WHAT NURSES KNOW...
CHRONIC FATIGUE SYNDROME
THE ANSWERS YOU NEED FROM THE PEOPLE YOU TRUST

LORRAINE STEEFEL, RN, MSN, DNP, CTN
WHAT NURSES KNOW...  

CHRONIC FATIGUE SYNDROME

© Demos Health Publishing
WHAT NURSES KNOW...
CHRONIC FATIGUE SYNDROME

Lorraine Steefel, RN, MSN, DNP, CTN-A

demosHEALTH
New York

© Demos Health Publishing
About the Author

Lorraine Steefel, RN, MSN, DNP, CTN-A, is a professional writer and an adjunct professor in the doctoral program at UMDNJ School of Nursing, Newark, NJ. Her interest in CFS developed when her daughter Trisha was diagnosed at age 12 with the illness. As a parent and an RN, she searched for information necessary to help her daughter cope with and manage this illness. She became a volunteer trainer in the program “Chronic Fatigue Syndrome (CFS): A Diagnostic & Management Challenge” prepared and sponsored by the CFIDS Association of America, and presented this program to RNs and other health care professionals across the country. In addition, she is a member of and volunteer for the New Jersey CFS Association. Her fact sheet Chronic Fatigue Syndrome (ME/CFS) Information for Family, Friends and Caregivers appears on the organization’s website. Lorraine lives in Marlboro Township, NJ, with her husband Peter. She has two daughters, Kimberly and Trisha, and son-in-law, Russ.
This is a sample from What Nurses Know... Chronic Fatigue Syndrome
Buy Now

© Demos Health Publishing
WHAT NURSES KNOW…

Nurses hold a critical role in modern health care that goes beyond their day-to-day duties. They share more information with patients than any other provider group, and are alongside patients twenty-four hours a day, seven days a week, offering understanding of complex health issues, holistic approaches to ailments, and advice for the patient that extends to the family. Nurses themselves are a powerful tool in the healing process. *What Nurses Know* gives down-to-earth information, addresses consumers as equal partners in their care, and explains clearly what readers need to know and want to know to understand their condition and move forward with their lives.

*Titles published in the series*

*What Nurses Know…PCOS*  
Karen Roush

*What Nurses Know…Menopause*  
Karen Roush

*What Nurses Know…Diabetes*  
Rita Girouard Mertig

*What Nurses Know…Multiple Sclerosis*  
Carol Saunders

*What Nurses Know…Gluten-Free Lifestyle*  
Sylvia Llewelyn Bower

*What Nurses Know…Chronic Fatigue Syndrome*  
Lorraine Steefel

*Forthcoming books in the series*

*What Nurses Know…HIV and AIDS*  
Rose Farnan and Maithe Enrique

*What Nurses Know…PTSD*  
Mary Muscari

© Demos Health Publishing
This book is dedicated to my daughter Trisha, whose journey through CFS inspired me to write. I would also like to thank the New Jersey Chronic Fatigue Syndrome Association, Inc. (NJCFSA) and its members who have shared their stories. Their courage and continued perseverance to get on with life despite—and with—symptoms that vary in intensity day to day, hour to hour, and minute to minute have touched me deeply. Because of this organization, I was provided with many of the tools necessary to support Trisha when she was diagnosed at the age of 12 with CFS.
Contents

Foreword  xi
Introduction  xiii

1  What Is CFS?  1
2  Getting a Diagnosis  15
3  CFS Symptoms  25
4  Your Health Care Team  37
5  Save Energy, Keep up With Living, Prevent Postexertional Malaise  51
6  Feelings, Mood Swings, and Depression  65
7  Medical Treatments for Chronic Fatigue Syndrome  75
8  Alternative Approaches  85
9  The Importance of Advocacy  97
10  Looking Ahead: Living With Chronic Illness  111

Glossary  121
Resources  129
Bibliography  143
Index  163

© Demos Health Publishing
This is a sample from What Nurses Know... Chronic Fatigue Syndrome
Buy Now

