnoses and conditions is constantly revised as the health care team interacts with the patient over time.

Since most physicians are trained to avoid treating symptoms without knowing the underlying etiology, many doctors appropriately focus on finding a cause and may become frustrated when faced with medically unexplained illnesses like CFS or FM. However, even if a known



Sleep dysfunction affects a significant percentage of CFS patients. Because sleep problems can exacerbate other symptoms of CFS—including pain, cognitive difficulties and fatigue—sleep issues should typically be addressed first by the patient's clinical team.

etiological mechanism cannot be established, it's essential to maximally treat all symptoms that are affecting the patient.

At the Fatigue Consultation Clinic, symptom treatment is initiated only after the clinical team assesses each symptom and its cause. Then, a “working list” of problems and a treatment plan are developed. While this plan will not “cure” the underlying syndrome, it can improve the symptoms and/or enhance daily functioning, allowing patients to manage their condition and achieve as great a quality of life as possible.

The initial assessment and intervention plan in Phase I includes a review of behavioral, psychological and social factors in addition to physical symptoms. At Albany Health Management Associates, Inc., patients participate in a psychosocial interview, which helps the clinician develop a chronological history or personal narrative and evaluate the patient's physical constitution and emotional hardiness, or level of coping.^{1,2,3,16} This

interview also helps identify any history of preexisting or comorbid trauma (divorce, abuse, etc.).

Within the limitations of time and financial resources, a psychiatric evaluation, couples/family assessment, workplace review or sleep evaluation may also be utilized to gain a comprehensive understanding of the patient.

An analysis of a patient's activity threshold can help in developing a plan for better symptom management.^{1,16} Activities may need to be reduced drastically or confined only to minimal activities of daily living (ADLs). Patients' activity levels should be evaluated and/or restructured according to their current level of functioning.

Phase I patients are often too functionally limited to carry out physical therapy or exercise regimens. Moreover, initiating too many interventions in this phase can potentially worsen the situation because patients will find it difficult to comply—compromising the effectiveness of

their care and frustrating them and their practitioners.^{1,3} As a consequence, when physicians identify a Phase 1 patient, in general they should consider attempting to introduce only the most necessary protocols until the patient stabilizes in Phase 2.

Phase 2: Stabilization

Definition: The individual begins to recognize and understand his or her symptom complex and starts to develop new norms and behaviors.

Task: Facilitate stabilization of symptoms through medical treatment and life restructuring.

In this phase, the goal is to bring all medical conditions and CFS symptoms under reasonable management. Frequent medical visits are utilized to modify medications and adjust the treatment plan. The goal for the physician is to systematically address the major CFS symptoms, and this treatment must be individualized for each patient. Any single treatment might be a godsend for one patient, while a curse for another.

Sleep problems typically should be treated first since poor sleep will tend to exacerbate every other symptom. Improving sleep hygiene and the utilization of sleep medications can help. After sleep, treatment should focus on alleviating mood and/or cognitive complaints with medication, counseling and/or other support. Pain is then addressed with a variety of interventions. Finally, fatigue is tackled following the treatment of other symptoms since it's the most challenging part of symptom management, and addressing it directly is often the most problematic. Success seems to be maximized when clinicians can address as many of the things that contribute to fatigue as possible. Treating sleep and mood usually improves pain and fatigue, so it is recommended that treatment addresses the major symptoms in the order described above.

Clinicians often use multiple medications in the beginning to help bring symptoms under better control. Over time, medications can often be simplified or reduced, and the symptom management plan can be fine-tuned. Working with patients to develop a regimen for pacing activities and combating physical decondition-

ing can also help manage ongoing symptoms.

