

LIVING AS A PRINCESS WITH PBC

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CHRONIC ILLNESS:

- 1 OF EVERY 2 AMERICANS HAS A CHRONIC ILLNESS
- 133 MILLION IN THE U.S. ALONE HAVE A CHRONIC MEDICAL ISSUE
- 19-402 CASES OF PBC PER ONE MILLION PEOPLE
- IN ADDITION TO THE PHYSICAL CHALLENGES OF AN ILLNESS, PSYCHOLOGICAL ISSUES TAKE THEIR TOLL

PSYCHOLOGICAL ASPECTS OF PBC

- PBC IS DIFFICULT TO UNDERSTAND
- SOCIETY ASSUMES YOU DRINK TOO MUCH
- CHALLENGES OF HAVING AN INVISIBLE ILLNESS
- WHO AM I NOW THAT I HAVE THIS ILLNESS?
- UNPREDICTABILITY AND UNCERTAINTY ABOUT THE FUTURE
- ADDITIONAL DIAGNOSES OVER TIME (1/3 OF PBC PTS DEVELOP ANOTHER AUTOIMMUNE DISEASE OVER TIME)
- DISAPPOINTING OURSELVES AND OTHERS
- SYMPTOMS SUCH AS ITCHING AND FATIGUE DO NOT CORRESPOND TO DISEASE SEVERITY

REACTION TO DIAGNOSIS

- SHOCK
- DISBELIEF
- SADNESS
- CATASTROPHIZING
- DENIAL
- RELIEF ABOUT FINDING AN ANSWER

PBC AND FATIGUE

- ONE OF THE MOST DISABLING SYMPTOMS
- OFTEN UNDERESTIMATED BY DOCTORS, FAMILY AND FRIENDS
- NOT ALWAYS HELPED BY NAPPING OR A GOOD NIGHT OF SLEEP
- DOES NOT CORRESPOND TO DISEASE SEVERITY
- DOES NOT ALWAYS IMPROVE POST TRANSPLANT
- NO EVIDENCE FATIGUE IS RELATED TO DEPRESSION
- SYMPTOMATIC TREATMENTS ARE AVAILABLE

TREATMENTS FOR FATIGUE IN PBC

- WELLBUTRIN XL (BUPROPION XL)
- NUVIGIL OR PROVIGIL
- STIMULANTS SUCH AS THOSE USED TO TREAT ADHD
- IF POSSIBLE, CHANGE BETA BLOCKER TO BEDTIME

REAL WORLD POINTERS FOR FATIGUE

- PLAN ACTIVITIES FOR BEST PART OF THE DAY
- LIMIT NAPPING TO AVOID DISRUPTING SLEEP
- OPTIMIZE SLEEP HYGIENE
- AVOID SUPPLEMENTS/ENERGY DRINKS
- DO SOME LOW IMPACT EXERCISE AT LEAST SEVERAL TIMES A WEEK. LIMIT TIME IN BED DUE TO DECONDITIONING

ITCHING IN PBC

- PRURITUS (ITCHING) EXPERIENCED BY UP TO 80% OF PATIENTS
- WORSE IN WARM WEATHER
- WORSE AT NIGHT
- TOPICAL TREATMENTS NOT ALWAYS HELPFUL
- ANTIHISTAMINES NOT HELPFUL
- BEST TREATMENTS: COLESTIPOL OR CHOLESTYRAMINE
- BRIGHT LIGHT THERAPY: 10,000 LUX LIGHT BOX

AM I

- SICK?
- TIRED?
- DEPRESSED?
- ANXIOUS?
- ALL OF THE ABOVE?

DEPRESSION

- ONE OF THE MOST COMMON COMPLICATIONS OF ALL CHRONIC ILLNESSES
- UP TO 1/3 OF PEOPLE WITH SERIOUS MEDICAL ILLNESSES EXPERIENCE SYMPTOMS OF DEPRESSION
- NOT A “NORMAL” PART OF ILLNESS
- TREATABLE
- TREATING DEPRESSION CAN RESULT IN BETTER QUALITY OF LIFE, IMPROVED COMPLIANCE, AND EVEN IMPROVE SURVIVAL

MAJOR DEPRESSIVE DISORDER

- DEPRESSED MOOD-FEELING SAD OR DOWN
- DECREASED INTEREST OR PLEASURE
- SIGNIFICANT WEIGHT LOSS OR GAIN
- SLEEP DISTURBANCE
- PSYCHOMOTOR AGITATION OR RETARDATION
- FATIGUE OR LOSS OF ENERGY
- FEELINGS OF WORTHLESSNESS OR GUILT
- POOR CONCENTRATION OR INDECISIVENESS
- THOUGHTS ABOUT DEATH
- 24 % OF PATIENTS IN ONE STUDY REPORTED SYMPTOMS OF DEPRESSION