© Demos Health Publishing
Foreword

Lorraine Steefel has penned an informative, well-written, and well-researched book worth reading by anyone affected by chronic fatigue syndrome (CFS) and those who know and love them. As a nurse and parent of a person dealing with CFS, she is uniquely qualified to write about the personal as well as medical aspects of this chronic illness. The first two chapters explain the syndrome and how it is diagnosed, which should help anyone interested in getting a better understanding of the illness as well as the difficulty and frustration with obtaining a diagnosis. The vignettes in each chapter bring home the various aspects that help the reader relate to the information presented.

As a nurse-author and a person living with a chronic disease myself, I especially liked the chapters concerning the importance of a supportive health care team, alternative and complementary therapies, and advocacy. The advice in Chapter 4 should be especially useful to caregivers who provide aid to those with CFS to seek balance in their own lives. Chapters 5 and 6 provide useful
Foreword

guidance in living with this often unpredictable syndrome, and Chapter 7 lists and explains the various current medical treatments for CFS.

When someone experiences an illness with symptoms as varied and changeable as those of CFS, it is helpful to read about the possibilities and be prepared to seek medical care in a timely manner if and when they occur. The research presented in this book should help health care practitioners to better understand the symptoms these clients experience, the many tests useful in ruling in or ruling out their connection to CFS, and providing appropriate care. Above all, these health care professionals should be encouraged to give respect and understanding the clients with this syndrome and their families deserve.

This book will shed some light on this chronic illness, of which 80 percent of those affected remain undiagnosed, according to the Centers for Disease Control and Prevention. People with CFS may recognize some of the symptoms described, be encouraged to seek help, and work toward turning their life around. Steefel has a proactive and positive approach to a complex and confusing syndrome. As Steefel states in this book, life is a balancing act. Through trial and error, clients with CFS must discover what works and what does not; what to avoid or minimize and when; how to ask for and get the help they need; and how this chronic illness affects them individually so they can improve their quality of life.

Rita Girouard Mertig, MS, RNC, CNS, DE
Author of What Nurses Know...Diabetes (Demos Health, 2011) and the Nurses’ Guide to Teaching Diabetes Self-Management, 2nd ed. (Springer Publishing Company, 2012)

© Demos Health Publishing
Introduction

In the mid-1980s, I read a magazine article about groups of people in Lake Tahoe, NV, and Lyndonville, NY, who were coming down with a flu-like illness that left them extremely fatigued. They were so fatigued, they couldn’t go to work or function the way they did before becoming ill. The article referred to it as the “yuppie flu” because the majority who reported the illness were young, upwardly mobile (YUPPIE), and from the middle class. At that time, people with fatigue, muscle pain, and depression were often diagnosed with chronic Epstein-Barr virus or chronic mononucleosis, so the illness took on these names and was eventually called chronic fatigue syndrome (CFS). Although the cause remained unknown, the illness remained a mystery.

I put down the article and wondered what this new illness was. What caused it? Would I ever contract it? Little did I know that years later, in 1995 to be exact, I would come face to face with it when our daughter Trish was diagnosed with CFS.
Introduction

Flash forward fifteen years, after helping our daughter deal with CFS and learn how to manage it, I’ve written *What Nurses Know... CFS* for people with CFS (PWCFS) and their families and friends to provide information drawn from research and reputable sources on the illness. This information is what patients need to know and want to know about their illness and move forward with their lives.

In an effort to make CFS “real” to readers, I’ve included true-to-life vignettes that describe some aspect of CFS as told to me by PWCFS, as well as examples of what our daughter has experienced living with a chronic illness. These demonstrate what it is like to live, manage, and cope with CFS. They demonstrate that CFS is not an “all in your head” illness. Indeed, in 2006, the U.S. Centers for Disease Control and Prevention began a campaign of awareness that CFS is a real illness, and released brief guidelines encouraging physicians to consider CFS in symptomatic patients when other illnesses are ruled out.

