

Coping with Primary Sclerosing Cholangitis

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Patient and their family/friends

Caregivers

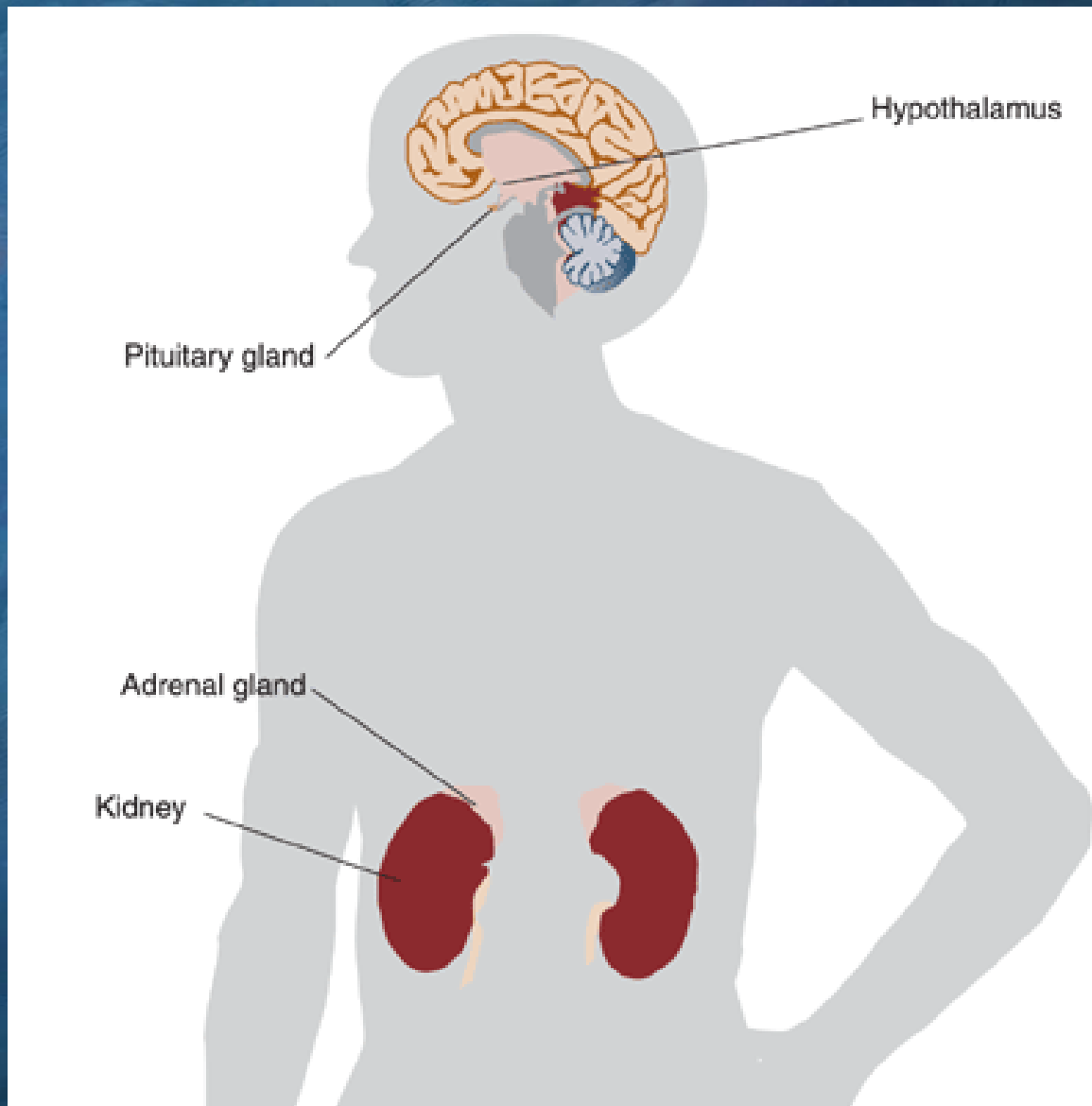
Primary Sclerosing Cholangitis

- **Chronic illness**
- **There is no cure**
- **May progress to ESLD requiring liver transplant**
- **A major risk is bile duct cancer**
- **Young people (30-50s)**
- **The majority are men.**

Mayoclinic.com

Definition of Stress

- **“Fight-or-flight” reaction**
 - **It is rapid and automatic switch into “high gear”**



Source: Adinoff, B., et al. Disturbances of the stress response: The role of the hypothalamic-pituitary-adrenal HPA axis during alcohol withdrawal and abstinence. *Alcohol Health & Research World* 22(1):67–72, 1998.

