

Summary – To Work or Not to Work

Lee Rachel Jurman

Transitions

The decision to transition from full time work to part time work or to no work is highly charged. The common assumption among most professionals and patients alike is that work is good and that people want to work and need to work in order to get benefits. Often the decision that is made first is to remain at work and try accommodations in the workplace first - then leave work in stages if it becomes necessary. This approach follows the advice of "planning for the worst but living the best," and gives as much control as possible to the patient.

Preparing for the future

Though we cannot predict the future, we can prepare for it. Some important questions to ask when considering to work or not are these:

- What has changed for me?
- What can I do?
- What can I no longer do?
- What do I know about the future?

To answer these questions, one has to take an honest look at his/her own personal situation. And because we are often not as objective as we should be, help should be obtained to do this "taking stock of things." Family, friends and professionals are all able to help in this task.

Considerations

What are some considerations? Ask the following: Can I make myself sicker by working? If yes, then you should make a change. Have I put my job in jeopardy? If yes, then again, a change is needed. Do not wait for others to make this choice for you (ie, employers); you can make the decision yourself.

There are obviously huge gains for you by working - self esteem, income, insurance, professional identity, etc. And likewise, there are consequences if you cannot work - isolation, loss of self worth, loss of income, and change in family role. But not working may give you an opportunity to do new things within the limits of your chronic illness.

So ask:

- What is the price of working?
- Where have you been and where are you now?
- What is coming in the future?
- How many hours/day, days/week can you sustain?
- How much physical exertion does work require from you?
- How much mental exertion/stress?

Try to consider all of these as you make the decision to work or not. Think about your own individual stamina and pain level as well as how much physical, mental and emotional stress you can handle. And, what happens when you do too much? Can you pace yourself in your current job? Do you need to travel and does this add stress? Do you need breaks during the day or do you need a day off each week or several days each month? Consider all of these as you consider whether to work or not.

Assessing Your Skills

Once you have answered the questions above, you still need to assess your own skill set. Can you do all the tasks required by your present job? Can you break down the skills and look at what you can do and what you need help with? What can you do differently? Can you still do the job, but do less of it (ie, be less productive or take longer to complete?). If you cannot do the job, then you need to stop and look at new skills which you can develop so that you can continue to work and be active. Don't be afraid to change - no longer do people stay at the same job for 30 years!

Accommodations

The Americans with Disabilities Act provides accessibility for all disabled persons. Title I of the Act protects persons with disabilities in the workplace who have substantial limits but can do the essential functions of the job with reasonable adjustments which are not an undue hardship to the employer. For example, someone who has a wrist injury can request that someone else do the data entry portion of the disabled persons job. Other examples might be an electric door opener for someone in a wheelchair or the need for written instructions for someone with attention deficit disorder.

Communicating with Employers

How do you communicate with employers about your disabilities and need for accommodations. First, use the idea of WIIFM (*What's in it for me*) approach. They will have a better employee and better outcome if accommodations are provided which meet your needs. The focus of the employer is to get the job done and that is what you need to stress. So, focus on your job performance and only specific health issues that effect this (ie, fatigue or muscle weakness), not all of your symptoms. This would be too much and is unnecessary. Also, keep a paper trail of all discussions and send a follow up email to employer/supervisor afterwards to be sure you both agree to all the points discussed.

You have to assume that you are educating your employer about your disease. This is especially true for Mitochondrial Disease since so few people know about it. Your discussions should begin with your supervisor to discuss the tasks of the job. The HR professionals will know the policies but may not have actually gone through the process of providing an accommodation before, so don't assume that they will know how to do this easily. You may also need to use a case worker from your insurance company if you are applying for benefits.

Decisions

You decide that you can no longer do this particular job - do you quit or go out on leave? Which is more beneficial? Generally it is better to go out on leave. For example, a professional person recently making about \$100,000 a year decided that he could no longer do his job and his neurologist recommended that he find another job. If he left entirely, he would have lost all benefits. Instead, if he went out on long or short term disability, he could retain his benefits, and he could look for a part time job. Individuals must consider not just the loss in income when they leave a job but also the loss in benefits. And this means, you must be knowledgeable about your benefits! Make sure you have copies of all medical documents. This process can be overwhelming, so consider getting help.