*What Nurses Know... CFS* provides validation to the more than one million PWCFS in the United States. It presents an overview of the illness and the latest information about, and description of, symptoms, as well as suggested management of them. It discusses getting a diagnosis and putting together a health care team; for example, readers may choose a neurologist for management of their newly acquired headaches or a rheumatologist for joint pain. Emphasis is placed on the importance of finding a knowledgeable, caring health care provider who is supportive, learning how to communicate with the health care provider and team, and making the most of appointment time.

Living with CFS is challenging. The book addresses coping with CFS physically and emotionally. Pacing oneself is one suggestion that addresses postexertional malaise (which can result from overextending oneself) and provides a basis for keeping up with daily living activities. Unique to this book are useful thoughts from PWCFS regarding what helped them with a specific symptom or how to cope when things got tough.
Introduction

Special attention is paid to how important it is for PWCFS to take care of themselves rather than trying to keep up with the crowd. For example, the “no pain, no gain” philosophy typical among the U.S. population is harmful for PWCFS and can cause the illness to flare up. Complementary and alternative medicine as well as integrative therapies are discussed as approaches that can be an effective part of a healing approach for care.

Self-advocacy is a major issue for PWCFS, who must learn to stand up for themselves and their needs, and have the knowledge and the courage to request specific services that will improve their quality of life. The debilitating symptoms of CFS can make it difficult and sometimes impossible to navigate through the employment, education, or health care systems; therefore, having the right people as advocates can make a significant difference.

The book is user friendly, so people can easily access the information they want and need without having to wade through unnecessarily complex data or details. For this reason, it contains bulleted lists; definitions of common terms; and resources such as lists of support groups, Web sites, and online tools.

Chronic fatigue syndrome is a chronic illness, meaning the person will not “grow out of it.” It is an up-and-down illness that demands attention and care lest the PWCFS have a flare-up. What Nurses Know... CFS, written by a nurse-parent of an individual with CFS, is meant to guide and assist PWCFS live the best quality of life possible and provide information to caregivers and loved ones who assist them on their journey.
What Is CFS?

Picture an inflated balloon. You are that balloon that develops a small pinprick so that air begins to escape. You deflate physically, emotionally, mentally, and spiritually so that all that’s left of you is an empty shell. All you want to do is sleep. You just can’t shake the fatigue. For me, fatigue is the worst of the CFS symptoms because you just can’t beat it.  

LYDIA

What’s in a Name?

Although chronic fatigue syndrome (CFS) was originally named for its most commonly noted characteristic, fatigue, CFS now has several names, which are defined in this chapter:

- Chronic fatigue immune dysfunction syndrome
- Myalgic encephalomyelitis/CFS
- CFS/myalgic encephalomyelitis
2 • • • CHRONIC FATIGUE SYNDROME

At publication of this book, the name CFS is still widely used in the media and among research circles in the United States, and therefore, to avoid confusion, this book will refer to the illness as CFS.

Researchers and advocacy groups have attempted to change the name CFS to one that they believe better reflects its nature. Some think that the name CFS can lead to misperceptions that trivialize the illness, for example, people in general complain about how fatigued they may feel at one time or another. The fatigue in CFS is very different. It is intense, overwhelming, cannot be relieved by simple rest, and can be made worse by physical and mental activity. Because CFS encompasses more than fatigue, the search for a name continues.

Some of the other names for CFS are as follows: CFIDS (chronic fatigue immune dysfunction syndrome) as defined by the CFIDS Association of America on the premise that people with CFS (PWCFS) have a defect in the immune system that may predispose them to the illness. Some researchers believe that CFS is an autoimmune disease similar to lupus, but this has proven inconclusive. In many PWCFS, the immune system is affected, resulting in a decrease in immune function.

