Abstract

Fatigue is a ubiquitous side effect of many cancer therapies. Nevertheless, after treatment is complete, many survivors continue to feel a profound tiredness that affects almost all aspects of life. Even after recovery, patients are often frustrated by their continuing need for extra rest. In this deeply personal, first-person account, a physician relates the various ways that cancer-related fatigue can affect family dynamics, job responsibilities, social interactions, finances, and intimacy. Clinicians can help by searching for treatable medical conditions, but also by taking cancer-related fatigue, and the frustrations it causes, seriously. Patients should be reassured that the fatigue they feel is real, and that by learning personal energy conservation, they should be able to improve their abilities to function, to socialize, to interact with others, and ultimately to adjust to a “new normal” baseline. (CA Cancer J Clin 1999;49:178-189.)

Introduction

Fatigue is invisible and without an objective unit of measure, yet it shapes most cancer patients’ lives during treatment, causing substantial distress. For many survivors, fatigue and its fallout of frustration persist following completion of treatment. As a physician and long-term survivor of non-Hodgkin’s lymphoma, my experience with this symptom on both sides of the stethoscope has taught me about overcoming the frustration of fatigue.

“Doctor Harpham, I’m so tired,” was an often-voiced complaint in my solo practice of internal medicine, one that I took seriously because fatigue is a sensitive though nonspecific indicator of underlying medical or emotional pathology. Caring for these patients introduced me to the frustration of fatigue.

History-taking has to be painstakingly detailed, the examination careful, the evaluation well-orchestrated, and the advice clear and reassuring. Patients are often ambivalent about the process of diagnosing fatigue. On one hand, they are usually eager to try to discover the cause of the problem. On the other hand, they may be distressed by the amount of time, money, and discomfort involved in testing that may very well reveal “normal” results.

Unless I found a treatable disease easily, the evaluation and treatment of fatigue was fraught with frustration and even a sense of failure. Those patients diagnosed with self-limited diseases were disappointed with my dull advice to get enough daily rest until they were better. Those with negative work-ups could be assured only of the diseases they didn’t have; our mutual desire to know the cause of their symptoms led to a nagging concern: Have I missed something? Even when I could reassure myself and my patients that the work-ups had been timely and complete, I dealt with the humbling reality that there was nothing in
my black bag that could fix their fatigue.

In 1990 I was diagnosed with non-Hodgkin’s lymphoma. Since then I’ve been through various courses of chemotherapy, radiation therapy, immunotherapy, and antibody therapy in clinical trials. During these years, both the disease and the treatments have affected my energy to one degree or another. Fatigue has become as tangible to me as my axillary adenopathy. Until only recently, frustration tainted my days, especially during remission, a time during which I expected renewal, not ongoing debility.

In certain ways, the adjustment to my energy limitations has been harder than managing many of the other challenges of survivorship, such as grieving the closure of my medical practice, taming the fear of leaving my children motherless, accommodating my nausea and leg pain, and dealing with the stress of routine check-ups and bad news.

With hope of improving my stamina, I explored the pathophysiology of fatigue, and made lifestyle changes. Yet, even after I did everything I knew of to improve my energy, I was still frustrated by residual fatigue. My frustration resolved only after I examined my thoughts and feelings about dealing with fatigue, and then shared my insights with family and close friends.

For professionals in oncology, a complete understanding of the psychosocial impact and consequences of their patients’ cancer-related fatigue is essential to overcoming obstacles to optimal evaluation and treatment. To this latter end, what follows is a discussion of the forces that can generate tension in tired survivors, and suggestions for helping them resolve the frustration of fatigue.

Fatigue: A Physical Problem

PHYSIOLOGIC EFFECTS OF DISEASE AND TREATMENT

A cancer diagnosis and the ensuing treatments precipitate a host of changes that can affect patients’ energy levels. The energy drain begins with the physiologic effects of the disease and treatments (including the medications used to offset side effects), and the practical and emotional stresses that accompany adjusting to the new reality—including the existential feat of facing one’s own mortality. Despite compromised reserves, patients undergoing treatment face increased demands in many, if not all, spheres of their lives.

Completion of treatments marks patients’ release from the rigamarole of procedures, tests, and therapies aimed at the cancer cells, but not from the physiologic consequences of these treatments: Antitumor activity continues for a while, and normal cells, injured as innocent bystanders, undergo repair. At best, a few weeks or months later, the cancer is cured and the normal tissues have returned to full, or nearly full, function. Often, however, some degree of subclinical and/or overt pathology persists, which may contribute to fatigue.

