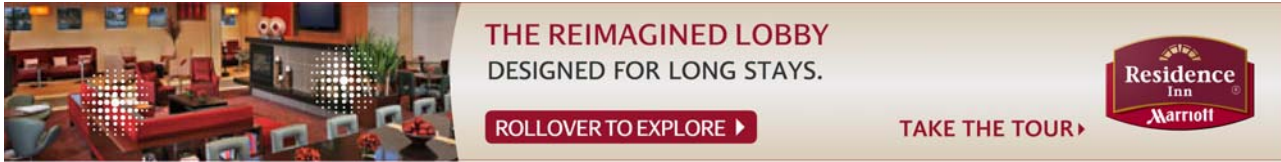


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Chemo Side Effects: Is 'Chemo Brain' a Disability Under the Americans With Disabilities Act?

I can't even begin to tell you the number of people who have contacted me since I co-authored "Your Brain After Chemo: A Practical Guide to Lifting the Fog and Getting Back Your Focus" (with Dr. Dan Silverman at UCLA). They say they are debilitated since cancer treatment; they struggle with attention and memory. They speak of issues with word retrieval, multitasking or following the thread of a conversation.

Chemotherapy may have cured them -- and they rejoice in that -- but they mourn the loss of the person they used to be. And they worry. Will these cognitive deficits interfere with their ability to function at home and on the job? Will they be able to provide for their families?

To find out about workplace protections, I interviewed Joanna Morales, an attorney and the director of the Cancer Legal Resource Center (CLRC), a national, joint program of the Disability Rights Legal Center and Loyola Law School Los Angeles. The CLRC provides free information and resources on cancer-related legal issues to cancer survivors, caregivers, health care professionals, employers and others coping with cancer. I hope you find the information helpful.

Q&A With Joanna Morales

ID: What is the legal standard to qualify for a disability?

JM: To have a disability under the ADA's definition of disability, you have to have a physical or mental impairment that substantially limits major life activities, have a history of an impairment, or be regarded as having an impairment.

Major life activities have traditionally been things like walking, talking, eating, breathing and working. But when the ADA amendments passed in 2008, they specifically delineated some additional major life activities that made it easier for someone with cancer to actually use the ADA's protections.

And those activities include sleeping, concentrating, thinking, communicating and operation of major bodily functions.

So, particularly the concentrating and thinking activities really speak to the side effects from treatment that we often call "chemo brain."

This really makes it much easier to argue that the effects of chemo brain are substantially limiting major life activities. That by itself has made it easier for people with cancer to use the ADA's protections.

Now what that means is you really get two types of protections in the employment arena. One is that you're protected against discrimination. And two is that you get access to reasonable accommodations.

ID: What would those accommodations be?

JM: Reasonable accommodations are things that could accommodate you in the workplace if you are experiencing chemo brain. That might mean having a note taker in a meeting or maybe your employer would buy you a tape recorder so that you can tape record meetings to help you remember what was agreed upon in that meeting.

That might also mean help with organization of your workspace or providing things that are going to make the concentrating piece, or sometimes the memory piece, easier for you in the work environment. So maybe your employer might provide access to a hand-held electronic device such as a PDA (personal digital assistant) so that you can take notes and have access to your contacts, calendar and to-do list all in the same place.

So there are lots of pretty simple things that can be reasonable accommodations and can ease your experience with chemo brain and are relatively easy for an employer to provide.

ID: But "chemo brain" may not be severe in every case.

JM: That's correct. We can never say across the board that everyone who experiences chemo brain has a disability, or even that everyone who has cancer has a disability. That analysis is always done on a case-by-case basis. It's how your particular diagnosis is affecting your particular major life activities and whether or not that effect is substantial.

ID: Who makes that evaluation?

JM: Eventually, if it were to go to that point, it would be a court. So you would hope that you wouldn't have to go to court to make the argument that you do have a qualifying disability.