While research has identified some immune system irregularities, evidence is not yet conclusive that problems with the immune system may be the cause of the symptoms. Interactions among the immune, endocrine, and nervous systems and the role they may play in CFS are under investigation, as well as the various infectious agents and genetic and environmental factors that may be involved in the origins and pathogenesis of the illness.

In countries like Great Britain, CFS is referred to as myalgic encephalomyelitis (ME)/CFS or CFS/ME, while some experts use the terms interchangeably. Myalgic means muscle pain or tenderness. Encephalomyelitis means inflammation of the brain and spinal cord. Some researchers say that E stands for
encephalopathy, which means altered brain function and structure caused by diffuse brain disease.

In Canada, CFS recently had a name change to ME/CFS. As of April 2010, ME/CFS was officially recognized as a neurologic illness by the government of Ontario, Canada, and given the diagnostic code 795. The ground-breaking implications are that people with ME/CFS (in Canada) can never be told by a health care provider that ME/CFS does not exist. This official recognition will help individuals who apply for disability and pensions in that country. The hope is that other provincial ministries of health in Canada (and the world) will soon follow.

In 2007, the CFS/ME Name Change Committee in the United States, consisting of researchers and clinicians, met in Florida, and reached a consensus that the name CFS be changed. The Committee prefers the name ME, saying it is more diagnostically accurate. ME refers to nervous system pathology with associated muscle pain. To avoid problems with insurance and disability claims, the committee recommended that CFS accompany ME as part of the name for a period of time.

Giving a name to your illness is of utmost importance. CFS might be a misnomer, but I’m not sure. What I do know is that the fatigue [in CFS] is the worst symptom. It takes everything out of you. I do know that putting a name to the illness meant that I would no longer be labeled a malingering by frustrated health care professionals who tried to dismiss me when they couldn’t find out what was wrong.  

LYDIA

In Search of a Definition

To understand and manage an illness, it is necessary to call it by a name that adequately reflects what it is and to construct a definition that clearly explains it. Researchers and advocacy groups continue their work to do this. Here’s a glance at historical
underpinnings from the late 1980s through the present naming and defining of CFS:

In 1988, experts from the Centers for Disease Control and Prevention (CDC) proposed that the name for chronic Epstein-Barr virus (from the Lake Tahoe and Lyndonville outbreaks) be changed to chronic fatigue syndrome to reflect the major complaint: fatigue. They defined CFS as an illness with two major criteria and at least eight symptoms:

- Persistent or relapsing, debilitating fatigue, lasting at least six months, in a person who has no previous history of similar symptoms, and
- Exclusion of other clinical conditions that may produce similar symptoms (e.g., malignancy, autoimmune disease, chronic psychiatric disease, and chronic inflammatory disease, among others)

To be diagnosed with CFS, the person had to have eight symptoms, which included mild fever, sore throat, painful lymph nodes, prolonged fatigue after exercise, joint or muscle pain, unexplained muscle weakness, headaches, and sleep disturbance.

About this time, researchers from Australia and Great Britain devised their own definitions of CFS. Australia accepted the CDC definition and added the symptoms of difficulties with short-term memory and concentration. Great Britain developed the Oxford criteria of CFS symptoms and defined postinfectious fatigue syndrome, a subtype of CFS that either follows an infection or is associated with a current infection.

In 1994, the International Chronic Fatigue Syndrome Study Group, headed by the CDC and including representatives from Australia and Great Britain, drafted a revised case definition of CFS, which is the one most widely used today. Named after Keiji Fukuda, the first author of the manuscript in which it is
published, the Fukuda definition is the accepted standard for research studies. Health care providers use this definition to diagnose CFS. According to the Fukuda case definition, to receive a diagnosis of CFS a person must have

1. severe chronic fatigue of six months or longer with other known medical conditions excluded by clinical diagnosis; and
2. four or more of the following symptoms concurrently (within the six-month time frame):
   - substantial impairment in short-term memory or concentration
   - sore throat
   - tender lymph nodes
   - muscle pain
   - multi-joint pain without swelling or redness
   - headaches of a new type, pattern, or severity
   - unrefreshing sleep
   - postexertional malaise lasting more than 24 hours

