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 Seifert with Betsy Seifert

• 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 Schlesel 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**
• **Insurance provider panel**
• **Local medical school Psychiatry department**
• **Employee Assistance Program through work**
• **Church or synagogue**
• **Support groups**
HAPPINESS IS A WARM BEAGLE