TRANSITION TO POST-TREATMENT LIFE

The final dose of a treatment course, far from marking the end of a patient’s cancer experience, marks the beginning of another transition. Occasionally patients slip back easily into their old normal life. More often, the physical and psychosocial fallout of patients’ survival moves them haltingly, and sometimes quite traumatically, to a “new normal” life that eventually integrates the physical, emotional, psychological, spiritual, financial, and social changes precipitated by the illness. Making necessary post-treatment lifestyle adjustments can add considerable strain on patients’ already diminished energy reserves.

My observations in the trenches of survivorship, supported by the literature, suggest that cancer-related fatigue can be manifested in many ways. Although “feeling tired and needing to go to sleep” are common and predictable, other prob-
lems, such as difficulty concentrating or learning new information, poor memory, irritability or emotional lability, dysphoria, weakness, clumsiness, loss of interest in people or things, malaise, or decreased sexual desire, may also be related to fatigue.5,7,8,13,19,34,45-50 And, patients often report fatigue-related mistakes and miscommunications.

Unlike the tiredness that healthy people feel, this fatigue is more difficult for patients to ignore, often impairs patients’ ability to function well, and is not relieved with one night’s rest. Moreover, onset may be sudden and without warning. Put succinctly, the underlying physical problem for patients is that extra effort is required for even normal activities and social interactions. Due to decreased energy reserves, some normal functions become virtually impossible.

Fatigue: An Emotional Problem

Throughout patients’ treatments and recoveries, fatigue can be as much an emotional as a physical problem.

A NEW CANCER DIAGNOSIS

The seeds of chronic problems with fatigue are often sown in the beginning, while patients are tackling the immediate, obvious, and consuming problems that accompany a new cancer diagnosis. When patients’ normal sleep cycles are disrupted by physical and/or emotional discomfort or distress, weeks may pass before anyone notices. And then, too often, because patients and their families assume that trouble sleeping is to be expected, nothing is done about it.

As patients settle into new routines that revolve around treatments, they may feel an urgency to be productive, ignoring physical signals of fatigue. Many dramatic changes at work and home can make life feel distressingly unreal. Performing any familiar task, albeit a tiring one, provides a comforting link to the patient’s normal pre-cancer world. Cancer can threaten a patient’s sense of self. Consequently, trying to continue one’s usual schedule at work or home as much as possible can soften this threat.

During the first few weeks after a cancer diagnosis, patients face an almost endless string of losses: Loss of role, (e.g., breadwinner or homemaker, disciplining parent or doting grandparent, jogging partner or caregiver); loss of physical comfort; loss of hair or other body part; loss of a sense of future; and loss of the illusion of control. The physical cost of going to work or doing household chores may seem less harmful than the emotional price of acknowledging yet another loss by delegating a task or leaving a job undone.

Patients’ attempts to be productive during the day (and at night when they can’t sleep) frequently concern family and friends. Some of those who dare to advise patients to relax may find their advice welcomed, but many are met with silence, anger, or tears. Why? It may be because cancer has precipitated a crisis of control, particularly for individuals who were accustomed to feeling in charge and doing things “their” way, and now find the most critical activities of their lives being dictated by others.

Whether it is characterized as regression or reaction formation, anything that patients can control may take on heightened importance, even trivial things, such as which route to take to the hospital or what snacks their children should eat. This need for a sense of control can make patients’ continued participation in activities at work or home seem a higher priority than resting.

DURING CANCER THERAPY

As the weeks turn into months and the shock of the diagnosis fades, fatigue-related psychosocial problems can mushroom. With each successive cycle of cancer therapy, patients’ energy typically wanes and, for some, resistance to resting paradoxically waxes. The existential problem of time is often the chief obsta-
cle both to recognizing and responding to progressive fatigue in a healthy way.

Life-threatening illness can create a sense of urgency surrounding everything: Projects at work, parenting, fixing up the home, repairing damaged relationships. With a sense of time running out, patients feel they need to say and do everything before they are cut short. Well-meant reassurances by relatives and friends, such as, “You can do that when you’re better,” only increase patients’ sense of urgency and can leave them feeling alienated.

“Magical” thinking can confound the time trap by offering an odd illusion of security—“I simply can’t die before this project is done.” Thus, some patients are caught between their drive to complete current projects (in case they don’t have much time left) and a need to keep starting projects so they are never free to succumb—not a good combination for conserving energy.