**Defining Continues**

Because the 1994 (Fukuda) case definition was developed with adults in mind, researchers called together a Working Group for a pediatric definition of CFS. In 2006, the International
Association of Chronic Fatigue Syndrome (now called the International Association of CFS/ME) published the *Pediatric Case Definition for Myalgic Encephalomyelitis and Chronic Fatigue Syndrome*. As part of meeting the diagnostic criteria for CFS within this pediatric definition, children and adolescents must have experienced fatigue and symptoms for at least three months, rather than the six-month criteria as with adults. The pediatric case definition includes a comprehensive questionnaire that doctors and other professionals can use to specifically assess CFS in children.

Although the 1994 CFS (Fukuda) case definition is widely used in the United States today, in 2003, researchers and clinicians from the United States and other nations developed another case definition for the illness, *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Definition, Diagnostic and Treatment Protocols*. This definition, published partially under the auspices of the Canadian Ministry of Health, is informally called the Canadian definition. It combines the findings from the CDC-sponsored research on CFS and the European research on ME.

**DEFINITIONS OF CFS AND CLINICAL GUIDELINES**

Because CFS has no known cause or cure, considerable debate continues regarding how to accurately define the illness. The CFS International (Fukuda) definition remains the accepted standard for research, which health care providers use to diagnose patients. The following are definitions and clinical guidelines as they were developed and published.

- CFS—The CDC definition (1988)
- CFS—The Australian definition (1990)
- CFS—The British definition (1991)
- CFS—The international definition (1994)
- The international CFS definition revisited (2003)
What Nurses Know...

Because the cause of CFS is still unknown, health care providers rely on a CFS case definition to help them diagnose the illness. The case definition encourages a diagnosis based on characteristic patterns of patients’ symptoms.


A Symptom-Defined Illness

My daughter Trish had more than four of the symptoms, including the overwhelming fatigue that researchers described. No matter how much sleep she got, she was still tired. Her pediatrician
found the tender axillary lymph nodes and the characteristic crimson-colored arc in the back of her very sore throat. Different joints or muscles hurt her on different days, and she used braces for her elbows, knees, or ankles and elastic bandages for achy muscles. Trish developed migraine headaches that pounded on the top of her head, often accompanied by a swollen area we called a bump on the top of her skull. At times, she seemed as if she were living in a fog and had difficulty concentrating or thinking of the appropriate word she wanted to say.

The physician who diagnosed Trish relied on her account of the symptoms that she experienced because there were, and still are, no tests to diagnose CFS. Reliance on subjective symptoms rather than tests for diagnosis is one of the reasons why CFS is considered an illness rather than a disease.

Scientists are moving closer to finding the pathogenesis of CFS, that is, what goes wrong in the body to cause such an array of symptoms. Once they find this, CFS might then be considered a “disease” as opposed to a “syndrome.” So far, researchers have identified abnormalities in the brain (central nervous system) and the immune system, providing evidence that the illness involves and alters the function of these two systems. For

The fog is what has always scared me the most. I remember once when I was 16 and living in the only home I’d ever known, I forgot where the toilet paper was. And I don’t mean that we had run out. I didn’t just forget if there was more under the sink or above the washing machine. I mean I was sitting on the toilet and literally could not remember how to reach for the toilet paper. Was it to my left? To my right? I got so exasperated and was so afraid, I started to cry. I remember thinking, “This is what Nana (my senile grandmother) must feel like.” TRISH
example, it is believed that low levels of the hormone cortisol could activate the immune system and result in brain dysfunction. This could lead to fatigue, cognitive dysfunction, pain sensitivity, and other symptoms.

Some studies have shown that CFS began after a viral illness. Some researchers of CFS study a possible link between CFS and EBV, the cause of mononucleosis. Some believe that EBV (and other infectious agents) or their reactivation can trigger CFS in people who are genetically predisposed to it, but more research is needed to confirm the links. It is possible that in CFS, different infectious agents interact to cause symptoms.

