

Start	End	Topic	Speakers
09:00	09:10	Introduction	• Ragi Doggweiler
09:10	09:50	• Sexuality and chronic pelvic pain	• Kristene Whitmore
09:50	10:30	• Neuromodulation and CPPS	• Michele Spinelli
10:30	11:00	Break	None
11:00	11:50	• How can I help myself, what can I do as a patient diagnosed with Interstitial Cystitis	• Barbara Mündner-Hensen
11:50	12:30	• Chronic Pain, Psychoneuroimmunology and the brain	• Ragi Doggweiler
12:30	13:00	Questions	All

### **Aims of course/workshop**

This workshop aims to discuss the importance of a multimodal approach in the treatment of patients diagnosed with chronic pelvic pain syndrome.

There is emphasis on a multimodal approach while recognizing the unitary psycho-physiologic nature of both illness and healing

Discussion of neuromodulation and neuroplasticity in the treatment of chronic pelvic pain will be undertaken

Specific consideration will be given not only the symptoms as guidelines to treatment but also the patient as a whole including the environment he or she is living and functioning.

Another talking point involves the degree of patient willingness to participate in self –help approaches to gain self-empowerment and self-care.

## Chronic Pelvic Pain

### Sexual Pain

- Often occurs with other sexual dysfunctions/disorders
  - Desire
  - Arousal
  - Orgasm
- Occurs in up to 80% of CPP patients
- >50% of CPP partners also develop sexual dysfunction

### Modality of Pain

- Continuous
- Cyclic

The Standardisation of Terminology in Lower Urinary Tract Function: Report from the Standardisation Sub-Committee of the International Continence Society. P. Abrams, et al. Urology. 2003 Jan;61(1):37-49.

Lee, S et al J Urol 2008; 7: 79-84

## SEXUALITY AND CHRONIC PELVIC PAIN

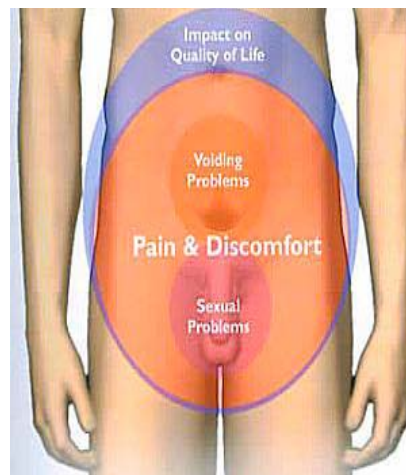


**Kristene Whitmore, MD**  
 Professor of Surgery/Urology and OBGYN  
 Chair of Urology, FPMRS  
 Drexel University College of Medicine  
 Philadelphia, Pennsylvania  
 Drexel University College of Medicine  
 Philadelphia, PA, USA

## CPP Syndromes

### The complex of CPP Syndromes:

- Lower Urinary Tract
- Male Genital Pain
- Female Genital Pain
- Gastrointestinal Pain
- Musculoskeletal Pain
- Neuropathic Pain
- Psychological overlay
- Sexual Pain
- Extra-Pelvic Co-Morbidities



## Chronic Pelvic Pain

### Duration

- Non-cyclical pain persisting for at least 6 months

### Location

- Pelvis
- Lower abdomen
- Low back
- Medial aspects of thigh
- Inguinal Area

### Perception of Pain

- Sharp
- Burning
- Pressure/Discomfort
- Dull ache
- Throbbing

The Standardisation of Terminology in Lower Urinary Tract Function: Report from the Standardisation Sub-Committee of the International Continence Society. P. Abrams, et al. Urology. 2003 Jan;61(1):37-49.

## Female Genital Pain

Dyspareunia

### Symptoms

- **Vulvodynia (skin)**
  - Vulvar, vestibular or clitoral
- **Uterine/Tubal Pain**
  - Dysmenorrhea, infection, endometriosis, adenomyosis
- **Vaginal Pain (Dyspareunia)**
  - Superficial/deep
- **Pelvic Floor Pain (Musculoskeletal)**
  - Childbirth injuries, POP
- **Pelvic Organ Malignancy**
- **Pain following Pelvic Surgery**
  - Mesh complications, organ or nerve injuries during surgery

Tunitzky E, Abbott S, Barber MD Interrater reliability of the International Continence Society and International Urogynecological Association (ICS/IUGA) classification system for mesh-related complications Am J Obstet Gynecol. 2012 May;206(5):442.e1-6.

## LUT Pain

Dyspareunia

### Symptoms

- **Bladder Pain**
  - Pain— pain, pressure of discomfort associated with bladder filling
    - » Experienced in the bladder; or referred from the abdomen, lower back and/or pelvic floor
  - Frequency –  $\geq 8$  daytime voids
  - Urgency – persistent urge to void to lessen fear of pain
  - Nocturia – at least one void from state of sleep, per session
- **Urethral Pain**
  - Intermittent
    - » During of after voiding
    - » During or after intercourse
  - Persistent

### Signs

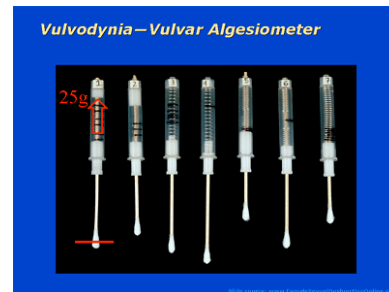
- **Bladder Pain**
  - Supra-pubic tenderness
  - Bladder tenderness
- **Urethral Pain**
  - Urethral tenderness

The Standardisation of Terminology in Lower Urinary Tract Function: Report from the Standardisation Sub-Committee of the International Continence Society. P. Abrams, et al. Urology. 2003 Jan;61(1):37-49.

## Female Genital Pain

### Evaluation

- **Vulvodynia**
  - Q-tip touch test, Algesiometry
- **Uterine/Tubal**
  - Imaging, C & S, Pathology
- **Dyspareunia**
  - Severity and QOL questionnaires
    - FSFI
- **Pelvic Floor**
  - Musculoskeletal assessment
  - POP-Q Exam for prolapse
- **Pelvic Organ malignancy**
  - Pathology, imaging
- **Following Pelvic surgery**
  - Mesh contracture
  - Imaging



DA Tripp, et al. Mapping of Pain Phenotypes in Female Patients with Bladder Pain Syndrome/Interstitial Cystitis and Controls. European Urology, Volume 62, Issue 4, October 2012, Page e74

## LUT Pain

Dyspareunia

### Evaluation

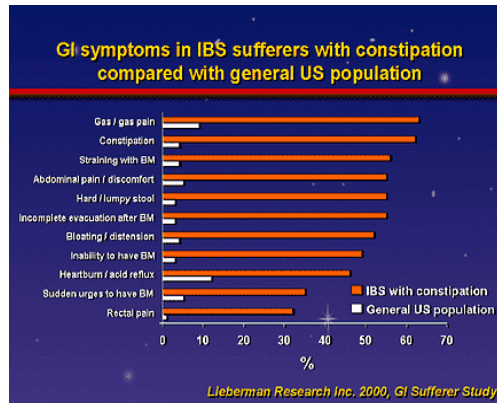
- **Bladder Pain/Urethral Pain**
  - Questionnaires: Voiding Diaries, O'Leary-Sant Indices, Visual Analog Sales(VAS), FSFI, IIEF
  - Post-Void Residual, Uroflow
  - Anesthetic Challenge to identify pain generator and/or referred sites
  - UA, Culture, Cytology
  - Urodynamics, Cystoscopy
  - Ultrasound, MRI, CT Scan
  - Rule-out Confusable Diseases

