



From the Living with FSHD series
Disability insurance and the decision to stop working

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As FSHD progresses, some people find that reduced stamina, growing fatigue, and intractable physical problems make it increasingly difficult to continue working. They want to continue but “hit a wall” in their ability to do their job, and they don’t want to risk accelerating the progression of their FSHD by continuing to work in the face of mounting difficulties. The decision to stop working and “go on disability” is one of the most agonizingly difficult decisions one ever has to make—emotionally, practically, and financially.

Making the right decision requires advice and support from one’s spouse or partner, other family members, doctors, and other professionals who might include occupational therapists, social workers, psychologists or psychiatrists, and lawyers. Taking the first step—talking candidly with your spouse or partner, family, and doctor about your difficulties at work—can be especially hard.

Well before deciding to stop working, you must ask your employer for a “reasonable accommodation.” The Americans with Disabilities Act requires employers to provide a reasonable accommodation for employees with disabilities. The employer must provide an accommodation, but it’s up to the employee to ask. Accommodations could include an evaluation by an occupational therapist or workplace ergonomics expert, assistive technology, changes in furniture, a change in job duties, reduced hours, more frequent breaks, and unpaid time off. But as people’s FSHD progresses, accommodations that once enabled them to work may no longer do so. They should consider going on disability only after having determined that no further accommodations are available or feasible.

Should you tell your employer that you are considering applying for disability? Obviously, the answer to this question depends on your individual circumstances, but, in general, it’s more prudent not to tell your employer until you’ve made your decision and have your documentation ready. If you consult a lawyer (see below), it’s advisable to discuss this question with him or her.

There are two types of disability insurance: Social Security Disability Insurance (SSDI), a program of the Social Security Administration, and long-term disability insurance (LTD), which is issued by insurance companies. Everyone who works and pays Social Security taxes is automatically enrolled in SSDI. Because SSDI will not provide nearly as much income as working, supplementing it with an LTD policy can significantly increase one’s disability income. But it’s not easy to get LTD insurance.

A group LTD policy, where individual underwriting is not required, can be one of the most valuable benefits provided by employers, but many don’t offer it. It may also be possible to enroll in a group LTD policy through a professional organization, alumni association, religious organization, or other group. Individual LTD policies are available but require medical underwriting, making it



difficult for most people with FSHD to qualify. Since a group LTD policy does not require underwriting, people with FSHD who have an opportunity to obtain coverage under a group LTD policy are well advised to seize that opportunity. If people have an opportunity to purchase an individual policy because their FSHD symptoms are mild, this is also an opportunity to be seized.

Central to disability insurance is the definition of "disability." SSDI has a strict, narrow definition of disability, known as an "any occupation" definition. People are not considered disabled if they merely cannot do their current job; they must not be able to perform any other job for which their age, education, training, work experience, and transferable skills would otherwise qualify them. Along with other essential information, the Social Security Administration website has a step-by-step explanation of this definition (<http://www.ssa.gov/dibplan/dqualify4.htm>). A comprehensive brochure about SSDI can be downloaded from the website (www.ssa.gov).

LTD policies vary in their definition of disability, ranging from "any occupation" to a more liberal "own occupation" definition, which means people are considered disabled if they are no longer able to perform their current occupation. For example, truck drivers may no longer be able to drive a truck but may be qualified by training and experience for office work; under an "any occupation" definition, they are not disabled, while under an "own occupation" definition, they are. Surgeons who can no longer perform surgery but are able to teach would be considered disabled under an "own occupation" definition but not under "any occupation."

The amount of the payment is critical. SSDI is based on average earnings over one's career, provides a modest fraction of the income earned while working, and has annual cost-of-living increases. LTD policies typically provide 60 percent or two-thirds of the income earned immediately before going on disability (subject to a maximum amount) and may or may not provide inflation protection. Some smaller LTD policies provide a fixed payment amount.

Many LTD policies require the claimant to also apply for SSDI. These policies offset (subtract) the amount of Social Security disability income from the amount they pay; however, cost-of-living increases in Social Security disability income typically are not subtracted. Even if you have a generous LTD policy, there are some advantages of making a claim for SSDI. Besides the fact that SSDI cost-of-living increases aren't subtracted from LTD payments, there are possible tax advantages and, very importantly, eligibility for Medicare (see below).

Another important element is the duration of disability payments. SSDI payments continue until normal retirement age (65 or older, depending on the year of birth); thereafter, they are converted to regular Social Security retirement benefits in the same amount. LTD policies vary, ranging from payments for a specified number of years to payments through normal retirement age.

