

Workplace Accommodation

Working with HD

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Cheryl Erwin

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Huntington's Disease Society of America

Presentation Outline

Personal accommodations for work life: lessons from positive psychology and the science of happiness

Accommodations from the inside out

Legal accommodations: what should your employer do to accommodate the individual with HD?

Americans with Disabilities Act, Rehab Act

HIPAA

Other things / Social and cultural accommodations: how can you make the world a better place for those who follow you?

Personal accommodations: what you can do

The new science of happiness: what is it and how can you promote greater happiness in your own life?

Happiness in patients leads to more effective coping strategies, improved immune function, longevity, and psychological well-being. All of these benefits have been demonstrated with scientific evidence. Laughter, it turns out, really is good medicine!

Patients who report a happy affect demonstrate increased cognitive abilities to handle complex decisions and tasks.

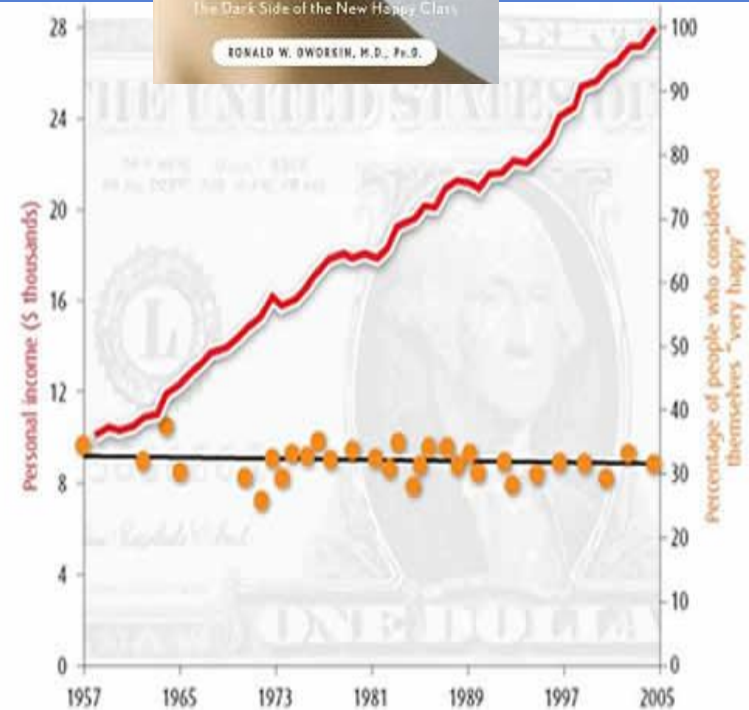
Happiness

Can you improve your happiness?

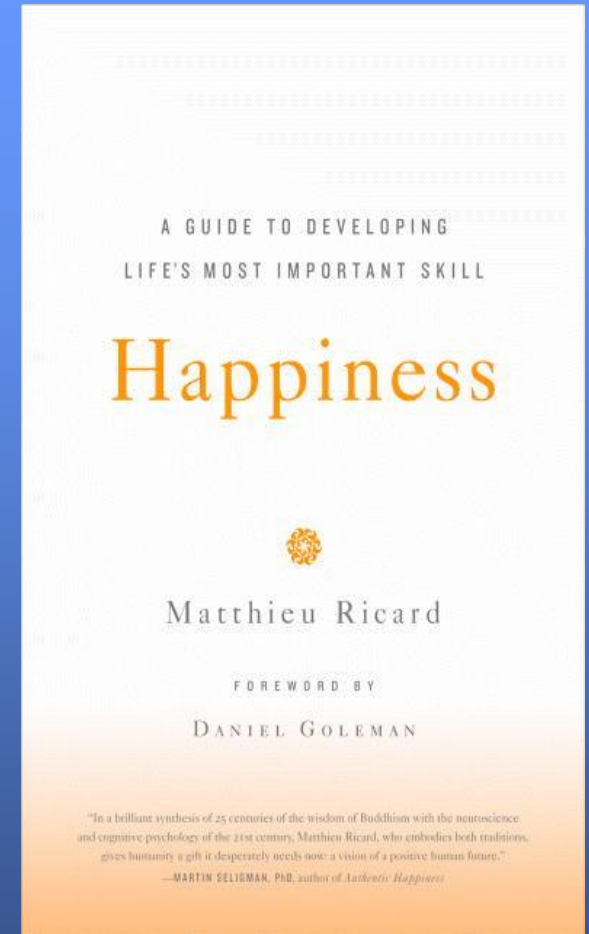
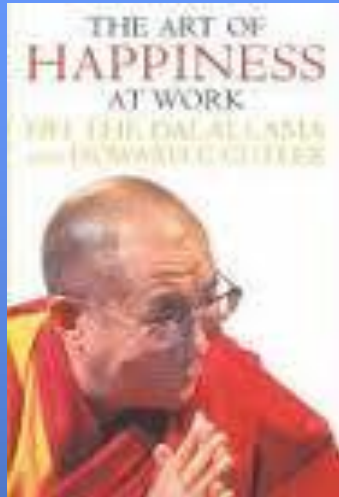
This question has been asked for thousands of years!