## GI Pelvic Pain

### GI Evaluation

#### • Anorectal/Colorectal

- Questionnaires
- Imaging
  - Ultrasound, CT, MRI
- Identify Pain Generators



## Male Genital Pain

*Dyspareunia*

### Signs

- Prostate
    - Tenderness with digital exam
  - Scrotal
  - Testicular
  - Penile
  - Urethral
  - Epididymal
- } Tenderness

### Evaluation

- Prostate Pain – secretion culture, UA, CPSI questionnaire
- Scrotal Pain – ultrasound (US)
- Testicular Pain – US
- Penile Pain
- Urethral Pain
- Epididymal Pain Syndrome
- Sexual Pain – Questionnaires
  - IIEF

## Musculoskeletal Pain

### Evaluation

- Identify pain generators
- Assess muscle strength
- SIJD and Sacro-Spinous Ligament
  - assess for mobility, posture, and symmetry
- Trigger point injections
- EMG, Manometry
- Imaging
  - X-Ray, MRI



## GI Pelvic Pain

### GI Symptoms - Anorectal

- Chronic proctalgia
- Levator ani syndrome
- Proctalgia fugax
- Unspecified
- Anal fissure
- Abscess
- Hemorrhoids
- Crohn's disease

### Colorectal

- IBS
- Colitis
- Crohn's Disease

## Psychological



### Symptoms and Signs

- Fear
- Anxiety

### Evaluation

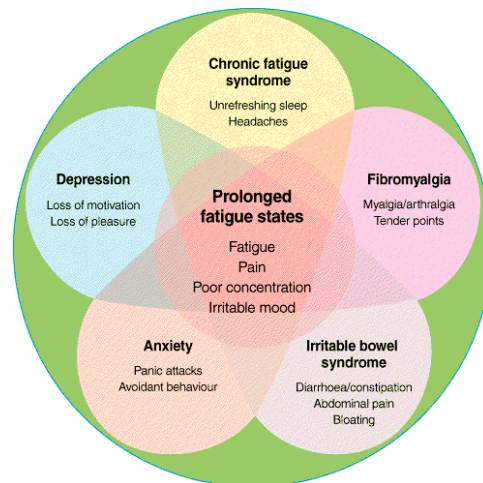
- The chief purpose of psychological assessment is to get a complete picture of the pain syndrome with all affected dimensions: somatic, affective, cognitive, behavioral and the individual consequences for the patient.
- Early referral to a psychological healthcare provider should be considered. Patients with sexual dysfunction may need sexual counseling.

## Neuropathic Pain

### Symptoms and Signs

- Infiltration of sacral nerves
- Somatic neuropathic pain
  - Iliohypogastric neuropathy
  - Ilioinguinal neuropathy
  - Genitofemoral neuropathy
  - Lateral femoral cutaneous neuropathy
  - Pudendal neuropathy
  - Neuroma formation/ Maladaptive neuronal plasticity
  - Complex regional pain syndrome (CRPS)
  - Pain following mesh injury
  - Post-herpetic neuralgia
  - Tarlov's cyst

## Extra-Pelvic Co-Morbidities



## Neuropathic Pain

### Evaluation

- Neuropathic pain questionnaires:
  - Leeds assessment for neuropathic symptoms and signs
    - not validated for chronic pelvic pain
  - Douleur neuropathic- 4 questions
  - Neuropathic pain questionnaire
    - may have unacceptable low diagnostic accuracy
  - PainDETECT
    - not validated for chronic pelvic pain
- Cotton swab sensory testing, quantitative sensory testing, sensory pain mapping, MRI, ultrasound, nerve block (LOE 4)

## Sexual Health is IMPORTANT

- Majority of women consider sexual health an important part of their overall health
- WHO considers maintenance of sexual health a *responsibility* of health care professionals
- WHO defines FSD as:  
“the various ways in which an individual is unable to participate in a sexual relationship ... as she would wish.”

Maverick, C. et al. JAMA, 1999;281:2173–4

## First-Line Therapy (for all CPP)

- Education
- Behavior modification
- Exercise and exercises (eg, relaxation, stretch)
- Avoidance of flare initiators
- Diet modification
- Support groups

## Does clinical practice show concern for sexual health?

- **Global Study of Sexual Attitudes and Behaviors Study**
  - only 14% of Americans aged 40-80 y.o. reported that a physician *inquired* about their sexual health concerns within the past 3 years
- **Berman et al 2003**
  - On line survey of women with sexual health concerns who had consulted a physician:
  - 52% - “physician didn’t want to hear about their problems”
  - 87% - “no follow up re: the complaint at subsequent visits

Laumann et al. Archives Sex Behav, 2006;35:145–64.  
Berman et al. Fertility Sterility 2003;79:572–6

## Treatment of Pain Generators Bladder (IC/BPS)

- Organ-specific therapy
  - Pentosan polysulfate (PPS)<sup>1</sup>
  - Intravesical therapies – DMSO, GAGs, alkalinized lidocaine<sup>2</sup>
  - Surgery – cautery, laser, cystectomy<sup>3</sup>
- Neuromodulation<sup>4</sup>
  - Amitriptyline, gabapentin, pregabalin<sup>1,5</sup>
  - Neurostimulation
  - Botulinum toxin type A
- Immunomodulation<sup>5</sup>
  - Hydroxyzine
  - Cyclosporine, mycophenolate mofetil
- Physiotherapy<sup>3,5</sup>
  - Specific pelvic floor physiotherapy<sup>6</sup>
  - General physiotherapy (massage therapy)
- Cognitive behavioral therapy<sup>3,5,7</sup>
  - Directed at depression, maladaptive coping mechanisms, social interaction including sexual functioning

DMSO = dimethyl sulfoxide.

1. Phatak S, Foster HE. *Nat Clin Pract Urol*. 2006;3:45-53; 2. Hanno P. *Int Urogynecol J*. 2005;16:S2-S34; 3. Moldwin RM et al. *Urol*. 2007;69:73-81; 4. Karsenty G et al. *EAU-EBU Update Series* 4, 2006:47-61; 5. Dell JR, Parsons CL. *J Reprod Med*. 2006;49:243-252; 6. Weiss J. *J Urol*. 2001;166:2226-2231; 7. Morley S et al. *Pain*. 1999;80:1-13.



## Male vs. Female “Wiring”

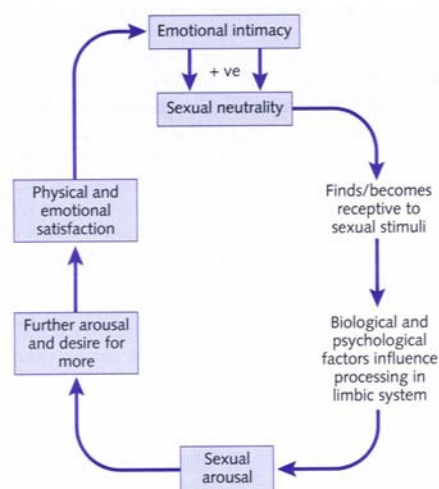


## Does clinical education show concern for sexual health?

- **Survey: N=125, 3<sup>rd</sup> and 4<sup>th</sup> year medical students**
  - 75.2% - considered taking a sexual history as an important part of their future career
  - 57.6% - considered themselves “adequately trained” in this area
- **Survey: 101 US and Canadian medical schools**
  - Only 10 hours of human sexuality education in 67% of programs (including contraception, STD prevention and treatment, etc.)