Stress response...

- **Digestive system**
- **Immune system**
- **Nervous system**
- **Cardiovascular system**
- **Other systems**
 - **Skin conditions**
 - **Asthma**

How to cope with Stress

- Identify your stress triggers
- Keep a stress journal.
- Make a list of all the demands on your time and energy for one week.
- Improve your time management skills
- Overcome burnout
 - Take care of yourself.
 - Develop friendships at work and outside the office.
 - Take time off.
 - Set limits.
 - Choose battles wisely.
 - Have an outlet.
- Seek help.

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Resilience

- **Main Entry:**
 - re·sil·ience
 - **Pronunciation:**
 - \ri-'zil-yən(t)s\
 - **Function:**
 - *noun*
 - **Date:**
 - 1824
- 1** : the capability of a strained body to recover its size and shape after deformation caused especially by compressive stress
- 2** : an ability to recover from or adjust easily to misfortune or change

Merriam Webster dictionary

Resilience

- **Strauss B. Brix C. Fischer S. Leppert K. Fuller J. Roehrig B. Schleussner C. Wendt TG. The influence of resilience on fatigue in cancer patients undergoing radiation therapy (RT). [Journal Article] *Journal of Cancer Research & Clinical Oncology*. 133(8):511-8, 2007 Aug.**
- **Roy A. Sarchiapone M. Carli V. Low resilience in suicide attempters. [Journal Article] *Archives of Suicide Research*. 11(3):265-9, 2007.**
- **Hjemdal O. Aune T. Reinfjell T. Stiles TC. Friborg O. Resilience as a predictor of depressive symptoms: a correlational study with young adolescents. [Journal Article] *Clinical Child Psychology & Psychiatry*. 12(1):91-104, 2007 Jan.**
- **Thompson CW. Durrant L. Barusch A. Olson L. Fostering coping skills and resilience in Home Enteral Nutrition (HEN) consumers. [Journal Article] *Nutrition in Clinical Practice*. 21(6):557-65, 2006 Dec.**
- **Friborg O. Hjemdal O. Rosenvinge JH. Martinussen M. Aslaksen PM. Flaten MA. Resilience as a moderator of pain and stress. [Journal Article. Research Support, Non-U.S. Gov't. Validation Studies] *Journal of Psychosomatic Research*. 61(2):213-9, 2006 Aug.**

Content of the Connor-Davidson Resilience Scale

- Able to adapt to change
- Close and secure relationships
- Sometimes fate or God can help
- Can deal with whatever comes
- Past success gives confidence for new challenges
- See the humorous side of things
- Coping with stress strengthens
- Tend to bounce back after illness or hardship
- Things happen for a reason
- Best effort no matter what
- You can achieve your goals
- When things look hopeless, I don't give up
- Know where to turn for help
- Under pressure, focus and think clearly
- Prefer to take the lead in problem solving
- Not easily discouraged by failure
- Think of self as strong person
- Make unpopular or difficult decisions
- Can handle unpleasant feelings
- Have to act on a hunch
- Strong sense of purpose
- In control of your life
- I like challenges
- You work to attain your goals
- Pride in your achievements

Development of a new resilience scale: The Connor-Davidson Resilience Scale (CD-RISC). *Depression and Anxiety* 18:76-82(2003)

Psychiatry

- **Psychiatrists**
 - **General**
 - **Psychosomatic medicine**
Academy of psychosomatic medicine
<http://www.apm.org/>