SOURCES OF DEPRESSION IN CHRONIC ILLNESS

- PAIN
- DISRUPTION
- STRESS ON RELATIONSHIPS
- PATIENT-DOCTOR CONFLICTS
- LOSS OF CONTROL
- UNCERTAINTY ABOUT THE FUTURE
- FINANCIAL STRESS
- FATIGUE
- MEDICATION SIDE EFFECTS

OBSTACLES TO DIAGNOSIS

- DOCTORS AND PATIENTS MAY FEEL DEPRESSION IS “EXPECTED” OR “APPROPRIATE”
- SPECIALISTS FOCUS ON THEIR ORGAN OF INTEREST
- DOCTORS ARE AFRAID OF OFFENDING PATIENTS BY RECOMMENDING PSYCHIATRIC TREATMENT
- PATIENTS ARE AFRAID OF “BEING NEEDY”
- PATIENTS ARE AFRAID THAT PSYCHIATRIC TREATMENT WILL RESULT IN MEDICAL ISSUES BEING DISMISSED
- FEAR OF EXPENSE OF PSYCHIATRIC TREATMENT

MEDICAL DISORDERS ASSOCIATED WITH DEPRESSION

- HYPOTHYROIDISM
- ASTHMA
- CUSHING'S DISEASE
- DIABETES
- AUTOIMMUNE DISORDERS (SLE, RA, ETC.)
- NEUROLOGICAL ILLNESS: MULTIPLE SCLEROSIS, STROKE
- NUTRITIONAL DEFICIENCIES (FOLIC ACID AND B VITAMINS)
- CARDIAC DISEASE

MEDICATIONS ASSOCIATED WITH DEPRESSION

- SOME ANTIBIOTICS (CIPRO AND FLOXIN)
- CORTICOSTEROIDS
- ORAL HYPOGLYCEMICS
- INTERFERON
- ZOVIRAX (USED TO TREAT HERPES INFECTIONS AND SHINGLES)
- SOME CARDIAC DRUGS (CLONIDINE, DIGOXIN, ETC)
- BIRTH CONTROL PILLS
- ANTICONVULSANTS
- ANXIETY MEDICATIONS (BENZODIAZEPINES)
- PAIN MEDICATIONS (OPIATES)

HOW DO I KNOW WHEN I NEED PROFESSIONAL HELP FOR DEPRESSION?

- SYMPTOMS IMPAIR FUNCTIONING
- SYMPTOMS CAUSE SIGNIFICANT SLEEP DISTURBANCE OR APPETITE CHANGE
- DEPRESSION INTERFERES WITH COMPLIANCE WITH MEDICAL TREATMENT
- YOU ATTEMPT TO SELF-MEDICATE THROUGH USE OF DRUGS OR ALCOHOL
- SUICIDAL THOUGHTS

TREATMENTS FOR DEPRESSION

- PSYCHOTHERAPY
- MEDICATIONS

PSYCHOLOGICAL TREATMENTS FOR DEPRESSION

- READING
- WORKBOOKS: *MIND OVER MOOD*
- JOURNALING
- SUPPORT GROUPS
- WRITING
- VOLUNTEERING
- EXERCISE
- PETS
- SURFING THE NET

MEDICATION MANAGEMENT OF DEPRESSION:

- CONSIDER MEDICAL CONDITIONS AS NOT ALL MEDICATIONS ARE SAFE IN THE CONTEXT OF LIVER, KIDNEY OR HEART DISEASE
- CONSIDER MEDICATION INTERACTIONS
- IDENTIFY TARGET SYMPTOMS
- SIDE EFFECTS OR FRINGE BENEFITS?
- TREAT HEPATIC ENCEPHALOPATHY LATER IN THE DISEASE

OFF THE BEATEN PATH: OTHER MEDICATION OPTIONS FOR DEPRESSION

STIMULANTS

IMMEDIATE EFFECT

SHORT DURATION OF ACTION

OFTEN BETTER TOLERATED THAN SSRI/SNRI

NUVIGIL OR PROVIGIL

WAKE PROMOTING AGENTS

HELPFUL FOR FATIGUE RELATED TO MEDICAL ILLNESS

FINDING AND KEEPING A SENSE OF PURPOSE

- LIVING BECAUSE OF INSTEAD OF LIVING IN SPITE OF..
- CONTINUE WORKING TO THE EXTENT POSSIBLE
- CONSIDER WORK MODIFICATIONS, IF NEEDED
- IF WORK IS IMPOSSIBLE, VOLUNTEER
- STAY INVOLVED AND GET OUT OF THE HOUSE EVERY DAY

ANXIETY: WHAT IS IT?