Wittenberg et al. J Sex Med, 2009; 6:362–8  
Solursh et al. Intl J Impot Research, 2003; 15:541–5

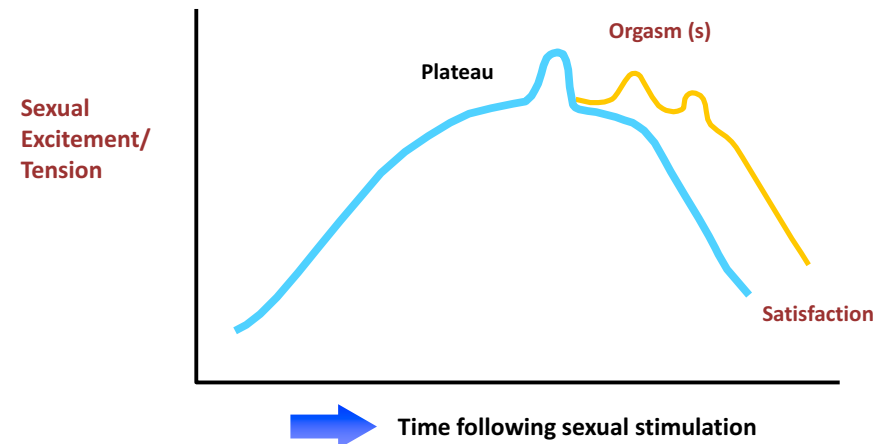
## Female sexual response: Basson Model



- ▶ Circular model, begins with neutrality, influenced by goal of emotional intimacy
- ▶ Physical desire may be reactive, rather than spontaneous
- ▶ Satisfaction = subjective reaction to the experience
- ▶ Importance of environment and stimuli that are conducive to sexual expression

▶ Basson, R, Sexual Dysfunction in Medicine, 2001, vol2, no3, pp.72-77.  
Basson, R, Sexual Desire and Arousal Disorders, NEJM, 2006, vol354, pp1497-1505.

## Traditional Sexual Response Cycle: Masters & Johnson Helen Singer Kaplan



Basson R. Obstet Gynecol. 2001;98:350-3.

## Female Sexual Function What do we know? Only the tip of the iceberg .....

### Primary mechanisms: VASOCONGESTION

- Genital vasocongestion begins within 30 sec of erotic stimuli
- Parasympathetic and Sympathetic nerves release:
  - Nitric oxide
  - Acetylcholine
  - VIP (vasoactive intestinal polypeptide)

### Hormones

- 40% of women with symptomatic vaginal atrophy due to low levels of estrogen confirm "adverse effects" on sexual function
- Low estrogen levels are associated with reduced baseline vaginal vasocongestion (i.e., in the *nonstimulated state*)

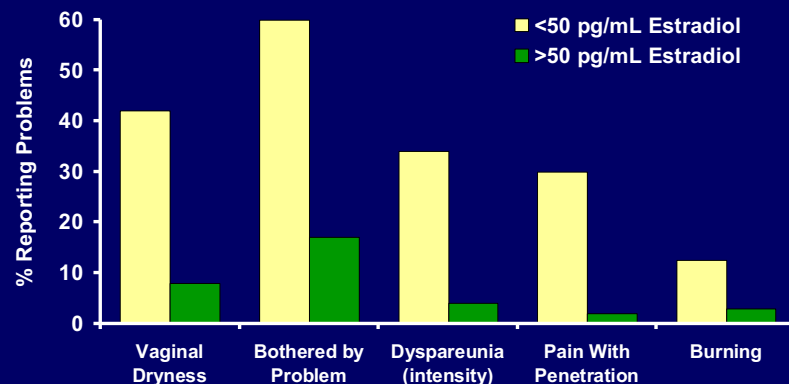
Glaser, R. Institute of Behavioral Medicine, Research, Ohio State Univ. 2004,  
Laumann, EO, Paik, A, Rosen, RC. JAMA, 1999;28:6,537-544.,  
Basson, R. Sexual desire and Arousal Disorders in Women. NEJM, 2006; vol 354, pp1497-1505.

## Female sexual response: Basson Model

- SWAN 2003 – Study of Women's Health Across the Nation
- 2400 multiethnic midlife women in 6 US cities (Hispanic, Caucasian, AA, Chinese, Japanese)
- Reported many motivations for engaging in sexual play. Primary = desire for *emotional closeness*
- 40% = never/rarely experience physical desire at initiation or between experiences
- 87% = satisfied with their sexual relationships

Basson, R. Sexual Dysfunction in Medicine, 2001, vol2, no3, pp.72-77. Basson, R. Sexual Desire and Arousal Disorders, NEJM, 2006, vol354, pp1497-1505.

## Lower Estrogen Levels Are Associated With Increased Prevalence of Sexual Problems



n = 93; significance not reported.  
Sarrel PM. J Womens Health Gend Based Med. 2000;9:S25-S32.  
Adapted from Sarrel PM. Sexuality and menopause. Obstet Gynecol. 1990;75(4 Suppl):26S-30S.  
©1990, with permission from the American College of Obstetricians and Gynecologists.

## Female sexual function

### Female sexual function POSITIVELY affected by:

- Stable mental health (past and current)
- Positive emotional well being and self image
- Rewarding past sexual experiences
- Positive feelings for a partner
- Positive expectations for the relationship

Basson, R. NEJM, 2006;354:1497-1506; Goldstein a et al, Female Sexual Function and Dysfunction, 2006. Leiblum, SR. J Gend Spec. Med. 1999;2:41-5



## Female Sexual Function : Aging

- Clitoral perfusion/ engorgement/arousal diminished = decreased lubrication
- Decline neurophysiologic response: **decreased touch perception, vibratory sensation and slowed reaction time** = lengthened O latency time
- **Decreased muscle tone**= PFM /Uterine contractions diminish = decreased O amplitude



Altman A et al, Patient Care, Spring 2002;4-12; Goldstein et al, Female Sexual Function and Dysfunction, 2006..

## Princeton Consensus Statement on Female Androgen Insufficiency

- ◆ Female androgen insufficiency consists of a pattern of clinical symptoms in the presence of:
  - Decreased bioavailable testosterone
  - Normal estrogen status
  - Clinical symptoms include impaired sexual function, mood alterations, and diminished energy and well-being

Bachmann G, et al. *Fertil Steril*. 2002;77:660-5.