But initially if you're having that conversation with your employer, your employer is going to get that information from your health care team. All you may need is just a letter from a health care professional that speaks to your particular medical condition and your ability to function in the context of major life activities.

ID: So the employee makes a request for an accommodation. What happens next?

JM: Once a request for an accommodation is made, the employer and employee are supposed to engage in what is called the "interactive process," so that there is a discussion about the accommodations that are being requested and if there are perhaps alternative accommodations that would work better. It's supposed to be a back-and-forth dialogue. But ultimately the employee is supposed to get an accommodation.

Now if along the way the employee doesn't feel as if he's getting heard, there are different options. One is mediating with the employer, filing a complaint with the state fair employment agency or the federal Equal Employment Opportunity Commission (EEOC) or pursuing legal representation. That can

be something as simple as a lawyer writing a letter on behalf of the employee, reminding the employer of their obligations under the law and what the employee is asking for, or it can be much more aggressive depending on the circumstances.

ID: What if you just can't work anymore even with accommodations?

JM: Then disability benefits are a pretty good option if you qualify for them. There are lots of different types of disability benefits. There are some states that have state disability insurance programs. There are employers who offer short and long-term disability insurance plans through your work. You can also buy your own private short or long-term disability insurance plan. There are also the two federal long-term disability insurance plans available through the Social Security Administration: Social Security Disability Insurance (SSDI), and Supplemental Security Income (SSI).

ID: What are the qualifications for each one?

JM: The qualifications for each are very different. In California, for example, the California State Disability Insurance (SDI) plan has the lowest standard of disability. You just have to have a medical condition that is keeping you out of work at least eight days. That's probably the simplest definition of disability.

For SSI and SSDI, you must have a disability that's expected to last longer than a year and is keeping you from substantial gainful activity.

And then for private plans, whether they are something you purchase yourself, or are purchased through an employer, the contract is going to define disability and the terms of the policy.

ID: What are the specific disability benefits for each program?

JM: It depends on the program. In California, SDI will pay approximately 55% of your income while you were working. It's a formula. They look back over a certain number of quarters of what you were making and then it's 55% of that amount.

Then there are the two federal long-term programs. SSI is a flat monthly rate and SSDI pays benefits based on what you have paid into the Social Security system over your work history.

ID: What if you don't work? Perhaps you're retired or you're a stay-at-home parent where functioning at home is difficult. What then?

JM: If you aren't working, but are in a situation where you are experiencing chemo brain and maybe other long-term side effects from treatment such as fatigue or depression you may qualify for other assistance programs. Getting assistance around the house, whether it be paying bills or daily chores, can bring up a number of different areas of the law. So if it's financial management, perhaps you would want to consider a power of attorney for financial affairs. If it's to keep track of the day-to-day things, you may be able to qualify for in-home support services, depending on your income and whether you qualify for that program.

ID: Where does that assistance come from?

JM: In-Home Support Services (IHSS) is a program related to Medicaid (Medi-Cal in California) that is available in some states (contact the Cancer Legal Resource Center for state information). And it's specifically available to assist people who would prefer to stay in their own home, rather than be forced into moving to an institutional environment like a nursing home. And they can have someone come into their home and help them.

IHSS will do an assessment to see what your capacity is and what you need help with and how many hours per week you require assistance, then they come up with a formula and they will pay for part or all of that care. But you do need to have an income level that qualifies you for the Medicaid

program in your state.

ID: How can people reach you if they have questions?

JM: People can contact our national, toll-free telephone assistance line at 866-THE-CLRC (866-843-2572) or visit our website at www.CancerLegalResourceCenter.org for more information about these topics and other cancer-related legal issues.

To learn more about "Your Brain After Chemo: A Practical Guide to Lifting the Fog and Getting Back Your Focus" by Dan Silverman, MD, PhD. and Idelle Davidson, visit www.YourBrainAfterChemo.com or find the book on Amazon.

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