



We know that old age impacts many aspects of life. But what role does it play in the life of someone with CFS? As more and more people with this illness reach their senior years, here's a look at some of the special issues they face.

CFS & Aging

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AT-A-GLANCE ►

- It's important to distinguish potential illnesses of older age from ongoing symptoms of CFS.
- Aging parents, reliance on caregivers and housing concerns pose extra challenges for the senior with CFS.
- Therapeutic strategies and medications may need to be adjusted as one gets older.

It's been more than 20 years since the Incline Village, Nevada, and Lyndonville, New York, outbreaks brought attention to the mysterious and complex illness now called chronic fatigue syndrome (CFS). Since then, we've seen research expand, health organizations become more engaged and the public slowly move toward greater awareness of CFS as a serious and debilitating illness.

That's how time is playing out in the historic sense. But what about how time plays out in the lives of the many individuals with CFS who are now reaching their senior years? What role does aging play in this illness and what are some of the special issues CFS patients, their families and their doctors face?

The physical

For many seniors with CFS, the challenges of aging begin with a body already compromised by illness. Immune system imbalances, orthostatic intolerance, sleep dysfunc-



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tion and years of reduced activity associated with CFS can make the body less resilient to the effects of aging. Says one 70-year-old Florida woman with CFS, “Old age is an insult to the body, but *my* body’s in poor shape already. It gives new meaning to the saying ‘adding insult to injury.’”

The process of *aging* can make the body less resilient to *CFS* as well. CFS patient Terry Hedrick, 59, describes how aging has interfered with a strategy she’s long used to deal with her orthostatic intolerance. She explains, “Sitting upright in a chair causes me dizziness. Until recently I’ve dealt with this by sitting down on the floor. Now I’ve developed symptoms consistent with arthritis, and it hurts significantly to get up and down. So I’ve lost the ability to forestall my orthostatic problems without paying a price.”

Sixty-nine-year-old John Trussler, who’s had CFS for 23 years, copes with CFS by giving himself time to recuperate from activities, to let his body recharge itself after any type of exertion. He shares, “Now that I’m older every trip or activity seems to take even more out of me than it used to. I must allow even more time to recover. . . . In general it’s harder to manage my illness because everything seems harder to do.”

Another big factor in CFS and aging is the interplay of symptoms. Joint pain, postexertional relapse, cognitive challenges, fatigue and unrefreshing sleep are all common to CFS *and* aging. This means that for many older people with CFS, age tends to reinforce the daily symptoms they experience.

It can also be hard to sort the effects of one condition from the other. As Trussler puts it, “Between CFS symptoms and aging, it’s hard to tell which one is causing the problems.”

More than simply frustrating, this can be a deeply troubling experience. Longtime CFS physician Dr. Nancy Klimas provides an example. “CFS patients often experience cognitive complaints. When a patient has these symptoms in her 50s and 60s, she may assume a progressive dementia is at fault. That can be very frightening. But it could also just be a symptom of her CFS. A cognitive assessment that can distinguish CFS from early Alzheimer’s can be very helpful.”

The opposite situation—where illnesses of older age can be hidden by CFS—can also be true. Says Dr. Lucinda Bateman, who runs a clinic specializing in treating CFS and fibromyalgia, “As people age, there are an increasing number of medical conditions that might masquerade

as the fatigue, exercise intolerance, pain, insomnia or cognitive complaints of CFS—conditions such as coronary artery disease, COPD, sleep apnea, dementia, malignancies and Parkinson’s disease.” She stresses the importance of discerning the onset of these conditions from the ongoing symptoms of CFS.

To many seniors with CFS, that means even more time and energy must be spent monitoring their health and managing day-to-day care. With energy resources limited to begin with, even trips to the lab for blood work can use up a patient’s “energy quotient” for the day.

Says Hedrick, “When the problems with aging were added on top of CFS, I had to make some tough decisions about how to reduce the demands on my life.”

The practical

As people with CFS age, they’re confronted with many of the same practical matters that most people face as they grow old: aging parents, increased reliance on caregivers, housing concerns and other needs. But here, too, CFS adds an extra element of complexity and uncertainty.

For example, few people with CFS, particularly in their older years, can physically or logistically shoulder

the responsibility of caring for aging parents.

Shares Hedrick, “Probably my biggest hurdle from aging has been the need to care for my parents. In the past couple of years, my mother suddenly died and my father’s health has deteriorated . . . I find myself having to monitor both his care and finances remotely.”

She describes challenges from not being able to travel alone to complications with staying in the decision-making loop when a sibling or other family member bears more of the day-to-day responsibility for an aging parent. She also describes the guilt CFS patients can experience from not feeling capable of providing enough care. To a person with CFS who knows firsthand the importance of good care and support, this dynamic can be deeply distressing.

What about people with CFS whose parents are their primary caregivers even now?