Patients’ concern for their family and friends also can be counterproductive. When patients sense their loved ones’ fear or sadness, or see evidence of lagging energy, they naturally want to make things easier. Receiving cancer therapy is passive. Rescuing a spouse from a crying child or mowing the lawn seems more like “doing something” to help. And, since their illnesses are causing the troubles, many patients harbor a subconscious, irrational sense of guilt that the overload is their fault and, therefore, they owe their loved ones relief.

Pain, either physical or emotional, can be a powerful contributor to the need to keep busy, interfering with patients’ ability to obtain adequate rest. Leisure deprives patients of the distractions that can ease the rigors of cancer therapy, leaving them free to ruminate about their misfortune and to fully experience discomfort.

In contrast, purposeful tasks and projects offer diversion and a sense of meaning that may provide greater relief than pills or meditation exercises. Many patients who are able to continue working or volunteering, far from feeling burdened, are most grateful for the opportunity to be distracted. This “busy-ness,” however, is not risk-free. The discovery that they can temporarily escape discomfort through activity may cause a blurring in patients’ minds of the distinction between healthy distraction and maladaptive overexertion. Patients may resist slowing down, afraid of feeling worse, especially as the cumulative unpleasant effects of irradiation or chemotherapy become more predictable.

SURVIVING RECOVERY
Activity not only distracts patients from pain, but it helps them hold onto the “non-cancer” image of themselves. Ironically, patients’ adaptive attempts to keep cancer from being the central focus of life may be sabotaged by fatigue: During treatment, but particularly during recoveries when everything else is fine, poor energy is a daily reminder that patients are surviving cancer. The contrast between the patient’s exhaustion and his or her friends’ or older relatives’ vitality makes cancer hard to forget.

Being a cancer survivor is not necessarily a terrible thing. Nevertheless, illness and its realized, as well as potential, losses are sad. Consequently, cancer-related fatigue can trigger sadness by reminding patients of their disease, consciously or subconsciously. The obvious solution—resting well to avoid fatigue—can be dispiriting, too: Patients trade the sadness that comes with feeling overtired for the grief that accompanies giving up activities they enjoy or want to do. Whether pushing themselves or resting adequately, patients must learn to live with daily “little griefs” on a regular basis.

Napping
Survivors’ need for a nap can became a lightning rod of frustration at home as family members struggle to encourage rest time without sounding bossy. The tension is similar to that which commonly
arises over patients’ diets because sleep, like nutrition (and unlike sophisticated cancer treatments), is an issue with which family members feel familiar.

Patients’ need for rest provides a concrete way for families to participate in their loved ones’ care. Nevertheless, the logistics of setting aside space and time for naps are not always simple. Working one’s schedule around sleeping patients can be burdensome. The sacrifice and difficulty of protecting the quiet when doorbells, telephones, pets, and children don’t abide can cause tension. If the quiet is preserved and patients still don’t rest as hoped, family members—both adults and children—can feel any mixture of anger, frustration, exasperation, worry, disappointment, resentment, and helplessness. Smoldering negative feelings of tight-lipped family members often ignite over other problems. On the other hand, open reproaches such as “Please take your nap!” can make patients feel humiliated or angry about being treated like children, overshadowing genuine gratitude for the family’s efforts.

Survivors’ frustrations persist as they try to make healthy adjustments in lifestyle. Accommodating diminished energy reserves is no easy task for busy people. Fitting in “rest time” often means that as naptime or bedtime approaches, many survivors rush to rest, clearly an oxymoronic situation. When patients delay their repose, their feelings of guilt duel with resentment at having to interrupt important activities. For some, an oppressive sense of gloom descends as they lie down, and persists until they drift off to sleep minutes later. Defense mechanisms may be lower at such periods and any residual grief over the many losses that accompany having cancer re-emerges when there is a heightened sense of losing time.

Even when survivors adopt the helpful mantra, “Sleeping is not wasting time,” the time crunch stirs the mix of negative emotions. The “good” hours take on heightened importance,pressuring some patients to use every minute wisely. Ordinary delays and setbacks become intolerable. Since prioritizing appropriately often lands mundane tasks at the top of the list, boring or distasteful chores that wipe out energy reserves become patients’ day-defining activities. Self-pity, anger, guilt, depression, or boredom can set in.