## Female Sexual Health in Urogynecology

- **National Health and Social Life Survey (1999):**
- **Strong assoc between urinary tract sx's and**
  - arousal disorders (odds ratio 4.2)
  - sexual pain disorders (odds ratio 7.6)
- **Screening, identifying, and managing sexual complaints can result in significant improvement in overall QOL for women**

Laumann, EO. et al. JAMA, 1999;281:537-44  
Laumann, EO. et al. Arch Sex Behav, 2006;35:145-61

## Female Sexual Function

### Hormones

40% of women with symptomatic vaginal atrophy due to low levels of estrogen confirm "adverse effects" on sexual function

Low estrogen levels are associated with reduced baseline vaginal vasocongestion (i.e., in the *nonstimulated state*)

- Peak androgen production mid 20' s
  - Halved by age 60
- Large scale study: FSD + low FAI
  - Significant decrease in desire, mood, well being
- Premenopausal women: HSDD + A-lowest quartile
  - Significant decrease in desire, energy

Laumann, EO, Paik, A, Rosen, RC. JAMA, 1999;28:6,537-544.  
Munizarez, R, Goldstein, I et al. 2001 Female Sexual Function Forum, Boston University, Davis, SR et al, Menopause, in press 2006.

## FSD is complex: Physiologic & Psychological Components

- Sexual function based primarily on *intimacy*
- Important to understand and quantify genital responses, but also consider how sexual stimuli are “processed”

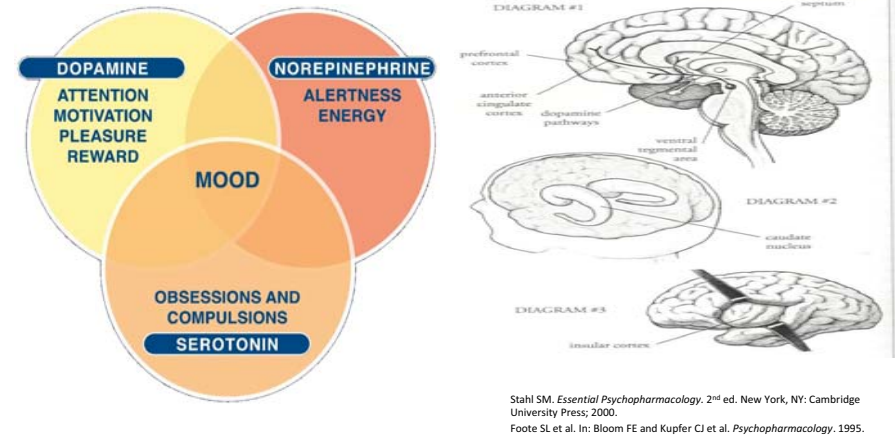
Important to assess if sexual symptoms are:

- reflecting normative changes across the lifespan
- adaptations to a particular situation
- related to her medical illness
- of unexplained etiology

Important to assess if patient is experiencing *distress* as a result of sexual changes, or simply reporting that they occur

## Neurotransmitters and Mood

- Neurotransmitters regulate mood, cognition, and behavior, including sexual motivation and reward seeking



## FSD: Diagnostic Inventories

### The Female Sexual Function Index (FSFI)

- 19 items, internal consistency, test-retest reliability
- Discriminates FSD in 5 domains:
  - desire, arousal, orgasm, satisfaction and pain

### The Sexual Function Questionnaire (SFQ)

- 31 items, reliability and validity established
- Discriminates FSD in 7 domains, including partner satisfaction

## FSD definitions

- **Hypoactive sexual desire disorder**
  - The persistent or recurrent lack of sexual fantasies, thoughts, desires and receptivity to sexual contact.
- **Sexual aversion disorder**
  - The persistent or recurrent fear or aversion of sexual contact.
- **Sexual arousal disorder**
  - The persistent or recurrent inability to become sexually aroused, often characterized by inadequate vaginal lubrication for penetration.
- **Orgasmic disorder**
  - The persistent or recurrent inability to orgasm.
- **Dyspareunia**
  - Pain during sexual intercourse.

**\*\* Must cause personal and/or interpersonal distress**

## Features of Dyspareunia

- Localized or generalized (or both)
  - Superficial or deep (or both)
  - Aggravated by penetration or thrusting (or both)
  - Primary or Secondary
  - Constant or Episodic
  - May or may not have a clearly discernible sentinel event
  - Mean time to dx=4.4 yrs
- Descriptions of Dyspareunia**
- Ripping
  - Tearing
  - Burning
  - Friction
  - Irritation
  - Itching
  - “Deep” pain
  - Feeling of need to urinate during vaginal intercourse
  - Feeling that something is “hitting” or “blocking”

Bachmann GB et al. JRM 2006; <http://www.reproductivemedicine.com/features/2006junfeature.htm>

## Most common sexual complaints in urology: Dyspareunia Lack of arousal

- Women may be unable to separate these two
- Dyspareunia leads to fear of more pain and altered arousal (psychological and physical)
- Poor arousal can lead to poor lubrication, which can lead to dyspareunia

Bimik, HM, et al. Arch Sex. Beh, 2005; 34:11–21

## Examination for sexual pain

- **Inspection of external genitalia**
  - Muscle tone, skin color/texture/turgor/thickness, pubic hair
  - Cotton swab test (pain mapping): vulva, vestibule, hymenal ring, Bartholin's and Skene's glands
  - Vulvar atrophy, vulvar dystrophy, vulvar vestibulitis, HPV infection
  - Retract clitoral hood and expose clitoris
  - Examine posterior fourchette and hymenal ring
- **Bimanual vaginal examination**
  - Palpate rectovaginal surface, levator muscles, vaginismus, bladder/urethra
  - Episiotomy scars, strictures, vaginal adhesions, vaginal atrophy, vaginal pH
  - Speculum examination and Pap smear
  - Evaluate for prolapse, vaginal length, vaginal mobility
  - Perform uterus, adnexa, rectal examination
  - Rectal disease, vaginismus, levator ani myalgia, IC, UTI
  - Postoperative or post-radiation changes, stricture
  - Fibroids, endometriosis, masses, cysts

Dhingra, C, et al, J of Women's Health 2011

## Dyspareunia

**Affects ALL aspects of the female sexual response (eg: desire, arousal, orgasm, satisfaction)**

### Dyspareunia : 2 types

- **Superficial (entry) :**
  - often due to inflammation at the introitus associated with: UTI, urethritis, vaginitis, provoked vestibulodynia
- **Deep (thrusting) :**
  - often occurs in women with CPP related to bladder, uterine, ovarian, bowel or pelvic floor muscle pathology

Hypersensitivity disorders can **cause or complicate** FSD symptoms in urogynecology  
CPP/IC/BPS, HTPFD, PVD, etc

Meston, CM et al. Ann Rev Clin Psychol, 2007;3:233–56

## Important Points about Sexual Pain

- The pain is REAL!
- Impacts QOL
- History taking/accurate diagnosis: KEY
- Realistic expectations
- Multi-disciplinary approach is necessary

## Neuromodulation and CPPS

Michele Spinelli MD NeuroUrology – Alberto Zanollo Center – Niguarda Hospital Milan (IT)

The field of sacral neuromodulation for functional urinary and bowel disorders and chronic pelvic pain has evolved rapidly over the past 15 years and is now at the forefront of available treatment options.