Adjustment disorders

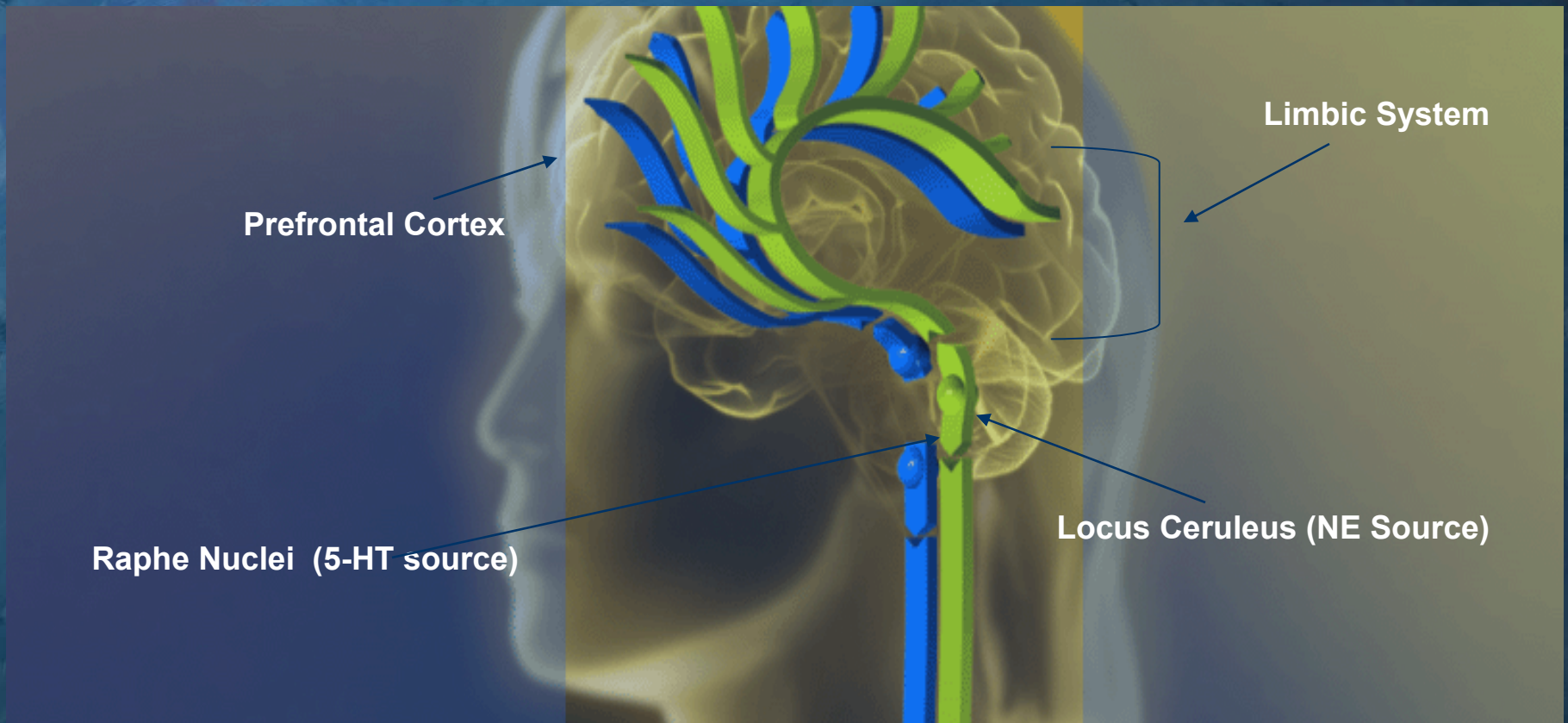
Emotional symptoms of adjustment disorders

- Sadness
- Hopelessness
- Lack of enjoyment
- Crying spells
- Nervousness
- Thoughts of suicide
- Anxiety
- Worry
- Desperation
- Trouble sleeping
- Difficulty concentrating
- Feeling overwhelmed

Behavioral symptoms of adjustment disorders

- Fighting
- Reckless driving
- Ignoring bills
- Avoiding family or friends
- Poor school or work performance
- Skipping school
- Vandalism

Serotonin^{5HT} and Norepinephrine^{NE} in the brain



Cooper JR, Bloom FE. *The Biochemical Basis of Neuropharmacology*. 1996.