Another negative emotion often triggered by cancer-related fatigue is disappointment. During remissions, survivors may wake up refreshed after a good night’s sleep and think, “I feel good. Maybe I’ll feel OK all day, or at least longer than yesterday.” The energy and sense of wellness can be exhilarating, even intoxicating. Yet, at the first hint of mid-morning fatigue or the sudden exhaustion that hits in early afternoon, they realize, once again, that they aren’t well. Every day brings a cycle of fresh hope followed by disappointment.

FLUCTUATING ENERGY LEVELS

Many patients do not struggle with any of the above-described emotions, yet they may experience frustration when the ability to plan activities and respite is undermined by weekly, daily, and even hourly variability in energy levels. Fluctuating energy levels make it difficult to get enough rest without slowing down unnecessarily. Unexpected medical or emotional problems sap waning reserves without warning.

Survivors’ unpredictable energy levels also affect the adults who work and live with them, disrupting previously agreed upon divisions of labor. Patients’ routine chores should be frequently re-assessed against available energy levels. Even then, problems can arise when, for example, survivors suddenly and without warning may be too tired to complete a task as planned. Patients deal with wounded self-image and/or guilt for not pulling their load (or creating extra work when they do a job poorly); coworkers
and well partners often battle the suffocating thought that they have to do everything themselves; resentment (real, imagined, suppressed, misplaced, denied, feared) resonates through relationships that would otherwise be sustaining.

The situation can be compounded if well partners, caregivers, or coworkers run out of steam. No matter how tired healthy people may be, they feel they can’t complain or take a rest because survivors are always more tired.

SOCIAL RELATIONSHIPS
When work and home responsibilities monopolize patients’ energies, social relationships are likely to suffer. Friends feel hurt, angry, frightened, or disappointed when survivors seem never to have time for them. When energy is limited, family usually comes first. Family members in difficult circumstances remain bound by blood; friendships under stress can dissolve. Survivors who are single and live far from family often feel an added burden of social responsibility, and an increased sense of vulnerability.

In and out of the home, simple social matters become complicated. Invitations to future events become emotionally charged: Should survivors decline potentially gratifying invitations because of uncertainty about future energy levels? Should they commit, with the understanding that they might have to cancel at the last minute? A life-enhancing, conditional “yes” keeps options open, encouraging patients to be hopeful about their future health, and allowing them to stay involved with the well world. Paradoxically, this same contingency clause forces discussion of activities intended to provide escape from illness to be shaped by it.

Social relationships are affected on other levels, too. “How are you?,” a universal greeting, carries distinct overtones when addressed to a survivor (“How ARE you?”). When survivors answer honestly, “I’m tired,” well-intentioned family and friends try to normalize the fatigue by responding, “Gosh, I’m tired, too, and I don’t have cancer” or “It’s because you’re older now,” or they might tease, “I wish I had an excuse to take a daily nap!”

Napping for survivors is a necessity, whereas healthy people can function without it. Because tiredness is a symptom that healthy people experience, their suggestion that they need the same rest can make the survivor feel frustrated or alienated (“They don’t understand how I feel.”). After hearing healthy people claim to be suffering the same tiredness, survivors may experience self-doubt: “Is my fatigue really worse than the usual tiredness people feel? Am I lazy? Do they think I’m malingering?” When months of feeling tired turn into years, survivors can lose their baseline.

PARENTS AND CHILDREN
Children of tired cancer survivors suffer, too. They get upset, angry, or frightened when their parents can’t “be there” (literally or figuratively): Parents may not pick up their children on time because of oversleeping or forgetting; Moms or Dads may be too tired to go to the library or park, or to just listen to a story or admire a crayoned drawing. Adults may become impatient with children who need extra understanding and loving. When tired parents do participate in group activities with their children, they may seem different from the other Moms and Dads, taking on less responsibility or sitting down more.

WHEN FATIGUE IS MISINTERPRETED
Another common phenomenon is a mismatch between a patient’s demeanor and the inner self, resulting in misinterpretation of affect by others. A survivor’s tense facial expression or body language may cause bosses, friends, coworkers, and family members to believe that he or she is angry, sad, or upset when, in fact, simple tiredness is the culprit. Children may worry, mistakenly, that their parents are angry with them.

Fatigue can strip survivors of the
healthy and adaptive control adults normally have over the public persona. Not only can cancer-related fatigue make it difficult to hold up one’s side of a conversation, fatigue can sometimes make it difficult, even impossible, to respond to minor frustrations and disappointments in a mature, socially acceptable way. The voices of tired survivors betray irritability or impatience when they would prefer to appear calm and pleasant.