Despite this, the exact mechanism of action still remains unclear and lot of work has been carried out to determine which parameters of stimulation produce optimal clinical results. SNM is believed to result in recruitment of mainly afferent pathways, with the motor effects observed at low amplitude stimulation being a spinal reflex response. Studies of patients undergoing SNM for urinary voiding disorders (retention and detrusor overactivity) have found that patients with co-existing bowel disorders (constipation and incontinence) can have subjective improvement in their symptoms . The effect of SNM for both bowel and bladder dysfunction is thought to arise by activation of the same afferent pathways. However, individual conditions may respond to different electrode configuration and stimulation parameters (pulse amplitude, frequency, width and mode of stimulation) . Lead placement into the third sacral foramen is frequently performed as this correlates with the position of the S3 nerve root, which is believed to offer the best outcome of therapy. Theoretically, asymmetry of afferent outflow at a single root level can be eliminated by bilateral stimulation of both left and right nerve roots. Not all patients get additional benefit from bilateral stimulation and unilateral stimulation may be sufficient in the majority. The use of physiological and /or electrophysiological markers to aid programming may be required in these patients.

It is hypothesized that pelvic pain syndromes may result from tissue ischaemia and that SNM diminishes symptoms by increasing blood flow to the pelvic floor, bladder and gut or by directly inhibiting pain pathways at the spinal cord level . The etiology and pathophysiology of chronic pelvic pain remain a mystery, although central neurological mechanisms are probably involved:

Neuromodulation is believed to restore the control at the spinal segmental gate as well as at supraspinal sites such as the brainstem and the limbic system nuclei

Another possible mechanism of action lies in the treatment of underlying pelvic floor dysfunction as hypertonia of the pelvic floor is a common source of pelvic pain and is also an important feature in the etiology of lower urinary tract disorders

SNM has been postulated to inhibit inappropriate excitation of the pelvic floor muscles, thereby facilitating voiding by interrupting the outflow to the urethral sphincter

The possibility starting from 2001 to use a minimally invasive, reversible and staged implant permits really to test patients and the introduction of an original method to perform chronic pudendal nerve stimulation with the same lead represent a further opportunity to treat difficult situations.

Failure of SNM may be due to poor surgical technique, incorrect patient selection, component failure, lead dislocation, progression of the underlying disease process or related to a placebo effect. Anatomic variation in the neurological innervation of the pelvic floor, bladder, rectum and anal sphincters may account for poor efficacy. Sacral neuromodulation safely and effectively provides long-term relief for appropriately selected patients with pelvic floor dysfunctions. It's a safe, reversible, minimally invasive method that may be an appropriate alternative to more invasive techniques for well selected patients. Although much has been learned, methods can still be optimized. Further research is warranted to elicit the mechanism of action, to improve patient selection and the sensitivity of percutaneous test stimulation, and to avoid failures and adverse events after implantation.



## Handout

# Self-Management of Interstitial Cystitis

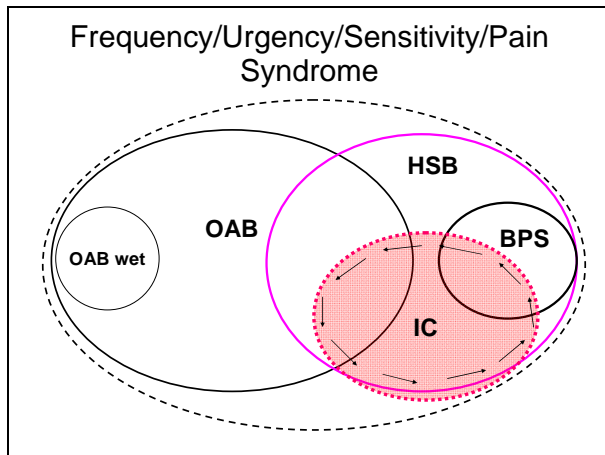
Barbara Muendner-Hensen

- 1st) Patient education: Acceptance and understanding of the disease**
- 2nd) Documentation: Voiding- and pain- journal**
- 3rd) Diet**
- 4th) Sleep**
- 5th) Stress management**
- 6th) Pain management**
- 7th) Bowel cleanse and detoxification**
- 8th) Sports**
- 9th) Clothing**
- 10th) Changing of lifestyle and circumstances**

## 1) Patient education: Acceptance and Understanding of the disease

Interstitial cystitis, or “IC,” as it is usually called, denotes a disease with hypersensitive bladder symptoms and typical cystoscopic and histological features. As the disease progresses, a defect of the bladder wall can be seen.

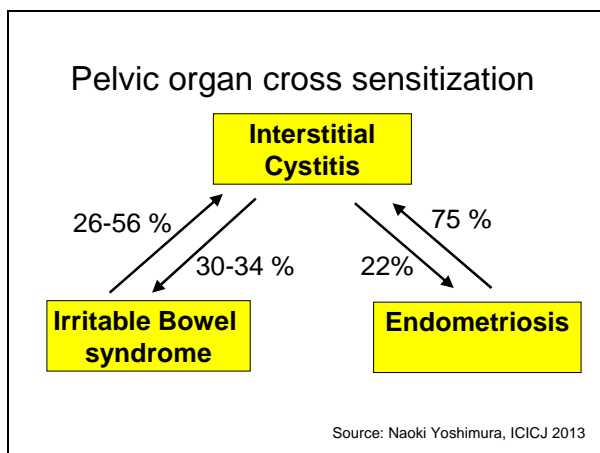
IC patients have recurring pelvic pain, pressure, or discomfort in the bladder and pelvic region, and urinary frequency (needing to go often) and urgency (feeling a strong need to go). So it is much more than—and more complicated than—a pain syndrome.



Source: Y. Homma, Tokyo

Many believe that there may be additional subtypes, called phenotypes, of IC. This also helps to explain why there is such disparity in how IC patients respond to treatments.

IC affects multiple dimensions of a patients' life, and patients often have other conditions as well, so they need multidisciplinary care. Two pelvic conditions, irritable bowel syndrome and endometriosis, which are often seen with IC, may coexist because of cross-sensitization of the pelvic organs.



Source: Naoki Yoshimura, ICICJ 2013

## 2) Documentation: Voiding- and pain- journal

The manager of this multidisciplinary care is the patient. **Documentation** is absolutely necessary

Describing interstitial cystitis can be difficult. Some people find it challenging to talk about IC, to find just the right words to describe what their pain feels like, to remember when IC pain

[illegible]

### 3) Dietary change, nutrition

For the next three to six months, he or she will need to do quite a bit of experimentation and perhaps even an elimination diet as to create a personalized list of foods and beverages that are either symptom triggers or are not bothersome.