Spectrum of Symptoms in Depression

Emotional Symptoms

Sadness, tearfulness

Loss of interest

Anxiety, irritability

Hopelessness

Concentration difficulties

Guilt

Suicidal ideation

Physical Symptoms

Tiredness, fatigue

Sleep disturbances

Headaches

Psychomotor agitation,
retardation

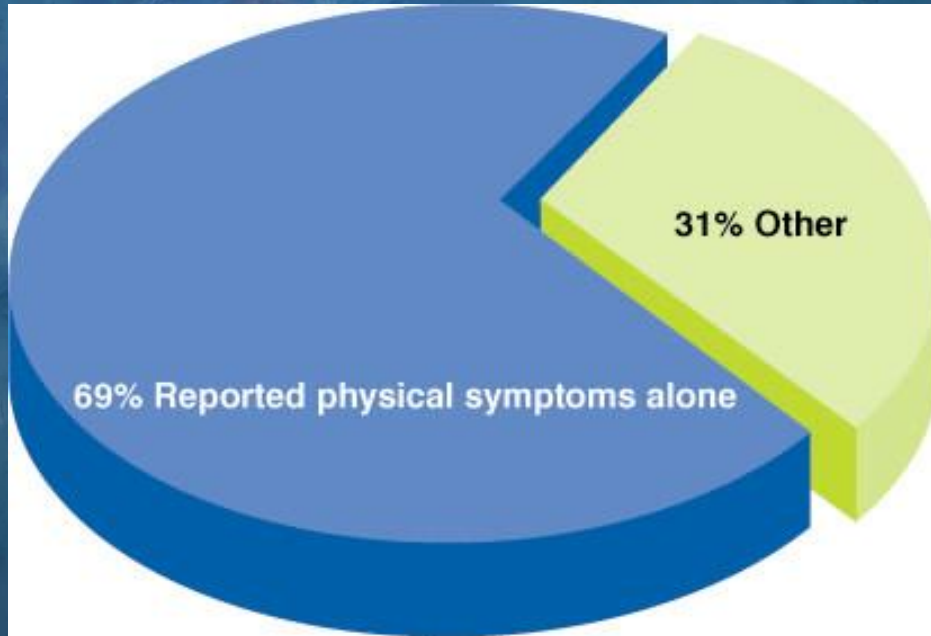
GI disturbances

Appetite Changes

Body aches and pain

DSM-IV-TR (2000). Washington, D.C.; American Psychiatric Association

The physical presentation



In a *New England Journal of Medicine* study, 69% of diagnosed depressed patients reported unexplained physical symptoms as their chief complaint¹

N = 1146 Primary care patients with major depression

Simon GE, et al. *N Engl J Med.* 1999;341(18):1329-1335.

Depression Is a Major Public Health Concern

- **>30 million adults (lifetime prevalence) in the United States¹**
- **4th greatest cause of global illness burden (morbidity + mortality)²**
- **Suicide is the 8th leading cause of death in the United States³**
 - **Causing more deaths annually than HIV and hepatitis combined³**

1. Kessler RC, et al. *JAMA*. 2003;289:3095-3105.

2. WHO World Health Report 2001.

3. National Vital Statistics Report; 2000.

Suicide

You can reach the Lifeline by dialing 1-800-273-TALK (8255). Although suicide prevention is our primary mission, people call the Lifeline for many reasons:

- Suicidal thoughts
- Abuse/violence
- Information on suicide
- Economic problems
- Information on mental health/ illness
- Sexual orientation issues
- Post disaster needs
- Homelessness issues
- Substance abuse/addiction
- Physical illness
- To help a friend or loved one
- Loneliness
- Relationship problems
- Family problems

<http://www.suicidepreventionlifeline.org/>

What Is Adequate Treatment?

- Remission of symptoms has been the standard goal for more than a decade¹⁻⁴
- Resolution of emotional and physical symptoms^{5,6}
- Restoration of full capacity for functioning^{5,6}
 - Return to work
 - Resume hobbies/personal interests
 - Restore personal relationships

1. *Clinical Practice Guideline, 5: Depression in Primary Care, 2: Treatment of Major Depression*; 1993. AHCPR publication 93-0551.

2. American Psychiatric Association. *Am J Psychiatry*. 2000;157(4 suppl):1-45.

3. Anderson IM, et al. *J Psychopharmacol*. 2000;14:3-20.

4. Reesal RT, Lam RW. *Can J Psychiatry*. 2001;46(suppl 1):21S-28S.

5. DSM-IV-TR™. Washington, DC: American Psychiatric Association; 2000.

6. Rush AJ, Trivedi MH. *Psychiatr Ann*. 1995;25:704-705, 709.

When to ask for professional help

Any time.....

- **Major Depression**
- **Anxiety Disorders**
- **Alcohol and drug addiction**
- **Suicidal thoughts and behavior**

Alcohol...How much is “too much”

Drinking becomes too much when it causes or elevates the risk for alcohol-related problems or complicates the management of other health problems. Men who drink 5 or more standard drinks in a day (or 15 or more per week) and women who drink 4 or more in a day (or 8 or more per week) are at increased risk for alcohol-related problems

Dawson DA, Grant BF, Li TK. Quantifying the risks associated with exceeding recommended drinking limits. Alcohol Clin Exp Res. 29(5):902-908, 2005

Substance Abuse and Mental Health Services Administration

<http://www.samhsa.gov/>

Who to ask for help

Primary Care Physician

Hepatologist

Mental Health Care Providers

- **Individual and Group Psychotherapy**

Psychologists

Psychotherapists

Social Workers

Psychiatric nurses

Mental health counselors

Marriage and family therapists

Pastoral counselors

Psychoanalysts

- **Medication Management**

Psychiatrists

Resources

- **Support Groups**

Thank you!