Looking Marvelous

More often, however, this mismatch between inner and outer life cuts the other way: Survivors often look better to others than they feel. When patients are bald or walking on crutches, everyone expects them to have limits. When incisions are healed and hair has grown back, however, friends and family shower tired survivors with compliments about how healthy they look, even how energetic they appear (or sound over the phone). Survivors’ attempts to explain their fatigue are often greeted with assurances, “Well, you look great!”

Wearing make-up or brightly colored clothing can lift survivors’ spirits (especially when they feel lousy) and help them fit more easily into the healthy world. Ironically, while patients want to be treated normally, they also need others to understand that they are not completely healthy so that expectations should be adjusted.

In public settings, the good health suggested by survivors’ physical appearance may be validated by their behavior. Patients’ enthusiasm at concerts or sports events, for example, may cause others to make comments like, “You can’t be too tired if you’re cheering like that,” or “No wonder you’re tired.” What these observers don’t realize is that the survivor may need to rest both before and after the outing in order to attend. Being doubted or blamed for fatigue is a considerable source of frustration for patients, particularly when they attempt to participate in activities that are energizing or provide escape from the “patient” role.

THE CANCER WARRIOR

The mystique of the “cancer warrior,” though meant to be inspiring, can be counterproductive. Patients win social points for persevering in the face of life-threatening illness. Those who never miss a day of work throughout cancer treatments are the stuff of legends. And, those who are obviously sick or disabled qualify as brave cancer warriors just by tolerating the procedures and discomforts of treatment. When survivors’ chief problem is fatigue, such as occurs during remissions or courses of mild treatment, however, the patient’s challenge (and courage) is less obvious.

Exhausted survivors who want to dispel myths about cancer (e.g., “All cancer patients are doomed”; “Cancer patients can’t perform adequately at work”) may try to prove to the world that they can do it all when common sense would dictate that they slow down.

The frustration of fatigue is compounded when patients, especially those who push themselves, wrestle with the myth of the omnipotent survivor. Popular books and articles promote the notion that survivors can control their health: Proper diet, activity, and attitude purportedly allow the self-healing potential of the body and mind to effect a cure (and, therefore, poor diet, activity, and attitude condemn one to a bad outcome.)

When patients suffer recurrences, for instance, it is not uncommon for well-meaning family, friends, and acquaintances to suggest, “You must have been pushing yourself too hard.” The average patient generally does not have a clear grasp of the molecular biology of carcinogenesis, and is vulnerable to such damaging explanations. Even to those patients who understand that recurrence is due to mutated cells that escaped the earlier round(s) of cancer therapy, the possibility
of having accelerated the recurrence can be disturbing. Just as believers in mind-over-matter worry that negative thoughts can cause cancer cells to multiply, those who want to believe that proper actions can control outcome worry when they get tired that they’ve set themselves up for progression of disease.

This minor anxiety is fed by a much greater one: Does fatigue mean that the cancer is progressing (or back)? Worsening fatigue can be a symptom of progressive or recurrent cancer. Such anxiety varies over time: During the weeks following good-news scans, x-ray evidence of improvement or remission encourages patients to interpret fatigue as a good sign, one of healing. The emotional comfort fades, however, as follow-up visits approach. Without the reassurance of a good news scan, the same level of fatigue fuels normal check-up anxiety, which surely worsens the fatigue (or at least patients’ perception of it.) A vicious cycle can begin, especially when the sensations of fatigue are similar to those experienced when cancer was active. The ever-present threat of recurrence makes it impossible to dismiss survivors’ concerns as totally unfounded. Fatigue can make patients anxious, and anxiety can exacerbate fatigue.

**FATIGUE AND SEX**

The frustration of fatigue is often felt in the bedroom, too. Couples’ sexual routines are usually disrupted, at least temporarily, when one partner is ill, certainly if treatments require surgeries or hospitalizations or when patients have medical problems that obviate their usual sexual play. When obstacles, such as the loss of a body part, discourage an easy resumption of sexual relations, fatigue may keep patients from investing the emotional and physical energy it takes to initiate intimacy that has become awkward.

