

## TESTIMONY

KAREN M. CAMPBELL

Dear members of CFSAC:

You have heard ad nauseam about the effects of the disease and the state of research, so I won't bore you with more of the same.

I'd like to address a different topic that is just as difficult for patients: basic survival.

A friend of mine, a medically-retired nurse, scrapes by on \$650 a month in Disability benefits. Where I live, that wouldn't even cover rent on a studio apartment.

Even though her income is far below the official government poverty level, she was told she was only eligible for \$10 a month in food stamps – not worth the gas to drive to the far end of the county to apply for it. Someone passed along to me information on two charity programs that provide food boxes, however, neither will put together a special box for someone with food allergies (suggesting that the recipient could donate back all the food that they can't eat, even if that's almost the entire box!), and one of the charities will only provide one food box per car – which means that anyone who is dependent on others to drive them will not be able to get any food if they ride to the location with someone else who is also there to pick up food. If you're paying cab fare to get there, you would do better to spend the same amount of cash at the grocery and get food that you know you can eat.

Making matters worse, many patients have mold issues or chemical sensitivities, so the sort of low-rent apartment they could afford on Disability benefits is precisely the sort that will make them sicker.

Personally, I have problems with paint fumes and carpet outgassing – I couldn't move into a newly-renovated apartment without being horribly ill for the first six weeks, and most landlords won't hold an apartment empty for that long unless you're paying the rent ... and with people on Disability barely surviving in the first place, they aren't going to be able to pay rent on two apartments for six weeks until the chemicals have dispersed.

What we need is safe-for-us housing at affordable rents. Constructed with “green” materials so there are no chemicals to make us sicker, and located in a climate warm enough so we don't spend 10 months a year bedridden from the annual winter exacerbation, as some of my northern friends do. Surely there is some government-owned land in the South or Southwest that could be used to create patient-centered villages for communal living.

Add an on-site infirmary with staff trained in CFS, so that patients don't have to travel too far for appropriate basic medical care, and, in fact, the staff can make house calls because all their patients live within a radius of a few hundred yards of the clinic.

Ideally, like “age in place” senior complexes, a combination of single-story houses for those patients able to do a little puttering in the yard, independent living apartments for those who aren't interested in gardening, and assisted living arrangements for those who are effectively bedbound.

An on-site kitchen could prepare healthy meals for those who need them, and provide a central location for residents to pick up fresh local produce delivered by local farmers so that the patients don't need to waste energy going all the way to a grocery store every few days to get fresh fruit and vegetables.

And trained, reliable housekeeping staff available for those tasks that patients can't or shouldn't do themselves. I've tried a number of hired

cleaners over the past 11 years. The agency cleaners walk in and hand me a brochure explaining that their workers' comp insurance carrier will not allow them to do the very tasks that I need help with; they're allowed to dust and mop, the things I can do for myself and don't need to pay anyone to do, but are not allowed to carry boxes to the basement or stand on a chair to clean the ceiling fans. The independent cleaners who have no such corporate-enforced constraints quickly prove why they're not working for an agency – either they're too irresponsible to show up without me phoning to remind them “tomorrow's Tuesday” or they don't actually clean once they get here.

One possibility that should be considered is to build apartments near medical schools and nursing schools, and offer a few recommended students free rent in exchange for “being on call” to deal with whatever minor medical issues the CFS patients might need help with.

This not only gives the students hands-on experience with treating basic issues, but, more importantly, by exposing them to the day-to-day lives of CFS patients, will help to overcome the stereotypes that we do nothing but lie on the couch, watching TV and eating bonbons. Most CFS patients I know – even the bedridden ones – try to accomplish something during the day: writing, knitting, perhaps a little cooking, making phone calls to cheer up other patients... We don't sit around all day crying and feeling sorry for ourselves, begging for sympathy, as some people seem to believe we do.

Knowing first-hand that patients will struggle to do things they physically are not capable of may make the students-in-residence more sympathetic medical professionals, not as inclined to just tell patients to take anti-depressants and get more exercise because they have a mistaken perception of what's wrong with us.

There may not be a treatment or a cure in the near future, but there ARE things that could be done to make life easier for patients. This is just one suggestion.