Getting Benefits

Benefits in the US come from either the employer or the government (Canada & UK may be slightly different). The Family Medical Leave Act offers up to 12 weeks per year

of unpaid leave if you have worked the previous 12 months. Though this is unpaid, it does protect your job and pays your benefits (ie, health insurance). Short term disability provides 6-12 months of full or part pay and long term disability may provide about 60-65% of your base salary. These disability plans are government based and depending on the employer may or may not provide health benefits, so you will need to inquire. If you have no health benefits through your employer once you are on leave, you may apply for COBRA - here you must pay 100% of your health insurance but can keep the same insurance plan you had while employed. The current federal government stimulus package may provide some help here which can decrease the amount you have to pay for COBRA. In all cases, you will need lots of documentation from all your medical care givers - so keep good records.

There also are government cash benefits through Social Security Disability Insurance (SSDI). If you can prove that you are/have been severely disabled for 12 months or have a terminal diagnosis and are, therefore, in either, case too disabled to work and make no more than \$940 month (current amount), then you are eligible. Eligibility for Social Security benefits depends on your work history so you may need to consult insurance or disability experts to help you with this. For example, those who have worked in government jobs and paid into government pension plans may not be eligible. Each year you should receive a statement from Social Security which indicates your benefits - be sure to save this! Supplemental Social Security Insurance (SSSI) provides benefits for those who qualify under an income and asset standard. Generally persons who qualify here are "deemed poor" by government definitions.

Medicare is a federal program which can provide health care for senior citizens who are entitled to Social Security benefits and to the disabled through SSDI 2 1/2 years after the onset of the disability. Medicaid is a state/federal partnership which differs from state to state but provides health care for those who fall below a certain income level. In some states you can get Medicaid if you are a working adult with a disability.

When applying for SS benefits, be sure to describe the functional issues - that is what they will be considering. Document the symptoms, describe what a typical day is like for you, or list your symptoms. Also list the various treatments you have pursued as well as the prognosis. Do not rely simply on the medical diagnosis.

How do you go about applying for these benefits? You can apply for SS disability on line. Have other people review your application for you to be sure it is clear and accurate. You may need to get a consultant. Gather all your medical records yourself from all your providers. If you haven't worked for the past 5 years, then you may need help to obtaining benefits. You may even need to seek an ERISA lawyer to assist you when you are trying to get governmental benefits.

Summary

To work or not to work is a difficult question. Think outside of the box when making this decision. In general when looking for a new job, it is probably better to self identify yourself as someone with a particular disability who may need accommodations - but stress what you can do. Consider volunteer work and doing what you love. Consider the quality of your time. Take care of yourself and prevent exacerbations of your illness. Maintain control of the situation and maintain the decision making - don't let others make the decision for you!

Summary by Joanne Turco, RN, MS & Cristy Balcells RN MSN

Useful Links related to this topic:

Health Insurance:

A Consumer Guide to Handling Disputes with Your Employer or Private Health Plan, Kaiser Family Foundation, <http://www.kff.org/consumer/guide/>

How to work with your managed health care, understand coverage and appeals process.

A Family Caregivers Guide to Hospital Discharge Planning, Hunt, Gail Gibson, and Levine, Carol, National Alliance for Caregiving, United Hospital Fund of NY and MetLife Foundation, 2002,

http://www.uhfnyc.org/pubs-stories3220/pubs-stories_show.htm?doc_id=113388

COBRA (Consolidated Omnibus Budget Reconciliation Act)

<http://www.dol.gov/dol/topic/health-plans/cobra.htm>

Family and Medical Leave Act (FMLA): History, Benefits, Coverage, Laws, Special Rules, Definitions, Health Conditions, Enforcement and more

<http://krilloil.com/blog/fmla/>

U.S. federal law giving workers and their families who lose their health benefits the right to choose to continue group health benefits provided by their group health plan for limited periods of time under certain circumstances.

COBRA Continuation Coverage Assistance Under The American Recovery And Reinvestment Act, 2009, <http://www.dol.gov/ebsa/COBRA.html>

Eligible individuals pay only 35 percent of their COBRA premiums and the remaining 65 percent is reimbursed to the coverage provider through a tax credit.