While many experts believe that CFS is linked to one or more infectious agents, like viruses, CFS is not contagious in the typical sense that you can “catch” it from someone. Although there have been at least three reported community “outbreaks” in the past twenty-five years, most have been isolated cases within the communities.

Researchers are looking for biomarkers, for example, proteins that show up in greater quantities in the blood of PWCFS, in order to create diagnostic tests for CFS. In 2011, CFS gained media attention when researchers at six institutions led by UMDNJ (University of Medicine and Dentistry of NJ) reported finding protein markers in the spinal fluid of PWCFS that distinguished them from people with Lyme disease, which has some similar symptoms, and healthy controls. The encouraging news from these findings is that this new data can be analyzed in the search to develop the cause or pathogenesis of CFS. As lead researcher for UMDNJ, Steven E. Schutzer says, “The next step is to narrow down the list of proteins to find the best biomarkers for what is going wrong in the central nervous system.”

Some have speculated on an environmental component, such as toxic exposure, as a possible cause of CFS, but this has yet to be proven. CFS appears to be triggered by a stressor of some kind, but this is not necessary. The apparent stressor is typically physiologic, such as a viral infection or toxic exposure,
but may be a mental or physical trauma that leads to CFS many years later. As yet, no single causative agent of CFS has yet been identified.

Rather than pointing a finger at the infectious agent as the cause, some researchers believe that CFS is the result of an abnormality in the way the body responds to the infectious agent. The immune system continues to fight off the infectious agent when it is no longer there.

People may use the words illness and disease interchangeably, but they are different. A disease has a known cause, and may have a diagnostic test, a cure, and a predictable course in the way it affects people. The disease tuberculosis (TB), for example, is caused by a pathogen, the bacterium *Mycobacterium tuberculosis*, and is treated with antibiotics. Tests of patients’ sputum can detect TB. Its signs and symptoms, clinical course, treatment, and prognosis are similar in the people it affects across the globe.

PWCFS experience periods of illness and relative wellness, with symptoms that change over time. Some grow progressively worse; others recover completely or improve enough to return to activities but still experience CFS symptoms. According to the CFIDS Association of America, the majority of PWCFS seem to

© Demos Health Publishing
What Is CFS?

improve within five years of becoming ill. Based on statistical data from the CDC, if symptoms last for five years, it is unlikely that the illness will improve significantly in subsequent years.

As its name suggests, CFS is also referred to as a syndrome, a collection of signs and symptoms known to frequently appear together but without a known cause. The word syndrome may tempt people to dismiss the seriousness of CFS and think, “Oh, it's just a syndrome.” However, the National Institutes of Health describes CFS as a debilitating complex syndrome that involves multiple body systems. Persons with CFS most often function much below the activity levels they enjoyed before its onset.

Who Gets CFS?

If you are the person who contracts CFS, you put a human face on this illness. Since mid-2006, a CFS photo exhibit “The Faces of Chronic Fatigue Syndrome” sponsored by the CFIDS Association of America has told the stories of PWCF: a mother and daughter, a twelve-year-old boy former athlete and academic achiever, a young man in college, a young mother with three children, a Vietnam Veteran, and more. It has traveled to more than forty venues across the country, showing the personal meanings behind the statistics.

Although numbers as such don't count for those who are struggling with the exhaustion, pain, cognitive dysfunction, and other symptoms, numbers are helpful because they remind PWCF that they are not alone. Statistics help to legitimize a real illness and assist researchers in their work to understand and help find the cause and cure.