- An effort that must be made consciously; it takes time and dedication, and is a continual process throughout one's lifetime.
- Aristotle said "happiness depends upon ourselves...and knowing yourself is the beginning of all wisdom"
- Why do we still describe happiness as an elusive feeling that is impossible to catch.

Happiness: What does NOT work



Research into happiness



Happiness at work ... is that possible?

Mihaly Csikszentmihalyi, *Flow: The Psychology of Optimal Experience*, 1990:

A joyful life is an individual creation that cannot be copied from a recipe.

It does not seem to be true that work necessarily needs to be unpleasant. It may always have to be hard, or at least harder than doing nothing at all. But there is ample evidence that work can be enjoyable, and that indeed, it is often the most enjoyable part of life.

It is how people respond to stress that determines whether they will profit from misfortune or be miserable.

Happiness at work: a picture = 1000 words



What makes for happiness

Not just the absence of misery (you knew that)



There are two main strategies we can adopt to improve the quality of life. The first is to try making external conditions match our goals. The second is to **change how we experience external conditions** to make them fit our goals better.

- Mihaly Csikszentmihalyi

Attitudes associated with happiness

- Amusement
- Contentment
- Relief
- Excitement
- Wonder
- Elevation
- Gratitude
- Compassion



Just Smile

The universal human expression of happiness



Challenges and Skills matching = Enjoy

$$\frac{C + S}{[C - S] + I} = E$$

C = Challenges

S = Skills

E = Enjoyment

We feel most engaged with life when we are involved in mastering a challenge -- in sports, art, or simply in the everyday activities of living. This sense of enjoyment we get when our skills match high challenges is what I have called "flow".

Mihaly Csikszentmihalyi

Enjoy, translated: Forget yourself

Relationships with others need to be nourished. Work with other people, stay active, engage in recreational activities, focus on a loved one, continue discovering, learning

Look for ways to adjust your work activities to match your changing skills level

Enjoyment of your work should be a goal, sometimes achievable. Throw yourself into your work, become absorbed in it

Focus on the things you can do, and do well

After you have done your part ... what can your employer do to help out?



Americans with Disabilities Act

- Passed in 1990
- Continuously modified by case law ever since
- Four parts
 - Employment
 - Public entities (and public transportation)
 - Public accommodations (commercial facilities)
 - Telecommunications
- Title I: applies to
 - employers with more than 15 employees

Americans with Disabilities Act

Prohibits discrimination against individuals with a **disability**

If you are diagnosed with HD you meet the criteria!

