

# To Work or Not to Work with Mitochondrial Disease

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**P E R S O N A L**  
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# Take Stock

- What's changed or changing for you?
- What does this mean about your ability to work now and in the future?
- At what point might you be too disabled to work?

# Still Working?

Ask yourself:

- Am I making myself sicker by working?
- Have I put my job in jeopardy?

Take action before the answer is “yes”

# What We Gain Through Work

- Money (pay expenses, care for family, achieve certain life style)
- Health insurance and other benefits
- Professional identity and satisfaction
- Value, making a contribution
- Experience our own competence
- Self esteem and self worth
- Social network, connections with others
- Structure and purpose

# When You Can't Work

- Loss of money and benefits
- Loss of stability
- Loss of purpose and structure
- Decreased quality of life
- Decrease in standard of living
- Lower self esteem
- Increased isolation
- Opportunities to do new things, heal
- Changes in family roles and functions
- Impact on your whole life

# The Price of Working

- Increased fatigue and stress
- Exacerbating symptoms
- Making yourself sicker
- Uneven work performance
- Can't keep up with job expectations
- Putting your job in jeopardy
- Nothing left over for family, friends or yourself

# Where are You Going: Previous Job, a Different Job, No Job?



Old You  
Previous Job

Current Abilities  
and Situation

Future Options  
and Goals

# Take Stock of Your Skills

- Can you perform your former or current job?
- Which of these tasks can you do?
- Which may you be able to do in the future?
- What about other tasks, different jobs?
- What do you need to be able to perform them?
- Can you do the “essential functions” of the job?
- Can you do them with “reasonable accommodations”?
- Do you need to acquire new skills?



# What Can Your Body and Mind Handle?

- How many hours per day can you work?
- How many days a week?
- What kind of physical exertion can you handle?
- What kind of mental exertion?
- How's your memory? Executive functioning?
- Stamina? Ability to handle stress? Pain level?
- What happens when you do too much?
- How can you pace yourself at work?
- Do you need breaks or time off?
  - how often, how long?

# “Reasonable Accommodations”

- “Qualified individual with a disability” is a person with a physical or mental impairment that substantially limits one or more major life activities who can do the essential functions of the job with or without accommodations
- Modification or adjustment to a job, employment practice or work environment
- Must not be an undue hardship to employer
- Title I, Americans with Disabilities Act (ADA)

# Examples of Physical Accommodations

- Physical changes in your workspace
  - Location, set-up of space, lighting/shades
- Adaptive equipment
  - Chair, desk, keyboard, mouse, software
  - Tools (reachers, grabbers, tape recorder)
- Someone doing specific tasks to assist you

# Examples for Time and Tasks

- Taking frequent breaks
- Flex schedule
- Telecommuting
- Reducing hours or days
- Reorganization, restructuring of tasks
- Reassignment of tasks
- Using FMLA (Family and Medical Leave Act) or sick time for scheduled medical appointments
- Change in work shift

# Examples for Processing Information

- Changes in how information is given to you
  - Written/email, verbally, on tape
- Changes in supervision structure
- Changes in meetings
  - One person talking at a time
  - Written agendas and follow up

# Communicating with Your Employer

- Focus on your job performance
- Discuss only those health issues that impact your ability to perform job.
- Tell your employer what can be done that will enable you to do your job
- Provide limited information from your doctor pertinent to what you need in accommodations
- Be clear and concise
- Don't dump your problems on employer

- Keep a paper trail of what was said/decided
- Assume you need to educate your employer about mitochondrial disease
- Talk to supervisor about accommodations
- Talk to Human Resources representative about accommodations, benefits and leave policies
- Case worker at insurance company will probably be contact for disability leave (STD, LTD) application benefits

# Job vs. Disability Leave: Money and Benefit Considerations

- Does your current employer offer short or long term disability insurance?
- If you take another job, will your income be significantly less?
- If you then become unable to work, will you have benefits similar to what you have in your current job or fewer/no benefits?
- Would you be considered “disabled” by Social Security or Long Term Disability?



# When You Can't Work

- Know your insurance options
- Communicate with appropriate personnel
- Apply for benefits
- Complete applications, provide required supporting documents for initial application and update requests
- Keep a paper trail, keep a log and follow up written communications
- Get help if you need it in the process

# Cash and Leave Benefits From Employer

- Family & Medical Leave Act (FMLA) job protection
    - Federal benefit up to 12 weeks unpaid time off/year; can use accrued sick/vacation/personal time to be paid
  - Short term disability insurance (STD) often up to 6 or 12 months at full or partial salary\*
  - Long term disability insurance (LTD) often up to 60% or 70% of base salary after STD ends\*
  - Retirement benefits, stock options
- \*Involve application with insurance companies, documentation and updates from medical providers

# Health Insurance Through Employer

- Continuation of health insurance with FMLA (employer continues to pay portion of premium)
- With STD and LTD, employer may or may not continue to pay portion of premium
- COBRA-continuation of health insurance where employee pays entire premium after terminating employee status. Premium reduction for employees who lost jobs since 9/1/08.

# Government Cash Benefits

- Social Security definition of disability:
  - severely disabled for 12 continuous months or expected to result in death, too disabled to perform “Substantial Gainful Activity” (SGA)
- Social Security Disability Insurance (SSDI):
  - based on work history, paying into Social Security, having worked long enough and recently enough (5 out of last 10 years)
- Supplement Security Income (SSI):
  - disabled and poor (limited income and assets)

# Government Health Insurance

- Medicare
  - Federal benefit based on paying into Social Security
  - Eligible after 29 months of determination of disability for SSDI (i.e., after 24 months of SSDI benefits) or at age 65
- Medicaid
  - Part federal, part state benefit. Varies by state
  - Disabled and poor (low income, usually low assets)
  - Automatic in some states with SSI
  - For uninsured working disabled adults in some states
  - Low income children and families

# Think Outside of the Box

- Create a new structure
- Find volunteer work that meets your needs
- Barter and trade for things you need
- Consider part time paid employment
- Do what you love
- Learn new things
- Have quality time with family and friends

# Guidelines

- Take great care of yourself
- Maintain your health, prevent exacerbations
- Maintain control and decision-making as much as possible
- Think about long term impact on money and benefits
- Maximize your long term income
- Keep health insurance coverage
- Keep quality of life for self and those you love

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