For many adults with this illness, one or both parents continue to be the primary source of care, transportation and shelter. As both the CFS patient and care-giving parents get older, this arrangement can be jeopardized by health complications on either side of the equation. These parents, who often provide extraordinarily dedicated support, may find themselves progressively unable to manage their adult child’s CFS-related needs.

Ilene Neely, a 73-year-old woman with CFS, is in the situation of caring for both her son with CFS and her husband who now lives in a nursing home. When asked about CFS and aging, her first thought is about the loved ones she struggles to care for.

“I can’t do what I’d like for either my husband or my son,” says Neely. “I visit my husband and bring him good food, but then I’m out of commission for one or two days afterward. I want to do so much more than my CFS allows. It’s anguishing.” She continues, “And as I age I also worry about what’s going to happen to my son and his CFS. Who will care for him when I no longer can?”

Even for a self-sufficient CFS patient, ambiguity exists about how to plan for the future. Hedrick explains, “Without benefit of good longitudinal data on the course of this illness, I wonder when I should be planning on leaving my house and finding a less burdensome environment.” She also worries about where to go once she decides to leave her current home. “Ads for ‘active-living retirement communities’ drive me batty given that I haven’t been active since age 45.”

Few resources exist to help aging CFS patients find appropriate elder care and housing. Although many retirement communities and assisted living programs are equipped to handle health limitations, finding a facility with specific knowledge and

experience dealing with the unique needs of CFS may be a challenge. Even the most extensive online senior living Web sites that provide customizable searches don’t include CFS in the long list of ailments and health issues a user can employ to refine their search. It’s likely that some CFS education and a frank discussion of needs will be required to determine whether a facility or program is a good fit.

For many people with CFS, retirement planning and extended care are further complicated by limited financial means stemming from years of being disabled.

Unfortunately, it’s not just the patients and caregivers who are aging and facing retirement. Many of the first doctors to recognize, legitimize and treat CFS are starting to retire or scale back their work load. Though these physicians have served the CFS community steadfastly for years and deserve to enjoy retirement, many CFS patients will certainly miss their care. And a new generation of CFS experts hasn’t yet been identified.

Aside from being another product of the aging CFS community, the retirement of the early CFS-focused physicians points to one more reason why it’s so important to educate the medical community about the illness. The more doctors, nurses, physician assistants and other health care professionals learn about CFS, the more

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likely that CFS patients will be able to find knowledgeable care wherever they seek it.

The medical

What are some of the special medical considerations when it comes to CFS and aging? According to Dr. Bateman, “The principles of geriatrics apply to seniors with or without CFS. Be more careful with medications. Use lower doses. Be aware of side effects and drug interactions.”

Dr. Klimas agrees and adds, “Most of my patients with CFS are drug sensitive to begin with, so I find I worry more about drug interactions and toxicity.” She offers the example of how statin medications for cholesterol can cause muscle pain and how diuretics for blood pressure can lower an already low blood volume associated with CFS.

Dr. Klimas also notes that some medications used in the treatment of CFS can be more problematic in older patients—particularly sleep medications that can cause excessive sedation and symptoms the following day. She shares, “I just saw a patient that was bedbound with what we thought was a CFS relapse, but was actually a side effect of her Xyrem dosage. Dropping the dose released her from a frightening daytime lethargy.”

Both Dr. Klimas and Dr. Bateman describe the importance of paying attention to effects from the duration of CFS in older patients. These effects include deconditioning from lack of activity, osteoporosis and vitamin deficiencies. Says Dr. Klimas, “Deconditioning for many years can cause a variety of problems. Though the CFS patient has limited capacity, some light exercise every day is key.”

Says Dr. Bateman, “I try to increase my vigilance across the board as my patients age—medication monitoring, lab screening, symptom management, physical conditioning, finances, support systems . . . I’m more attentive to monitoring everything since so many additional things can go wrong.”

The outlook

As we begin the third decade in the history of this illness, aging is an issue more and more people with CFS are facing. Even the children from the noted 1984 Lyndonville outbreak of CFS are now in their 30s.

As in the rest of society, old age complicates many aspects of life, from physical to emotional to practical; and as usual, the challenge is further increased if you have CFS.

Hedrick shares, “It seems that just when I’ve developed a ‘paced’

lifestyle that works for me, along comes old age and all its attendant difficulties that require revisiting the decisions I previously made . . . But I’m in the process of figuring out how to deal with the new challenges.”

Trussler, having reassessed some of his priorities now that he’s older, shares his outlook. “Over the past 23 years I’ve been involved in 12 experimental programs to treat my CFS, but none has helped. As I’m approaching 70, I’ve come to the conclusion that I don’t want to do that any more. That doesn’t mean I’ve given up on life—far from it. Life is very meaningful, even if more difficult.”

As Hedrick, Trussler, Neely and other people with CFS navigate their way into and through their senior years, increased attention to the role of aging may help make the way a little smoother. The CFS community, with its advocacy, support, education and research, owes it to itself and its aging members to keep the subject in view. ■

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