The Most Bothersome Foods*	The Least Bothersome Foods*
<b>Coffee</b> - Regular & Decaf <b>Tea</b> - caffeinated <b>Carbonated beverages</b> - cola, non-colas, diet & caffeine-free <b>Alcohols</b> - Beer, Red Wine, White Wine, Champagne <b>Fruits</b> - Grapefruit, Lemon, Orange, Pineapple <b>Fruit Juices</b> - Cranberry, Grapefruit, Orange, Pineapple <b>Vegetables</b> - Tomato & Tomato Products <b>Flavour Enhancers</b> - Hot peppers, Spicy foods, Chilli, Horseradish, Vinegar, Monosodium glutamate (MSG) <b>Artificial Sweeteners</b> - NutraSweet, Sweet 'N Low,	<b>Water</b> <b>Milk</b> - low-fat & whole <b>Fruits</b> - Bananas, Blueberries, Honeydew melon, Pears, Raisins, Watermelon <b>Vegetables</b> - Broccoli, Brussels Sprouts, Cabbage, Carrots, Cauliflower, Celery, Cucumber, Mushrooms, Peas, Radishes, Squash, Zucchini, White potatoes, Sweet potatoes/yams <b>Poultry</b> - Chicken, Eggs, Turkey, <b>Meat</b> - Beef, Pork, Lamb <b>Seafood</b> - Shrimp, Tuna fish, Salmon

Equal (sweetener), Saccharin  
**Ethnic foods** - Mexican, Thai, Indian food

**Grains** - Oat, Rice  
**Snacks** - Pretzels, Popcorn

*\*Friedlander J. et al. Diet and its role in interstitial cystitis/bladder pain syndrome (IC/BPS) and co morbid conditions. BJU International. BJU Int. 2012 Jan 11.*

#### 4) Sleep

For IC patients it is very hard to get enough sleep. They are getting up a number of times at night to urinate. Going to bed at the same time in the evening is very important. The body has to get used to relaxing and calming down at night.

#### 5) Stress management, Avoidance of Stress

Most people with IC recognize that stress plays a part in exacerbating symptoms or bringing on flare-ups. Simply dealing with having IC and the accompanying symptoms can be a source of stress in itself. A good psychotherapist can teach coping skills and stress reduction techniques. Helpful techniques include

- Learning basic relaxation.
- Using meditation tapes and/or visualization.
- Learning self-hypnosis.
- Receiving massages.

#### 6) Pain treatment

Healthcare providers recommend a variety of pain medications, including:

- Non-Narcotic Pain Medicines
- Topical Medicines
- Narcotic Pain Medicines

Patients have often found these complementary and alternative therapies to be helpful.

- Acupuncture
- Homeopathy: Bladder Globules: Belladonna D 6 , Cantharis D 12 , Equisetum D 6 , Apis D 4 , Solidago D 6
- Magnesium
- Vitamin B
- D- Mannose (used by E-Coli Infection)
- Music
- Hypnosis

#### 7) Intestine regulation

In addition, some patients get help for their symptoms with supplements that can bind the toxins in the intestines and allow them to be excreted.

#### 8)...Exercise

- Low impact aerobics
- Tai Chi
- Pilates for IC
- Walking

- Yoga

## **9) Clothing**

- Comfortable and warm clothes
- Warm packs or heating pads
- No high heels

## **10) Changing lifestyle and circumstances**

Patients have to accept the illness of IC and have to change their lifestyle.

They have to find out for themselves the things they can and cannot do.

With the help of their doctor and with the contribution of their own work, the goal of each treatment should be to reach a high and good quality of life. .

Workshop 22      Tuesday, August 27.2013      09:00 – 13:00

## **Neuroplasticity, Self-Help, Sex and Pain**

Chair: Ragi Doggweiler, United States

This workshop aims to discuss the importance of a multimodal approach in the treatment of patients diagnosed with chronic pelvic pain syndrome.

There is emphasis on a multimodal approach while recognizing the unitary psychophysiological nature of both illness and healing

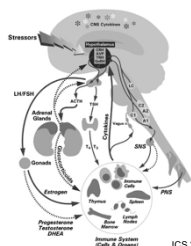
Discussion of neuromodulation and neuroplasticity in the treatment of chronic pelvic pain will be undertaken

Specific consideration will be given not only to the symptoms as guidelines to treatment but also to the patient as a whole, including the environment in which he or she is living and functioning.

Another talking point involves the degree of patient willingness to participate in self –help approaches to gain self-empowerment and self-care.



## CHRONIC PAIN AND THE BRAIN PSYCHO-NEURO-IMMUNOLOGY



Ragi Doggweiler,  
MD, ABIHM

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## Definition of Pain By IASP

- Pain is an unpleasant sensory and emotional experience associated with actual and potential tissue damage, or described in terms of such damage



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## Pain



Pain is a more terrible lord of mankind than even death itself.

Albert Schweitzer, 1931

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## Pain and the Brain

- Pain is generated in the brain
- It is physical and it is mental
- It is physical in the sense that the nerve cells and their activity are physical
- It is mental pain in the sense that it is subjectively experienced in: what is generally called the mind

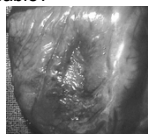


Howard Field, pain and its transformations

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## Pain (like the mind) occupies a strange position between biology and culture

- What is Pain exactly?
- What is its relation to suffering and to stress?
- How many sorts of pain are there?
- Can "physical" pain be separated from "mental" or "spiritual" pain?
- Is pain private and incommunicable?



Sara Coakley, Pain and its Transformations  
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## The Dynamics Between Stress, Disease and Pain

- To understand the relationship between stress and disease and pain, one needs to understand that several factors act in unison to create a pathological outcome including:
  - Cognitive perceptions of a threatening stimulus (Perception: conscious view of the external world. Shaped by beliefs, values and expectation)
  - Activation of the sympathetic nervous system
  - Engagement of the endocrine system
  - Engagement of the immune system

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- ❑ Heart pumps harder
- ❑ Sweat glands increase activity
- ❑ Stomach starts to feel queasy

Is this a mental or a physical phenomena?

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## Stress

- ❑ Perception that something in the environment taxes or exceeds the resources for coping and endangers the well-being

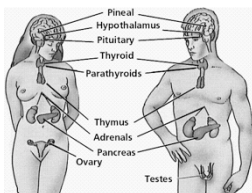


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## Prolonged Stress

...May contribute in a significant way to every major illness and condition including:

- ❑ Heart disease
- ❑ Diabetes
- ❑ Cancer
- ❑ Infections
- ❑ **Chronic pain**
- ❑ Anxiety
- ❑ Depression
- ❑ PTSD
- ❑ as well as early death.



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## Psycho-Neuro-Immunology



..... It is now clear that immune function is influenced by autonomic nervous system activity and by the release of neuroendocrine substances from the pituitary.

- ❑ Conversely, cytokines and hormones released by an activated immune system influence neural and endocrine processes.
- ❑ Regulatory peptides and receptors are expressed by both the nervous and immune systems enabling each system to monitor and modulate the activities of the other.
- ❑ It is hardly surprising that immunologic reactivity can be influenced by stressful life experiences or by Pavlovian conditioning.

Brain Behav Immun. 2003 Feb;17 Suppl 1:S51-7

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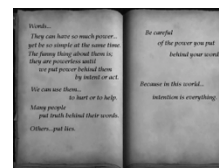
## Psycho-Neuro-Immunology

- ❑ There is increasing scientific interest in the area of brain-immune system interactions and the physiological changes that are induced by activation of the immune system.
- ❑ It is apparent that behavioral and psychological factors can modify the function of the immune system and health. Susceptibility to viral infections, activation of latent viral infections, and relapses/remissions in patients with HIV positive individuals are influenced by interactions between the brain, endocrine, nervous, and immune systems.
- ❑ Stress and other behavioral and psychological factors may be linked to disease susceptibility and progression through either direct CNS-immune system links or CNS-endocrine-immune system pathways.

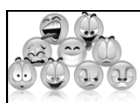
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## Do Words Hurt?