- Disability is something that impairs a “major life function” including (but not limited to):
 - Caring for oneself
 - Walking
 - Seeing, hearing, speaking
 - Learning
 - Working

The ADA covers you even if you are merely “regarded as” having a disability; or if you have a history of disability

Americans with Disabilities Act

Some exceptions to the question of who is able to seek benefits under the Act:

- **Direct threat** to self or others when performing the job
 - Duration of risk
 - Nature and severity of risk
 - Likelihood of harm
- **Undue burden** on employer

Americans with Disabilities Act

What is prohibited? No discrimination against a person with a disability in:

- Hiring
- Firing
- Recruitment
- Job Assignments
- Pay differences
- Layoffs
- Training
- Promotions
- Benefits
- Other employment related activities

Americans with Disabilities Act

To be covered you must have the requisite skills

“Otherwise Qualified”

- Skills, education, experience necessary to perform the job
- Can perform essential functions with or without reasonable accommodation
 - Position exists to perform that function; or
 - Limited # of employees for that function; or
 - Function is highly specialized

Americans with Disabilities Act

A continuing obligation for employer to make **reasonable accommodation**

Will not be satisfied by a single effort

No duty to provide an employee whatever they want or prefer

Employer need only provide some reasonable accommodation

The term "**reasonable accommodation**" may include

- making existing facilities used by employees readily accessible to, and usable by, individuals with disabilities
- job restructuring, part-time or modified work schedules,
- reassignment to a vacant position
- acquisition or modification of equipment or devices
- appropriate adjustment or modifications of examinations, training materials or policies
- provision of qualified readers or interpreters

Americans with Disabilities Act

Reasonable Accommodation

The ADA may require an employer to reassign a disabled employee to a different position where the employee can no longer perform the essential functions of his or her current position.

However, reassignment is only a reasonable accommodation if a position for which the plaintiff is qualified is available.

The ADA does not require an employer to create a new position for an employee or move another employee from a previously held position in order to accommodate him or her.

Americans with Disabilities Act

How well does the ADA protect you?

American Bar Association survey in 2001:

At the EEOC level only 26.7% of plaintiffs win

Lawsuits filed by individuals only 4.3% wins (estimated)

Mental illness cases only 1.4% wins

ADA Take Home Message

It is almost always better to try and work things out

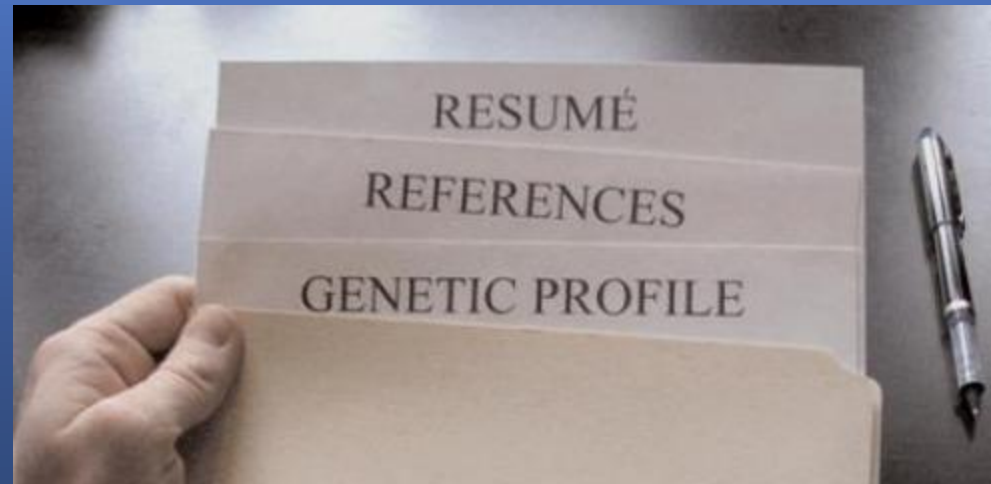
Do everything you can to resolve issues without a formal complaint

- Negotiation
- Mediation
- Arbitration

Huntington's disease as basis for disability claims: a search of published caselaw reveals no published cases!

Genetic Information Non-discrimination Act

- Prohibits discrimination in employment against individuals based solely on **genetic information**
 - No requirement of a disability
 - GINA will cover you until you are diagnosed and then the ADA will cover you



GINA

What is prohibited?