Severe fatigue by itself can diminish or extinguish patients’ interest in sex. In situations where patients’ sexual desire thrives, fatigue can then dampen it over the course of the day’s activities. On those evenings when the fire still flares and partners connect, intimacy itself can be tiring and, therefore, less satisfying. For patients who find out that they pay the next day for staying up late, the once second-rate “quickie” holds new appeal.

And, it takes two to tango. Caring healthy partners may fear pushing loved ones with their sexual advances; not knowing how much is safe, they may withdraw altogether. As well partners get tired, too, the couple’s window of mutual sexual availability becomes smaller and smaller. Fatigue creates sexual difficulties where, otherwise, there were none. By stealing the couple’s spontaneity, fun, and intimacy, fatigue spoils a natural respite from the seriousness of illness.

**FINANCIAL STRESS**

An often-neglected contributor to the frustration of fatigue is financial stress and anxiety. Cancer treatment is expensive, even for patients with good medical insurance. Loss of income, and non-medical costs of treatment, can strain financial resources and prompt practical changes that further tax patients’ energy, such as giving up help with housework or childcare, or taking an extra job.

The emotional stress of financial worries, big or little, can take a serious toll. Patients feel guilty when insurance needs cause their spouses to become “locked in” to unsatisfying jobs, or when their illness dries up vacation or home improvement funds. Tension rises when patients’ inability to go back to work or pull their usual weight at home is attributed by family members to laziness. The link between financial stress and fatigue may go unrecognized and unaddressed at home because many people consider discussion of money taboo. During office visits, financial strain remains a silent symptom because it falls outside the medical arena; neither doctors nor patients bring up the subject.
The Clinician’s Role

Obstacles to honest and healing communication between survivors and their physicians can perpetuate the frustration of fatigue. Patients often don’t volunteer that they suffer from fatigue in much the same way that pain is under-reported. When patients are in treatment, they may not want to complain or appear ungrateful—fatigue seems too minor a symptom. Cancer patients believe they are supposed to be tired and/or the doctor can’t do anything about it. And patients don’t want to distract the doctor from taking care of the cancer; they want to appear tough and optimistic. Patients may be terrified that fatigue portends disaster (and they don’t want to know). Often, doctors don’t ask.

When patients are in remission, they may feel like they are in better shape than before (a so-called “response shift”) and they certainly look better than the frail people in the doctor’s waiting room. Survivors want to please the doctor (“You’re a success because I’m doing great”), or they want to fulfill the image of complete recovery that sustained them throughout their course of treatment.

Unlike patients’ pain, which is often brought to doctors’ attention by family members, fatigue is less likely to be recognized by family members as a key factor in other problems at home. And, family members are susceptible to the same misinformation and misperceptions that keep patients from volunteering information about their energy limitations. When patients are in remission, their loved ones may be intent on putting the cancer experience behind them all, hoping the doctor will coax the patient into resuming normal activities.

Unfortunately, even when patients try to discuss fatigue with their doctors, they may be told that there is nothing that can be done, or that fatigue is expected. Patients in remission may be told that, since test results are normal, there is no reason to be inordinately tired. Or, the clinician may suggest that the patient is depressed.

In summary, the root of the frustration of fatigue is the complex nexus between fatigue, expectations, anxiety, and depression. Fatigue can trigger a cascade of practical, social, financial, and emotional problems that interfere with patients’ functioning and resting, and which, in turn, exacerbate the fatigue, dampen patients’ outlook, and worsen anxiety and depression—all of which can exacerbate fatigue.

Especially during remission, when patients expect their sense of well-being to improve, these vicious cycles undermine reason and lead to confusion about their own role in contributing to fatigue. Fatigue affects survivors’ relationships with others, ability to function, self-perception, and sense of hope. An invisible wound, it shapes their daily lives and future plans, posing a great challenge to finding a healthy “new normal” baseline after cancer.

Resolving the Frustration of Fatigue

Over the years, I’ve developed a philosophy of healthy survivorship. Based on three steps—obtaining sound knowledge, finding and nourishing realistic hope, and acting effectively—this philosophy helps patients get good care and, at the same time, live as fully as possible under the circumstances. Knowledge, hope, and action can lead patients toward resolution of the frustration of fatigue by minimizing the physiologic causes of fatigue, and by helping survivors adjust to the energy limitations that remain.