- ❑ Processing of pain-related words leads to activations within regions of the pain matrix.
- ❑ "This job is a real headache."
- ❑ "You are a 'pain in the neck'"
- ❑ "This makes me feel bad"
- ❑ "This is sickening"
- ❑ "My IC"
- ❑ "My Headache"
- ❑ I could "die" for this
- ❑ "S/He kills me"

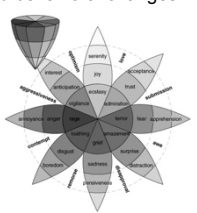


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## Emotions

- ❑ A conscious mental reaction (as anger or fear) subjectively experienced as strong feeling usually directed toward a specific object and typically accompanied by physiological and behavioral changes in the body
- ❑ Holding back emotions
- ❑ Release emotions
- ❑ Can we choose?




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## EMOTIONAL INTELLIGENCE

### FIVE DIMENSIONS

1. Self-awareness: Being aware of what you're feeling
2. Self-management: The ability to manage your own emotions and impulses
3. Self-motivation: The ability to persist in the face of setbacks and failures
4. Empathy: The ability to sense how others are feeling
5. Social Skills: The ability to handle the emotions of others



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## Keys To A Happier, Healthier Life

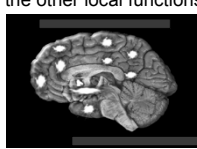
Research suggests that certain personal attributes—whether inborn or shaped by positive life circumstances— help some people avoid or healthfully manage diseases such as heart attacks, strokes, diabetes, and depression:

- ❑ Emotional Vitality
- ❑ Optimism
- ❑ Supportive network
- ❑ Being good at “self-regulation”

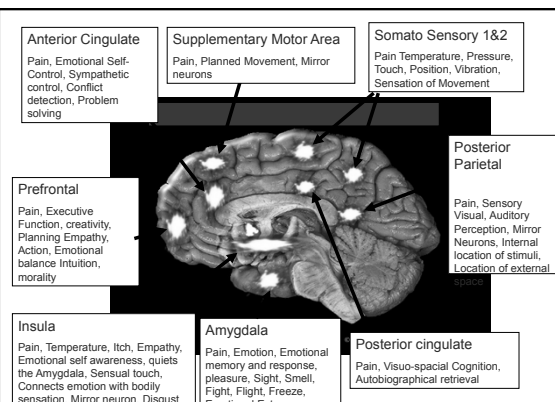
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## Persistent Pain

- ❑ We perceive pain in 9 regions of the thinking brain
- ❑ In each of those 9 regions only 5% of the nerve cells and their connections are dedicated to pain processing
- ❑ In chronic pain the constant firing and wiring leads to an increase of 15% to 25% of the cells in those regions being dedicated to pain processing.
- ❑ This steals from the other local functions



[www.bayareapainreduction.com/.../page28-brain-and-pain-lecture-2.p](http://www.bayareapainreduction.com/.../page28-brain-and-pain-lecture-2.p)



**Anterior Cingulate**  
Pain, Emotional Self-Control, Sympathetic control, Conflict detection, Problem solving

**Supplementary Motor Area**  
Pain, Planned Movement, Mirror neurons

**Somato Sensory 1&2**  
Pain Temperature, Pressure, Touch, Position, Vibration, Sensation of Movement

**Prefrontal**  
Pain, Executive Function, creativity, Planning Empathy, Action, Emotional balance Intuition, morality


**Posterior Parietal**  
Pain, Sensory Visual, Auditory Perception, Mirror Neurons, Internal location of stimuli, Location of external stimuli

**Insula**  
Pain, Temperature, Itch, Empathy, Emotional self awareness, quiets the Amygdala, Sensual touch, Connects emotion with bodily sensation, Mirror neuron, Disgust

**Amygdala**  
Pain, Emotion, Emotional memory and response, pleasure, Sight, Smell, Fight, Flight, Freeze, Emotional Extremes

**Posterior cingulate**  
Pain, Visuo-spatial Cognition, Autobiographical retrieval

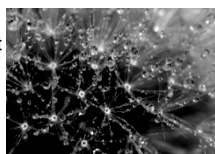
ICS 2013 Barcelona Michael H, Moskowitz, MD, MPH



- Our brain changes automatically, instantly, efficiently, seamlessly and constantly in response to changes in our body.
- The messengers are our senses, thoughts, beliefs, memories, emotions and movement. They bring in constant brain altering data.
- The brain also changes in response to injuries, disease, traumatic events and stressful situations.

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- Synapses form and disconnect at about the same rate

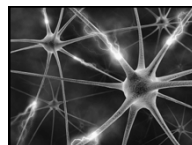


- Areas of the thinking brain have shown rates of 7% per week of making and breaking connections

- Hippocampus (memory) and olfactory bulb (scent) actually make new brain cells - 9000 per week in adult hippocampus



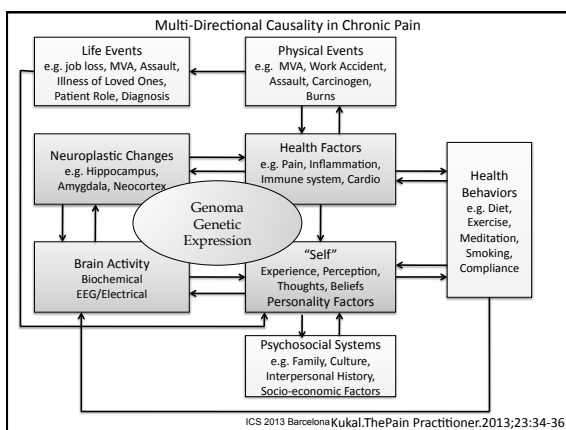
www.bayareapainmedical.com/.../page28-brain-and-pain-lecture-2.p



## Stopping Persistent Pain

- To decrease pain we must increase other regional functions
- What gets fired gets wired. What you don't use you lose During pain spikes - pain nerve cells fire and wire
- If this is countered by the firing of other regional nerve cells during pain spikes, then the population of firing pain nerves is decreased
- Eventually the brain rewires away from pain

www.bayareapainmedical.com/.../page28-brain-and-pain-lecture-2.p



## Access to the Brain



- We do not need to be brain surgeons
- Seven holes and the biggest organ we have **Eyes, Ears, Nose, Mouth, and the Skin**
- Sensation comes from billions of receptors in skin, muscle, bones, joints, etc
- The **thinking brain makes decisions based upon sensory input**
- Touch, position, vibration, movement, temperature, pressure, itch, pain, vision, scent, taste, sound

www.bayareapainmedical.com/.../page28-brain-and-pain-lecture-2.p

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## How do we shrink the map?

**Brain is a learning machine:** Learn self-efficacy

Flood the brain with other input during pain spikes with intention of changing brain.