SSDI and LTD insurance both have waiting periods before payments are made. SSDI payments begin on the sixth full month after the date disability began. LTD policies vary in their waiting periods. It's important, therefore, to consider how to replace your lost income, and how to



reduce your expenses if need be, during the waiting period. Some employers provide short-term disability benefits to cover part or all of the gap. Some states, including California, have universal short-term disability insurance programs, funded through payroll deductions, that provide some income before SSDI and LTD payments kick in.

It is impossible to overstate the importance of getting professional advice and support. The Social Security Administration and insurance company determinations (both initial and ongoing) about whether or not you are unable to work because of your FSHD will be based on a certification from your doctor and a review of your medical records. Having a doctor who knows you well and has been familiar with your FSHD for a long time is extremely advantageous in helping you consider such a difficult decision, and because he or she will have much greater credibility with the Social Security Administration and the insurance company than a doctor who has known you only a short time or who is not very knowledgeable about muscular dystrophy.

Before deciding to apply for disability, it is highly advisable to consult a lawyer who is an expert in disability insurance law—a specialized area of law that is separate from the field of disability civil rights law. (The latter is concerned with discrimination in employment, physical access, government programs, etc.) Lawyers who are expert in SSDI tend not to be familiar with LTD law, and vice versa. If you don't have LTD coverage, you would need to consult only with an SSDI lawyer. If you have an LTD policy, it is advisable to consult with two lawyers—one for SSDI and one for LTD. Disability insurance lawyers can advise you about eligibility, what documentation you need, how to fill out the claim forms, policy terms (in the case of LTD), and how to deal with your employer, the Social Security Administration, and your LTD carrier.

Your local bar association probably has a referral service where you can find lawyers with this expertise. Nolo, a publisher of self-help legal guides, publishes a guide to Social Security disability (www.nolo.com). This book is a good place to start, but the fees for a few hours of legal advice before filing a claim will be money well spent.

Taxes and medical insurance must be considered. Federal income tax treatment of Social Security benefits is complex and depends on the overall level of income. In many states, including California, SSDI payments and Social Security retirement benefits are exempt from state income taxes. Generally, federal and state taxability of LTD payments depends on who paid the insurance premium—payments are usually taxable if the employer paid the premium and tax exempt if the employee paid it. Also, if you are receiving LTD payments, you may still be eligible to contribute to an IRA; eligibility depends on the amount and nature of your LTD payments. The IRS website (www.irs.gov) has comprehensive information. See Publication 907 (Tax Highlights for Persons with Disabilities), Publication 575 (Pension and Annuity Income), and Publication 590 (Individual Retirement Arrangements).

Everyone who receives SSDI payments is automatically eligible for Medicare beginning two years after the date of disability. “Traditional” or “original” Medicare is fee-for-service and includes



Parts A and B. Medicare Part A (hospital insurance) is free for most people. Most have to pay for Part B (medical insurance), and premiums are deducted from monthly SSDI payments. An alternative to traditional Medicare is Medicare Advantage, which is typically provided as an HMO or PPO.

Parts A and B do not cover everything, so most people on traditional Medicare also choose to get Medicare supplemental insurance—Medigap—which is provided by private insurance companies and paid for by the insured. People who are on Medicare because they are receiving retirement benefits have an automatic right to purchase Medigap insurance from any company serving their geographic area. But the situation is different for those on Medicare because of disability. State law, not federal, governs whether or not private insurers are required to offer Medigap insurance for people who are on Medicare because of disability; some states (including California) require it, and others do not.

One must also consider how to maintain health insurance coverage from the last day of work until the beginning of Medicare coverage. Possible options include continuation of your employer’s insurance through COBRA (although this can be expensive), obtaining insurance through your spouse’s employer, and coverage under the Affordable Care Act.

California Health Advocates (CHA) (www.cahealthadvocates.org) and the Kaiser Family Foundation (KFF) (www.kff.org) offer comprehensive information about Medicare. Although CHA is geared toward California consumers, much of the information applies to residents of all states. Besides information about Medicare, KFF has lots of useful information about health insurance and healthcare policy in general.

Working gives us creative fulfillment, intellectual stimulation, social camaraderie, and a sense of accomplishment. It fills our waking hours and is an important part of our identity. Being forced to stop working because of FSHD is difficult, emotionally and socially. It is one of the biggest losses caused by our disease. Mental health professionals and social workers can greatly help those who are faced with the decision to stop working.

Finally, if you do decide it’s time to stop working, it’s also time to start planning your post-work life. Don’t put this off until after your disability claim is settled. There are many fulfilling, productive ways to spend your time without overdoing it physically. One door closes and another opens.

*Author’s note: This article is provided for general informational and educational purposes only. **The FSHD Society does not provide medical, legal, financial, or other advice or recommendations.** People who are considering filing a claim for disability should consult their professional advisors. Moreover, the information in this article is subject to change.*