



Fibromyalgia Fallout

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Much has been written in the last three decades by a small group of medical researchers determined to prove that fibromyalgia (FM) is a psychiatric disorder. Even today, despite scores of carefully designed research studies which point to genetic links, biochemical abnormalities, and ANS dysfunction in FM and disprove such contentions, the nay sayers persist in casting FM patients as chronically depressed, unhappy in life, hysterical, and/or malingering. Nothing could be further from the truth.

Nevertheless, fibromyalgia patients have reason to be unhappy. Not nearly as much attention has been paid to the considerable psychosocial toll that the symptoms of FM and related conditions have taken on them. As a chronic condition which can be quite severe at times, FM can often severely undermine a patient's life at work and at home with family and friends. Its onset frequently requires them to do significant "rebuilding" of their lives at a time when they are least capable of doing so, health-wise. The emotional impact and social consequences can be huge.

Once a patient has been diagnosed, physicians can offer a treatment plan which includes medications, referrals to physical rehabilitation specialists, and recommended life-style changes, but it is usually up to the FM patient, on his/her own, to develop a new road map for life, learn how to manage difficult new constraints on activity levels and expectations, and deal with the emotional upheaval inherent in a medical condition like fibromyalgia. This renewal process typically begins when FM first develops, but it often reappears over time especially when the patient's

circumstances change or when family emergencies or new health concerns arise.

With this in mind, it is useful to consider the types of human responses that can arise as a result of FM ("fibromyalgia fallout"). If we can identify them and better understand them, then we can build our emotional strength and fortify ourselves for future challenges from fibromyalgia.

Disbelief, Fear: For someone who has had a reasonably trouble-free life health-wise (i.e., nothing more than normal childhood ailments or minor illnesses or injuries), the arrival of fibromyalgia is often a shock. Questions like "How can this be happening?" or "Why me?" are common. In a society where medical technology and expertise are highly developed and taken for granted, it seems inconceivable that an effective treatment or cure for fibromyalgia is unavailable. Meanwhile, a frightening array of symptoms, such as severe pain, fatigue, and cognitive symptoms (among others) are making themselves known. Worst of all, they keep on coming in wave after wave. Patients are typically told to exercise, but worry whether it is even safe to walk and move around. In time, these and other concerns diminish if an effective treatment plan can be found. Meanwhile, major changes are in order.

Sacrifice, Insecurity: It doesn't take long to discover that fibromyalgia, when severe, can threaten job security and many other aspects of life formerly taken for granted. Symptoms can interfere with job or school performance — i.e., a nurse whose FM-related cognitive problems make it dangerous for her to dispense medications; an assembly line worker whose pain is too great to handle repetitive work; a homemaker with very young children who cannot risk taking sedating pain medications lest she fall asleep on the job; or a young law student who just can't seem to keep up with classes. Deadlines at work may be suddenly difficult to meet. Plans to have a family or engage in social and recreational activities or travel may have to be postponed or cancelled. Having a social life is often difficult. Friends may drift away if the person with FM cannot easily engage in the usual activities of the group or is ill much of the time.

The result can be severe stress, disappointment, and loneliness, to name but a few possible emotions. We live in a very competitive, active society in which youthful vigor is valued. An individual with fibromyalgia may feel that he has forfeited his youth to illness. Lucky patients may find effective treatment(s) and/or a disciplined life-style that will allow them to

compete in their chosen professions. Accommodations may be possible, or significant changes may need to be made. Either way, it takes emotional as well as physical energy and commitment, and that is one good reason to come to grips with physical and emotional barriers early on.

Loss of Dignity, Shame: Being incapacitated by chronic illness often means relying on others for help: shopping for food and clothing, getting to medical/dental appointments, and finding help for other necessities. Physical changes due to illness may make persons with fibromyalgia feel and look less attractive, making it embarrassing to socialize or to be seen by persons from the past. Some people with FM and related conditions are forced to stay in unhappy or even abusive relationships because they are unable to live independently or be self-sufficient.

Self-Image, Self-Doubt: Sooner or later, a person with fibromyalgia will begin to feel that she is no longer a whole person. Afraid of rejection, she may ask: “Who will want me?” or “Am I to blame for my illness?” When on a job interview or asked out on a date, she will need to decide whether or not to disclose her fibromyalgia. It may be awkward and risky to admit to FM (could cost her the job or the date), but sometimes honesty is the best policy. The answer is not always clear-cut. On the other hand, it is not necessary to announce FM to everyone. This can be tiresome and make it hard to separate your self from your fibromyalgia. It is restful to “go off duty” sometimes!

Letting Others Down, Guilt: Intrinsic to FM is the necessity to cancel plans at the last minute when symptoms flare up. Not surprisingly, this causes embarrassment and frequent guilt when friends/ family must be disappointed, sometimes repeatedly. It is also quite common for parents with FM to worry that they aren’t good enough parents or aren’t available enough to their children and that their children will suffer as a result. Alternatively, healthy parents of children with FM may feel that their offspring’s ill health is their fault since research suggests FM can run in families.

Often embarrassing and stressful is the necessity to have less intimacy with a spouse or significant other on some occasions because of a flare-up of symptoms or because of fear of pain or injury.

In all of the aforementioned situations, it is important for people to make a concerted effort to communicate with each other, not only to avoid hurt feelings on both sides but also to make it possible for use-

ful solutions or compromises to be made. Patients may feel hurt when others do not notice their “invisible” symptoms, but they may forget that well family members or friends have their own problems, too.