The CDC says between one and four million people in the United States have CFS, with almost twenty percent having symptoms but remaining undiagnosed. The CFIDS Association of American says that CFS strikes more people in the United States than multiple sclerosis, lupus, lung cancer, or AIDS.
CHRONIC FATIGUE SYNDROME

CFS is sometimes seen in members of the same family. Researchers are studying the possibility of a familial or genetic link to the risk of developing CFS. There may be genetic factors that predispose someone to get CFS. Research into the genes themselves has led to the identification of eighty-eight genes whose genetic expression differs significantly in CFS patients compared with healthy people in control groups. (Genetic expression refers to the products that genes produce, typically proteins.) Research in London led by Dr. Jonathan Kerr has found that there are seven likely genomic subtypes. These subtypes correlate with clusters of different types of CFS symptoms and with how severe the symptoms are. Each genomic subtype is believed to be a distinct condition.

CFS can affect people of all ethnic and socioeconomic backgrounds. Although some studies say that rates are higher in Hispanics, African Americans, and those with lower socioeconomic status, larger epidemiologic studies are required to confirm these findings. Research indicates that CFS is at least as common among African Americans and Hispanics as it is among whites.

Although no one knows why, statistically more women than men, with a ratio of 4 to 1, appear to contract CFS, but that does not place CFS into a category as a “woman’s disease.” Noted Australian infectious diseases specialist Andrew Lloyd and colleagues say that CFS has nothing to do with gender, age, personality type, or mental health. CFS is most commonly triggered by an acute illness, like glandular fever, and it is the severity of this illness that determines whether someone will develop the syndrome. “The sicker you are at the beginning of the infection, the more likely it is to result in a prolonged illness,” says Dr. Lloyd.

The majority of people are diagnosed with CFS in their forties and fifties, but children and adolescents can develop the illness. It is difficult to determine how many children have CFS because there was no pediatric definition used to diagnose them until 2006. Pediatric CFS can range in severity from mild to moderate...
What Is CFS?

(moderate symptoms at rest that become severe with effort, unable to attend school) to severe (often completely housebound or bedbound). Although CFS is the same illness in adults and in children, the symptoms and course of the illness can vary.

Is CFS Contagious?

There is no evidence that CFS is contagious; however, researchers believe that infectious agents may trigger and perpetuate CFS and that the infectious agents cannot be fully eradicated by the immune system. Also, CFS can follow a new infection, such as after Lyme disease.

The National Cancer Institute and CFS Advocacy organizations like the CFIDS Association of America have historically discouraged PWCFS from donating blood or organs, based on safety concerns for both the donor and the receiver. PWCFS have low blood volume and orthostatic intolerance (dizziness related to low blood volume). They have frequent infections that may or may not be passed on to receivers.

The AABB (formerly the American Association of Blood Banking) recommends that blood collectors actively discourage potential donors who have been diagnosed with CFS from donating blood. This response was made after the publication of a paper in the journal Science that reported the discovery of xenotropic murine leukemia virus-related virus (XMRV), a retrovirus previously linked to prostate cancer, in 67% of 101 patients with CFS, and 4% of 218 in the healthy control group. Although the findings have not been repeated in the European research community, and conflicting data are a cause to warrant more research, concerns were raised about a possible role for XMRV in CFS. More research is being conducted. In the meantime, not donating blood or organs mitigates the possible risk of transmission of XMRV. The recommendations have been implemented by the American Red Cross and America’s Blood Centers.

© Demos Health Publishing
CHRONIC FATIGUE SYNDROME

What Nurses Know...

Eighty percent of PWC remain undiagnosed. An early diagnosis of CFS means that treatment of symptoms can begin sooner, leading to a better quality of life.

When to Seek Treatment

If someone has symptoms of CFS, they could have this medical condition or another illness that shares many symptoms of CFS. They should not delay seeking a diagnosis. Although it took almost one year for Trish to be diagnosed with CFS, there is now greater awareness of CFS among the medical community that generally means an earlier diagnosis and earlier management of symptoms.

Like any chronic condition, learning about CFS is of utmost importance. Any chronic illness can affect an individual’s friends and family. Family education and seeing a therapist may foster good communication and reduce the adverse effect of CFS on the family.