HIPAA (Health Insurance Portability and Accountability Act)

<http://www.dol.gov/dol/topic/health-plans/portability.htm>

U.S. federal law governing group health insurance plans, privacy of medical information, and limits exclusions of coverage due to preexisting conditions.

Medicaid,

<http://www.cms.hhs.gov/MedicaidGenInfo/Downloads/MedicaidAtAGlance2005.pdf>

U.S. federal program administered by each state, providing health insurance for low income individuals who meet specific criteria. Check your state's Medicaid program for specific information.

Medicare, www.Medicare.gov,

U.S. government website that provides information on Medicare benefits, prescription discount cards, home health care agencies, nursing homes, and other Medicare programs.

Medicare Rights Center, www.medicarerights.org, hotline 800-333-4114

Medicare Rights Center (MRC) is the largest independent source of Medicare information and assistance in the United States. Clear information for consumers.

Needy Meds, www.needymeds.com/, 215-625-9609

Non-profit agency that provides information on prescription drug assistance programs.

Cash and Food Benefits:

Social Security Administration www.socialsecurity.gov

800-772-1213, 800-325-0778 (TTY)

Website of US Social Security Administration. SSA pays Social Security retirement, disability, and survivors' benefits to workers and their families and administers the SSI program. Provides information, publications and forms for all programs.

SNAP (Supplemental Nutrition Assistance Program), formerly Food Stamps, <http://www.fns.usda.gov/FSP/>, U.S. federal program providing debit card for the purchase of food to low income and asset households.
Employment Related

ADA Title 1 <http://www.eeoc.gov/laws/statutes/ada.cfm>
U.S. federal law. Overview and links to information about Title 1, employment.

ADA Amendments Act of 2008, JAN, <http://www.jan.wvu.edu/bulletins/adaaa1.htm>
Clear summary of ADA as of January 2009

ADA as Amended in 2008, US Dept. of Justice, <http://www.ada.gov/pubs/adastatute08.htm>, Current U.S. regulations, as amended.

DBTAC, <http://www.adata.org/index.html>

The DBTAC is a national network of 10 regional DBTAC/ADA Centers that provide information, referrals, resources and training to individuals and professionals on the ADA.

FMLA (Family and Medical Leave Act) Amended January 2008, <http://www.dol.gov/esa/whd/fmla/fmlaAmended.htm>
Current regulations of the U.S. federal Family and Medical Leave Act.

Job Accommodation Network <http://www.jan.wvu.edu/>
800-526-7234 (V/TTY)

JAN is free consulting service designed to increase the employability of people with disabilities by: 1) providing individualized worksite accommodations solutions, 2) providing technical assistance regarding the ADA and other disability related legislation, and 3) educating callers about self-employment options.

One-Stop Career Centers, <http://www.servicelocator.org/>
Link to local career centers in the U.S. which provide job seekers and employers assistance with job search, training resources, and issues around economic development.

Vocational Rehabilitation Agencies-State Listing, <http://www.jan.wvu.edu/cgi-win/TypeQuery.exe?902>
U.S. state vocational rehabilitation agencies assist individuals with disabilities who are pursuing meaningful careers with training, education, and funding.

Workers' Compensations-State Listing, <http://www.dol.gov/esa/owcp/dfec/regs/compliance/wc.htm>

U.S. workers' compensation is for employees who are injured on the job. Each state has its own workers' compensation statute.

Working with Chronic Illness, Rosalind Joffe, <http://workingwithchronicillness.com/>
Rosalind is a coach living with chronic illnesses who has a blog and e-newsletter about working with chronic illnesses. She lives in MA, and coaches people via phone. Rosalind@WorkingWithChronicIllness.com

Other Benefits:

Benefits CheckUp, National Council on Aging, https://www.benefitscheckup.org/moreprograms.cfm?partner_id=0
Calculator that identifies public programs for people ages 55 and over that may pay for some of their costs of prescription drugs, health care, utilities, and other essential items or services.

U.S. Department of Veterans Affairs, <http://www.va.gov/>
Information about benefits, health care, other resources for U.S. veterans.