In this phase, patients often face conflict with those around them—loved ones, acquaintances or employers who become frustrated with the many limitations imposed by this illness. In addition, CFS sufferers often face a stigma associated with a poorly understood illness. Patients must struggle to find their place in a cultural dichotomy of being either “sick” or “well,” with no good models for the variable and often unpredictable nature of CFS. Patients need assistance with coping with these challenges and with developing a new definition of self and new norms and values.^{1,3,16}

Patients must learn to balance ADLs with the other activity groups (work, social and personal enrichment) in order to create a life that they can sustain.^{1,3,16} The level of activity a patient can maintain may increase over time; however, a realistic assessment of the current situation is essential. Patients also need to develop “illness etiquette” in order to communicate with others regarding the illness. Social workers, mental health professionals or other practitioners can help individuals determine with their families what to say, to whom to say it and how and when to discuss their illness.

It's important to note that the intensity of psychological symptoms in the first two phases may depend on the severity of physical symptoms and the reactions of those surrounding the patient. Many patients get caught in a continuous loop between Phase 1 and 2, cycling between periods of relapse and remission. Each plateau period a patient experiences seems to signal a cure to them, their families, friends, co-workers and doctors. They attempt to return to the old life, only to find that they relapse, which sets off a new crisis. Patients typically need assistance to move into Phase 3, and this assistance may be provided by a doctor, therapist or clergy member. In all phases, physicians should work together as a team with allied health professionals, which may include social workers, psychologists and others.

Phase 3: Resolution

Definition: The individual fully recognizes that his/her old life will probably not return and wrestles with life-defining existential questions.

Early in this phase patients can experience profound despair.

Task: Ongoing management of medical plan, finding meaning in suffering and establishing an authentic new self.

In Phase 3, the physician should institute a regular review of the symptom list, monitoring medications and adjusting the treatment plan as needed. Routine health screenings, such as mammograms, pap smears and colon cancer screenings should be carried out just as they would for non-CFS patients. Long-term patient self-care and maintenance should be encouraged, utilizing healthy behaviors to sustain the highest level of functioning possible.

In the psychological domain, patients who have undertaken in Phase 2 the important work of developing new norms, values and ways of being often experience a grief response in Phase 3 as they continue to confront what they can no longer do and acknowledge the loss of their former selves. It's important to note that this is an appropriate response to the losses they have experienced and should be differentiated from clinical depression or other organic mental illness. Ironically, patients in the early period of Phase 3 may seem more distressed than Phase 2 patients. This is because they have actually grasped the chronic nature of their condition and its ambiguity.

With a compassionate response and proper assis-

tance, individuals in this phase can develop meaning in their suffering and learn to adapt to their chronic situation as they become more comfortable with ambiguity and chronicity and more sophisticated about handling their symptoms and limitations.^{1,3,16,17}

As patients progress on the journey toward integration, the psychological focus should be less on “the light at the end of the tunnel” and more on a recognition and respect for the time spent in the tunnel, and on finding new meaning in the illness experience.

Patients in Phases 1 and 2 may repeatedly try unsuccessfully to return to work or struggle to sustain part-time employment. Phase 3 is an appropriate time to determine whether a return to work is

possible, and patients often need assistance in evaluating this question. For some, job modifications can be negotiated that allow a return to the previous type or place of employment; for others, job separation and/or an exploration of other vocational pursuits must be undertaken.^{1,3,16} Helping patients manage the question of employment can be crucial to effective therapeutic management of this illness because the profound fatigue and postexertional malaise associated with CFS can trap patients in a cycle of relapse and make it impossible to reach Phase 4 and integrate the illness into their lives.

Phase 4: Integration

Definition: The individual defines a new self in which the illness may be an impor-



MANAGING MEDICATIONS FOR CFS PATIENTS

- Clinicians may need to systematically try various and multiple drug interventions to determine which works best for symptom management. A drug that is effective for one CFS patient may be ineffective for another.
- Find the most effective and cost-effective medication regimen. Prescribe single drugs that treat multiple symptoms whenever possible. For instance, choose meds for sleep and mood that also improve pain.
- Monitor drug side effects like weight gain, secondary fatigue, daytime sedation, cognitive dysfunction and sleep disturbance.
- Select interventions aimed at primary underlying mechanisms. This will allow the use of fewer drugs to address multiple symptoms with minimal side effects.
- When you move into long-term management in Phases 3 and 4, simplify medications and prescribe the lowest effective doses. Shift gradually to more nonpharmacological interventions whenever effective. Taper or reduce medications when possible, and discontinue them when no longer needed.

tant factor, but not the only or even the primary element in his/her life.