Makes it illegal to request, require or purchase genetic information

May not refuse to hire or discharge any applicant or employee due to genetic information

May not discriminate with regard to terms, conditions of employment, compensation or privileges based on genetic information

GINA Requirements

GINA may cover you if you are discriminated against due to a family member's HD

- **Genetic information** is defined as information about
 - an individual's genetic tests;
 - the genetic tests of family members of an individual; or
 - the occurrence of a disease or disorder in family members of an individual

Health Insurance Portability and Accountability Act

What is covered? Two parts – Portability and Privacy

Portability:

- Insurers may not deny coverage based on pre-existing condition (if covered within 60 days of prior policy)
- No increase in group premiums or exclusion based on health status
- Must cover within 30 days an employee who lost other coverage
- Must offer family coverage after any waiting period
- Waiting period for pre-existing condition cannot ever exceed 12 months

Health Insurance Portability and Accountability Act

What is covered? Two parts – Portability and Privacy

Privacy:

- May not disclose private patient information except for treatment, payment, or operations
 - No consent required in these cases
- Must disclose the minimum necessary
- Business associates may not re-disclose without consent
- Patients have the right to access medical information and make corrections
- Civil and criminal penalties for non-compliance

Patient Protection and Accountable Care Act

What is covered? Provides health insurance for almost all

Key dates (selected: these will affect the HD population)

- 2010 - High risk pool for individuals with pre-existing conditions; **no lifetime limits on benefits**; states get \$\$ for covering adults with no children on Medicaid
- 2011 - CLASS Act long term care for individuals
- 2012 – Medicare and Medicaid demonstration projects include mental illness provisions, Accountable Care Organizations
- 2013 – Phase in subsidies for prescription drug costs (Medicare)

For more information see:

<http://healthreform.kff.org/Timeline.aspx>

Patient Protection and Accountable Care Act

What happens in 2014:

- Medicaid will cover everyone under 133% federal poverty line (FPL)
- Cost increase will be paid by federal govt thru 2016 then down to 90% by 2020
- Community health centers funded \$2.5B more
- Everyone is required to have health insurance or pay penalty of \$690 per year or 25% income (includes illegal immigrants)
- People with incomes between 133% and 400% of FPL will get federal subsidy premium credit
 - Federal cost sharing subsidies – tax credits for those up to 400% FPL
- **Employers with > 50 full time employees must pay \$200 per employee up to 30 employees**
 - Must pay \$2000 if the employees get the tax credit
- Insurance exchanges will make health insurance available to everyone at federally regulated rates
 - States also will establish these exchanges

What happens when you cannot work any longer?

Social Security Disability Income was designed for people who cannot work but are too young to qualify for Medicare.

An excellent article for people with HD can be found at:

<http://huntingtondisease.tripod.com/benefits/id10.html>

- by Phil Hardt, 1995

Some final thoughts

The more you read, the more you know. The more you learn, the more places you'll go.

- Dr. Seuss

BELIEVE IN YOURSELF
AND ALL THAT YOU ARE.
KNOW THAT THERE IS
SOMETHING INSIDE YOU
THAT IS GREATER
THAN ANY OBSTACLE.

(CHRISTIAN B. TARSON)

Happiness on the web

Matthieu Ricard on the necessity of compassion and meditation

http://www.ted.com/talks/matthieu_ricard_on_the_habits_of_happiness.html

Rick Warren on living a life of purpose

http://www.ted.com/talks/rick_warren_on_a_life_of_purpose.html

Further reading:

Tugade MM, Fredrickson BL, and Barrett LF. Psychological Resilience and Positive Emotional Granularity: Examining the benefits of positive emotions on coping and health. *Journal of Personality*, Vol. 72(6):1161-1190.

Bruno S. Frey. Happy People Live Longer. *Science* 2011, Vol.331, No. 6017:542-543.

Cutler, HC and The Dalai Lama. The Art of Happiness: A Handbook for Living. New York, NY: Riverhead Books, 1998.