- STRESS
- FEELING UPTIGHT
- TENSION
- IRRITABILITY
- WORRY
- NERVOUSNESS
- PANIC ATTACKS

ANXIETY: MEDICAL CAUSES

- HEPATIC ENCEPHALOPATHY
- THYROID PROBLEMS
- HEART DISEASE
- ASTHMA OR OTHER LUNG DISEASE
- HEART DISEASE
- SUBSTANCE ABUSE OR WITHDRAWAL
- MEDICATIONS:
 - STEROIDS
 - ASTHMA MEDICATIONS
 - DECONGESTANTS
 - IMMUNOSUPPRESSANTS

KNOWLEDGE IS POWER

- LEARNING ABOUT YOUR ILLNESS EMPOWERS YOU TO BE YOUR BEST ADVOCATE
- COMMUNICATE MORE EFFECTIVELY WITH YOUR TREATMENT TEAM
- PROVIDES A SENSE OF CONTROL DESPITE THE CHAOS OF CHRONIC ILLNESS

MEDICATION TREATMENT OF ANXIETY

- ANTIDEPRESSANTS
- BENZODIAZEPINES---USE WITH CAUTION IN ADVANCED DISEASE OR ELDERLY.
HIGH RISK OF DEPENDENCE/WITHDRAWAL
- BUSPAR
- BETA BLOCKERS

ANXIETY MANAGEMENT: MORE THAN MEDICATION

- LIMIT CAFFEINE
- EXERCISE REGULARLY
- GET ADEQUATE SLEEP
- LEARN RELAXATION STRATEGIES
- DEVELOP A LIST OF STRATEGIES TO MANAGE ANXIETY
- AVOID WATCHING THE NEWS
- MAINTAIN A WORRY LIST
- SET ASIDE TIME TO WORRY EACH DAY
- WEBSITES: WWW.ANXIETIES.COM

PATIENTS ARE FROM PLUTO, DOCTORS ARE FROM DOWN UNDER

- “PBC AND THE TREATMENTS AREN’T THE BIGGEST STRESSOR. IT IS DEALING WITH DR _____.”

WORKING WITH YOUR DOCTOR

- DO YOUR HOMEWORK
 - PREPARE UPDATED MEDICATION LIST
 - PROVIDE A BRIEF SUMMARY OF CURRENT SYMPTOMS
 - SUMMARIZE VISITS TO OTHER DOCTORS
 - IDENTIFY THE APPROPRIATE DOCTOR FOR AN ISSUE
 - PREPARE A SHORT LIST OF QUESTIONS
- IDENTIFY GOALS FOR APPT
- REQUEST REFILLS AND LETTERS DURING APPT

BOOKS ON CHRONIC ILLNESS:

- STRONG AT THE BROKEN PLACES: VOICES OF ILLNESS, CHORUS OF HOPE BY RICHARD M. COHEN
- KEEP WORKING, GIRLFRIEND! WOMEN, WORK AND AUTOIMMUNE DISEASE
- AFTER THE DIAGNOSIS: TRANSCENDING CHRONIC ILLNESS BY JULIAN SEIFTER WITH BETSY SEIFTER
- THE LONELY PATIENT: HOW WE EXPERIENCE ILLNESS BY MICHAEL STEIN, M.D.

BOOKS ON CHRONIC ILLNESS

- THE CHRONIC ILLNESS EXPERIENCE: EMBRACING THE IMPERFECT LIFE BY CHERI REGISTER
- HAPPINESS IN A STORM BY WENDY SCHLESSEL HARPHAM, M.D.
- LIFE DISRUPTED: GETTING REAL ABOUT CHRONIC ILLNESS IN YOUR TWENTIES AND THIRTIES BY LAURIE EDWARDS

FINDING HELP:

- CHECK WITH YOUR PHYSICIAN
- CALL LOCAL BRANCH OF MENTAL HEALTH ASSOCIATION
- www.healthy minds.org (AMERICAN PSYCHIATRIC ASSOCIATION)
- INSURANCE PROVIDER PANEL
- LOCAL MEDICAL SCHOOL PSYCHIATRY DEPARTMENT
- EMPLOYEE ASSISTANCE PROGRAM THROUGH WORK
- CHURCH OR SYNAGOGUE
- SUPPORT GROUPS

HAPPINESS IS A WARM BEAGLE