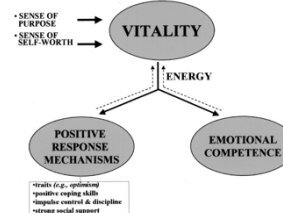
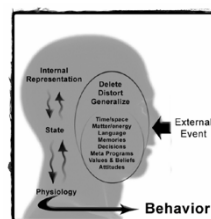
- **Thoughts:** Opposition to pain, feeling good, shrinking pain map
- **Images:** brain maps, brain clear of pain, pleasant imagery
- **Sensations:** touch, temperature, pressure, auditory, visual, olfactory, taste, movement (proprioception)
- **Memories:** Pleasant and strong memories other than pain
- **Calming emotions:** mindfulness, pleasure, peacefulness, serenity
- **Movement** or thoughts of movement

www.bayareapainmedical.com/.../page28-brain-and-pain-lecture-2.p

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## Emotional vitality

- A sense of enthusiasm, hopefulness, engagement



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## Optimism

- ▣ The perspective that good things will happen, and that one's actions account for the good things that occur in life



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## Supportive Network



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## Being good at "self-regulation"

- ▣ Bouncing back from stressful challenges and knowing that things will eventually look up again.
- ▣ Choosing healthy behaviors such as physical activity and eating well.
- ▣ Avoiding risky behaviors such as unsafe sex, drinking alcohol to excess, and regular overeating



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## Healing the Body with the Mind

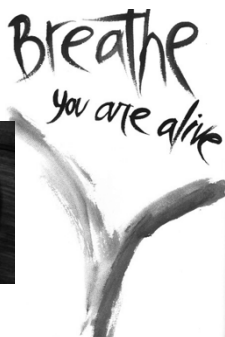
Guided Imagination exercises help the body repair itself after surgery

Maddison, Prapavessis, Clatworthy, et al Guided imagery to improve functional outcomes post-anterior cruciate ligament repair: randomized-controlled pilot trial Scand J Med Sci Sports 2012;22: 816–21

Broadbent E, Kahokehr A, Booth RJ, A brief relaxation intervention reduces stress and improves surgical wound healing response: a randomised trial. Brain Behav Immun. 2012;26:212-7

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## Breath



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## Autogenic Training

- Hyperventilation
- Asthma
- Constipation and diarrhea
- Pain
- Ulcers and gastritis
- Tachycardia, arrhythmia
- Hypertension
- Raynaud Syndrome
- Headache
- Thyroid problems

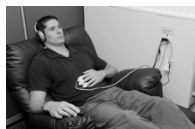


<http://www.webmd.com/balance/tc/autogenic-training-topic-overview>

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### Biofeedback Improves Relaxation Therapy's Effects

- Biofeedback, when used in **conjunction** with other forms of relaxation therapies such as music, and autogenic and imagery training **significantly** improved physiological components including respiratory and heart rate and athletic performance in college students.



Blumenstein, B., Tenenbaum, G. *Journ of Sports Science*. May 1999; 31(5)  
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### Imagery



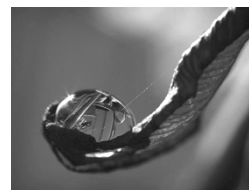
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« When we wish to perfect our senses,  
neuroplasticity is a blessing,  
when it works in the service of pain, plasticity can be a  
curse »

Norman Doidge



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### fMRI to control Pain

- ▣ Individuals can learn to directly control activation of localized regions within the brain
- ▣ Control over the endogenous pain modulatory system can enable a mechanism for clinical control over pain
- ▣ Using real-time functional MRI (rtfMRI) to guide training, subjects were able to learn to control activation in the rostral anterior cingulate cortex (rACC), a region putatively involved in pain perception and regulation. When subjects deliberately induced increases or decreases in rACC fMRI activation, there was a corresponding change in the perception of pain caused by an applied noxious thermal stimulus.
- ▣ Chronic pain patients trained to control activation in rACC reported decreases in the ongoing level of chronic pain.

deCharms et al. *Nat'l Acad Sci U S A*. 2005 20; 102(51): 18626–18631.  
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### Mind over Pain

- ▣ Grant and Rainville exposed 13 Zen masters and 13 comparable non-practitioners to equal degrees of painful heat while measuring their brain activity in a functional magnetic resonance imaging (fMRI) scanner.
- ▣ The meditators reported feeling less pain than the control group.
- ▣ **The meditating group reported feelings of pain at levels below what their neurological output from the fMRI indicated.**
- ▣ Researchers also found that compared to people who don't meditate, **meditators have thicker gray matter**, specifically in an area known to influence perceptions of pain (the anterior cingulate).
- ▣ **The neuroplastic differences found in the brains of meditators were the real cause of their lower sensitivity to pain.**

<http://www.mindful.org/news/mind-over-pain>  
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## Mirror Therapy

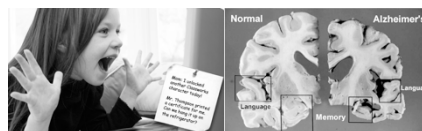
- ❑ Mirror visual feedback originally devised as a therapeutic tool to relieve perceived involuntary movements and paralysis in the phantom limb.
- ❑ Since this pioneering work was conducted in the mid-1990s, the technique has been applied to relieve pain and enhance movement in other chronic conditions such as stroke and complex regional pain syndrome (CRPS).



McCabe, Haigh, Blake, *Chronic Pain Headache Rep.* 2008 Apr;12(2):103-7

## Learning

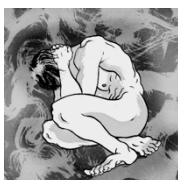
- ❑ If prefrontal functioning is impaired placebo responses are reduced or absent similar to dementia seen in patients suffering from Alzheimer's disease.
- ❑ The placebo effect is a learning phenomenon



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## Pain and the Brain

- ❑ Clinicians who specialize in treating chronic pain recognize that it is not merely a sensation, like vision or touch, but rather **chronic pain is strongly influenced by the ways in which the brain processes the pain signals.**



Andrew R. Block, PhD, Chronic Pain Coping Techniques - Pain Management  
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## Brain and the Pain

- ❑ The important role the mind plays in chronic pain is clearly recognized in the medical literature, as well as in the International Association for the Study of Pain's definition of pain, which states that **pain is always subjective and is defined by the person who experiences it.**



Andrew R. Block, PhD, Chronic Pain Coping Techniques - Pain Management  
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## The Exceptional Patient what we learned from Cancer Survivors

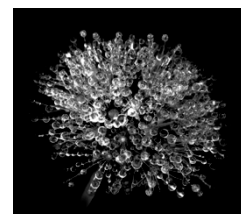
- ❑ Strong social relationship, support family and friends
- ❑ Control, participation, communication
- ❑ Mood, courage and hope
- ❑ Belief in higher power, spirituality, confidence



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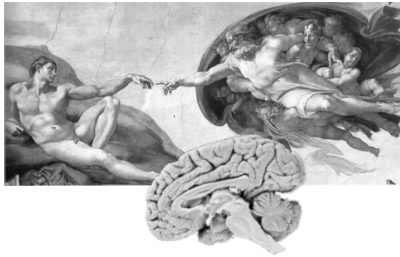
## Supporting the Terrain

- ❑ Nutrition
- ❑ Physical activity
- ❑ Stress reduction
- ❑ Hope
- ❑ Empathic communication
- ❑ Community
- ❑ Social connection



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SISTINE CHAPEL CEILING,  
PAINTED 1508-1512  
COMMISSION OF POPE JULIUS II



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## Formula for Good Health

0            5            10            30            150

- ▣ 0 cigarettes
- ▣ 5 servings of fruits and vegetable / day
- ▣ 10 minutes of silence, relaxation or meditation / day
- ▣ Keeping BM index less than  $30\text{kg/m}^2$
- ▣ 150 minutes exercise / week

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