Vulnerability, Desperation: An individual with fibromyalgia may sometimes find herself cornered by well-intentioned family or friends who make unhelpful suggestions on how she can get all better — “If only you did this!” or “Maybe you should do that!” or “I heard about a terrific new study you **MUST** sign up for!” Such situations are awkward! Alternately, family members or friends may be totally indifferent to the pain and other symptoms of a FM patient.

In addition, a patient, desperate to get better, can be vulnerable to unscrupulous health product sales people or medical providers who promise a “miracle cure” or amazing results when a advertised treatment, in fact, offers no benefits whatsoever. It is always good to remember in such situations that if a given treatment approach is **THAT** good, chances are you would have heard about it on the evening news or from other people! Also, it’s not just individuals who can rip a person off. Big companies can, too.

The Future: Many people with fibromyalgia worry about what will happen to them when they grow older. Will my fibromyalgia get worse with age? Will I end up alone with no one to help me? Are long-term insurance and retirement funds available to cover my living expenses in later years?

Growing older can also increase the likelihood of developing other medical conditions like osteoarthritis, menopausal suffering (women), prostate problems (men), or more serious conditions which can all wreak havoc with FM. Ironically, in later life, the playing field can become more level for fibromyalgia patients because “normal people” of similar age are also beginning to slow down, head toward retirement, and develop the same age-related chronic health complaints as those with FM. Already experienced with the difficulties of life with fibromyalgia, FM patients arguably have an edge as far as coping with such chronic conditions. Many already know how to cope.

Adding Perspective

Fibromyalgia can take a substantial toll on patients not only when they are alone but also when they interact with others. Sometimes enormously difficult life changes must be made to get on with the business of living. To succeed, it is crucial to learn

not to engage in self-blame so that it is possible to move forward. Sometimes, with a little investment of time and thought, those with FM can put matters into better perspective. Consider, for example, the case of guilt.

If you think about it, guilt is already widespread in our society as a whole. People laughingly say they have been “raised on guilt,” or they shower loved ones with cards and gifts to assuage real or imagined wrongdoings. In the case of fibromyalgia patients, however, guilt takes on special importance since it is attached to a chronic medical condition, consuming inordinate amounts of energy and stress on a daily basis. In doing so, guilt detracts from the ability of patients to manage fibromyalgia and get on with their lives.

One of the earliest lessons most of us learn after developing fibromyalgia is that we suddenly need special help from others to survive on a day-to-day basis, particularly when we are suffering symptom flare-ups. This can be a difficult bone to swallow for those of us who previously imagined ourselves as independent and self-sufficient. Those severely debilitated by FM may need to depend even more on friends or loved ones to help them move about, prepare meals, and obtain needed medical attention. Even with modest disability, they may be unable to drive a car, perform certain routine tasks, or fulfill the tasks that others have grown to expect from them. Because none of us wants to be an undue burden on those we care about, the result is often guilt combined with a sense of inadequacy and a fear that others will think us a burden or a bore and cast us aside.

Ironically, the truth is that our guilt is often unfounded, for those who care about us usually do not mind helping out particularly if we are working hard to manage our illness and improve our outlook and level of functioning. Stop for a moment and think about what your response to a loved one would be if (s)he had fibromyalgia, and you will find this to be true. Furthermore, with a little imagination, most of us with FM can find pleasing ways to reciprocate favors done for us. Even “healthy” individuals need assistance (much as they may hate to admit it) or appreciate small gifts or good deeds from others. Arguably it is guilt, along with the anger and resentment that can grow from it, which is most likely to drive others away from us. What could be more unappealing than a person who asks you for assistance but despises you for providing it? What could be more boring than a person who mourns endlessly for his/her lost capabilities?

If you stop and think about it, we all waste time reproaching ourselves for situations over which we



have little or no control. While such self-blame on our part may illustrate the love and concern we have for others, it can become noxious if we become obsessed with guilt. Once we have come to terms with certain realities, it is to our advantage to let ourselves off the hook and allow others to do so, too.

Much of the more difficult guilt we shoulder with fibromyalgia results from the unfulfilled expectations we (and others) have for ourselves. Perhaps in the past we excelled at our jobs, were world-class tennis players, or threw the best parties. Maybe we were model individuals who skillfully balanced work, family, and social lives. Maybe we were just average people who worked hard at our chosen occupations.

If fibromyalgia meddles with what we used to be good at, we are bound to feel a certain level of guilt or inadequacy for being unable to maintain former standards. We may begin to persecute ourselves because we feel that we are letting others down (not to mention ourselves). Unfortunately, it is not always possible for individuals with fibromyalgia to recapture their highly active past life-styles, so we are forced to either devote precious energy to refashioning our lives or contend with attacks of chronic guilt.

Moreover, it is often difficult to imagine that we will be able to find alternatives that will yield us the same pride and fulfillment we once had. However, many individuals with fibromyalgia do find satisfying, alternative careers and life-styles that allow them to discover previously hidden talents/interests or find effective new ways to moderate the daily schedules of their original profession.

In considering all these “truths” about guilt and about life with fibromyalgia, we would do well to remind ourselves that our friends and family often look to us for leadership in getting on with life. While they share in our pain and disappointments and celebrate our progress, they also need our help in discovering what new approaches are possible and what help they can lend us. That means a lot of responsibility for us and not much time/energy left over for guilt or other emotional baggage.

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