Task: Integration of the illness into a meaningful life.

In this phase, medical interventions are minimal and stable and should be effective and well-tolerated. Lowest effective doses and non-drug interventions should be emphasized. Patients must learn to maintain a balance between experimenting with new treatments and “just living” as they work to integrate the illness into their lives.

Continued monitoring of patient functioning—including pain, sleep and other symptoms—is necessary in this phase, in addition to routine health screening. From a social perspective, individuals in the patient’s life who withdrew or disconnected during the other phases may be reintegrated. In addition, new means of support and meaning can be discovered and incorporated into a new full life. Workplace modifications may need to be continually reevaluated, and alternative vocations and/or activities are often undertaken in this phase.

Individuals who attain Phase 4 have constructed new selves that incorporate salvageable aspects of their pre-crisis selves, but are adapted to their new life situations. They work to maintain the insights they have gained during the earlier phases, and they have engaged in what will be an ongoing quest for meaning and purpose that is individually authentic to them.^{1,2,3,16}

Providers play key role

In summary, matching medical interventions to phase of illness can potentially reduce practitioner frustration, while treating patients more effectively. By utilizing the characteristics of each phase to assess the individual and identify each patient’s current phase, interventions can be tailored to these needs. If patients get the proper assistance in each phase, they can better adapt to their symptoms and circumstances. ■

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MATCHING BEST PRACTICES WITH PHASES OF ILLNESS IN CFS

	Phase 1 Crisis	Phase 2 Stabilization	Phase 3 Resolution	Phase 4 Integration
Definition	Individual moves from illness onset (sudden or gradual) to emergency period when the patient knows something is seriously wrong	Patient begins to understand symptom complex and develops new norms and behaviors	Patient recognizes that old life will not return and wrestles with existential questions	Patient defines a new self in which illness may be an important factor, but is not primary in his/her life
Task	Contain the crisis; manage urgency and possible trauma	Facilitate stabilization of symptoms through medical treatment and life restructuring	Continue ongoing management of medical plan and help patient develop meaning in suffering	Assist patient in integrating the illness into a meaningful life
Medical Assessment & Intervention	Complete a comprehensive medical history; conduct physical exam; do lab tests as indicated (may include CBCdiff, expanded chemistry panel, ESR, TSH, UA, fasting lipids, etc.); confirm CFS and/or other diagnosis; develop a working list of problems and treatment plan	Schedule frequent patient visits to systematically address major symptoms (sleep, mood/cognitive, pain, fatigue, etc.); review lab tests and do routine ongoing screening; manage all comorbid and secondary conditions; monitor medications and simplify when possible; coordinate rehabilitation efforts (physical therapy, occupational therapy)	Monitor and manage symptoms, modifying treatment plan as needed; simplify and/or reduce medications as appropriate; continue routine health screenings; continue regimen to improve physical fitness within the confines of CFS/FM limitations	Continue monitoring of patient functioning; continue focus on guarding against deconditioning utilizing physical conditioning regimen; emphasize lowest effective doses or nondrug interventions; help patient balance trying new treatments with “just living”
Phase Assessment & Intervention	Conduct psychosocial interview and other relevant evaluations (may include neurological/psychological tests, sleep studies, etc.); establish multidisciplinary team; build relationship with patients; analyze activity threshold and restructure activity levels as needed	Initiate values clarification and development of new norms; review and modify activity levels; assist patient in coping with challenges like grief and “illness etiquette”; patient/family case management; workplace intervention and/or modification, or exploration of disability options	Facilitate patient’s exploration of existential questions and developing meaning; encourage patient to become own care coordinator and advocate; consider job modifications or workplace separation	Continue meaning development and integration of pre- and post-crisis self; review workplace modifications and/or alternative vocations and activities; maintain dialogue among members of multidisciplinary treatment team