MEDICAL EVALUATION

The medical evaluation of fatigue in cancer survivors must be complete, and repeated at appropriate intervals. All medical conditions that can contribute to fatigue, including pain, must be discussed with the patient and treated whenever possible. Although the list of possible causes...
conditions that cause fatigue in cancer patients is long, some of the most common reasons include the cancer itself, antineoplastic therapy, intercurrent systemic pathology (e.g., anemia, infection, renal insufficiency, pulmonary disorders, malnutrition, etc.), disordered sleep, centrally acting drugs, and psychosocial stressors.

Patients who know which medical conditions are likely contributing to their current fatigue can have more realistic expectations. Patients who are clear about which problems have been ruled out are less likely to waste energy worrying.2

The patient’s activity level, sleep pattern, and nutritional status must be re-assessed at each stage of survivorship. By offering specific guidance and encouragement about exercise as patients’ conditions change, health care professionals can help their patients stay relatively conditioned safely.50,56-58

Optimizing the quantity and quality of patients’ sleep can be more of a challenge. Side effects of anxiolytics, antidepressants, stimulants, or soporifics may be intolerable or overlap the very symptoms the drugs are intended to treat, making it difficult to know when less, not more, drug is needed. Educating patients about healthy sleep habits50,54-55 and trial and error regarding the timing and duration of afternoon naps, should improve patients’ baseline energy level. So, too, should adjusting patients’ diet according to the nutritional demands of treatments and recoveries.

When fatigue persists, especially when it is not easily explained by a medical condition, the patient’s psychological state,59-60 including financial concerns and social stresses, should be explored. Certainly, patients may benefit when treatable depression or anxiety is perpetuating the fatigue; lifting depression or relieving anxiety, no matter how mild, improves quality of life even when fatigue persists unchanged. Malingering and Munchausen’s syndrome are two diagnoses that carry enormous consequences, either when missed or when diagnosed in error.

Without an objective measure of the contribution of psychosocial stress to an individual patient’s fatigue, counseling can be offered with three goals in mind: Resolving illness-precipitated psychological conflict that might be contributing to energy problems; providing professional advice about personal energy conservation and coping with the consequences of being tired all the time; and clearing up confusion surrounding the patient’s mental state (Am I depressed? Am I lazy?).

SPIRITUAL SUPPORT

Just as physical problems can present emotional challenges for the cancer patient, they can also precipitate spiritual difficulties. Beliefs are tested, often for the first time in a meaningful way. For the patient with fatigue, addressing the spiritual side of survivorship may be helpful.

Spiritual tension, a crisis of faith, or a debilitating primal fear may be contributing to fatigue, either directly or indirectly. Spiritual support may help transform spiritual angst into spiritual strength. Even when patients’ faith is unwavering, discussing their fatigue in the context of their spiritual selves may facilitate hopeful acceptance.

Optimizing medical care, nutrition, exercise, sleep, finances, and emotional and spiritual adjustment to illness lay the foundation for minimizing patients’ fatigue, and maximizing adjustment to their “new normal” life. Yet the frustration may persist until patients unlink any emotional turmoil from the physical experience of fatigue, and, thus, stop the vicious cycles of anxiety, depression, and fatigue.

Helping patients perceive needed rest not as a loss but as a way to regain control may help lessen the sadness and frustration of interruption and make it easier to lie down before getting to the point of feeling unwell. Validation from the health care team that patients’ fatigue is real and different from the tiredness that healthy people feel7,13,14,19,31,34,45 helps patients ac-
Except and respect their limits while, at the same time, nourishes hope that energy levels will improve over the long term.

In 1994, I coined the term “Post-cancer Fatigue” for the fatigue that persists when a cancer patient is in remission and all known causes of fatigue have resolved or been ruled out. The introduction of additional vocabulary for talking about the fatigue that accompanies serious or chronic illnesses may facilitate healing communication between patients and their health care teams and/or with families, friends, and coworkers.

When the health care team informs a patient and family that the outward expression of fatigue is often mistaken as anger or irritation, misunderstandings can be prevented or more easily resolved.

Health care professionals need to dispel the mystique of the cancer warrior and instead lift up as a hero the survivor who adjusts to necessary changes and limitations with hopeful acceptance.

Comprehensive care of the cancer patient demands that clinicians invest the same kind of expertise and energy directed at malignant cells toward the fatigue that cancer spawns. Cancer survivors should be supported in their efforts to meet the unique challenges they face every day. Learning about the causes and treatments of fatigue, nourishing hope that fatigue is a treatable condition, and acting on this knowledge in life-enhancing ways will help patients and their health care teams resolve the frustration of fatigue.

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