

# THE ART AND SCIENCE OF ENDOMETRIOSIS

Standardizing the Measurement of Pain and  
Diagnostic Criteria

## WHAT'S IMPORTANT TO PATIENTS



Mary Lou Ballweg  
President/Executive Director  
Endometriosis Association  
International Headquarters  
Milwaukee, WI USA  
Founded 1980

# Endometriosis Association

## Who We Are:

- Several hundred thousand women, girls, and families affected by endo
- Clinicians and healthcare providers of all types
- Scientists

**What's Important to Patients**

# Endometriosis Association Programs

- Support
- Education
- Research

# Endometriosis Association — Support Program

- Support groups
- Crisis call assistance
- Individual help from headquarters
- Networking services (contact lists, correspondence networks, Request for Contact, internet services)
- Financial assistance (prescription drug savings plan, revolving loan membership program, travel assistance)
- Healthcare Provider List
- Teen Program (correspondence network, mentoring program, *TeenSource* newsletter, etc.)
- Support group development and consulting

# Endometriosis Association — Education Program

- Accurate, informative literature
    - Public Education
      - international newsletter with research news, coping help, etc.
      - *TeenSource* quarterly
      - brochures in 29 languages
      - Three popular books
        - *Overcoming Endometriosis*, in 10<sup>th</sup> printing (1987)
        - *The Endometriosis Sourcebook*, in 7<sup>th</sup> printing (1995)  
(*Endometriosis: Libro de consulta* Spanish translation)
        - *Endometriosis: The Complete Reference for Taking Charge of Your Health*, in 4<sup>th</sup> printing (2004)
      - continuous assistance to media
      - outreach at conferences, community health fairs, etc.
      - response to informational inquiries via phone, Internet, and mail
- What's Important to Patients

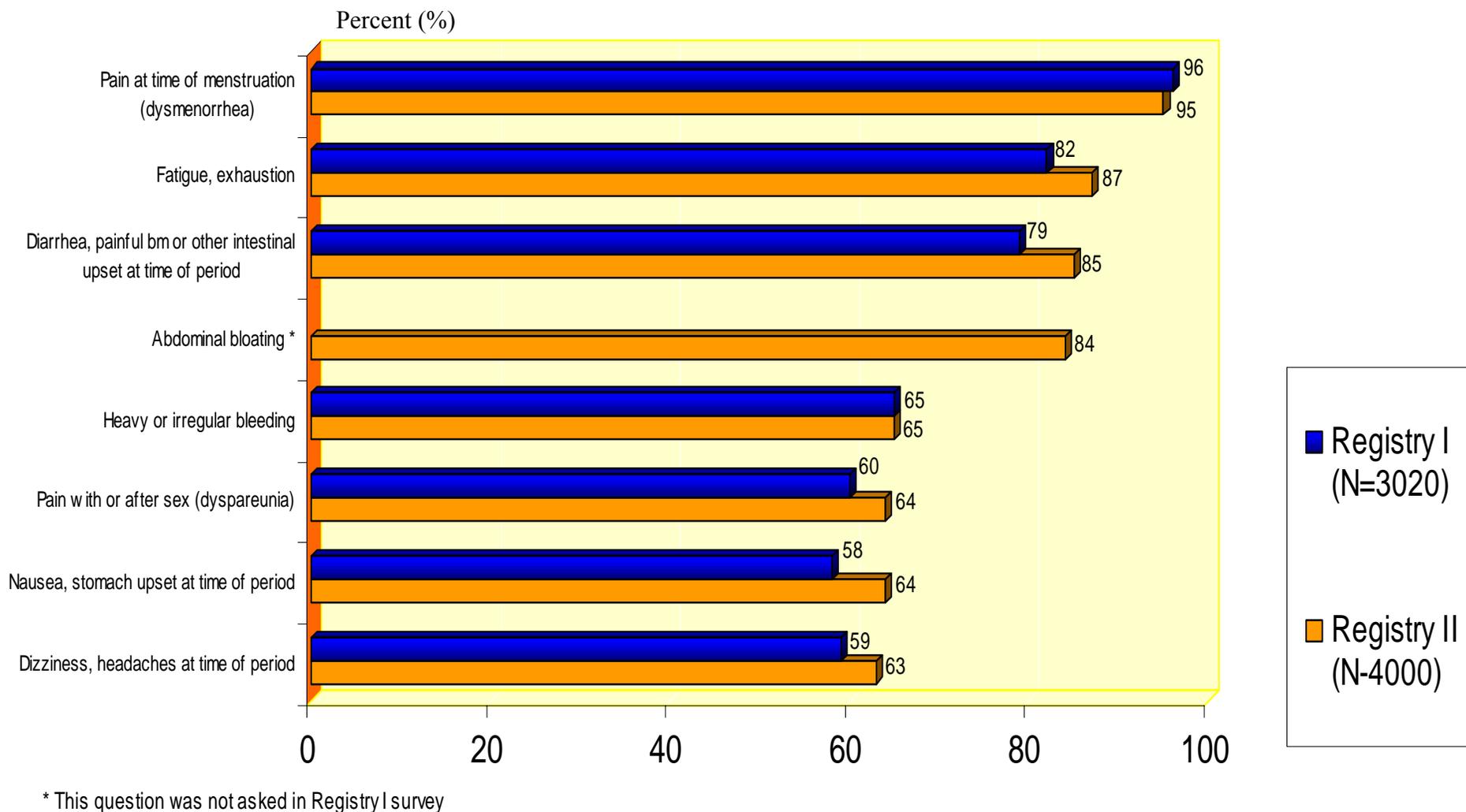
# Endometriosis Association – Research & Medical Education Program

- Maintain world's largest research registries (now in collaboration with U.S. National Institutes of Health)
- Ongoing epidemiological studies
- Data analysis
- Flagship research program at Vanderbilt University School of Medicine
- Technical assistance for researchers
- Ongoing technical and funding advice to researchers
- Funding for research worldwide
- Participation in research conferences
- Efforts encouraging new directions in research
- Assistance in obtaining research study participants

## – Medical Education

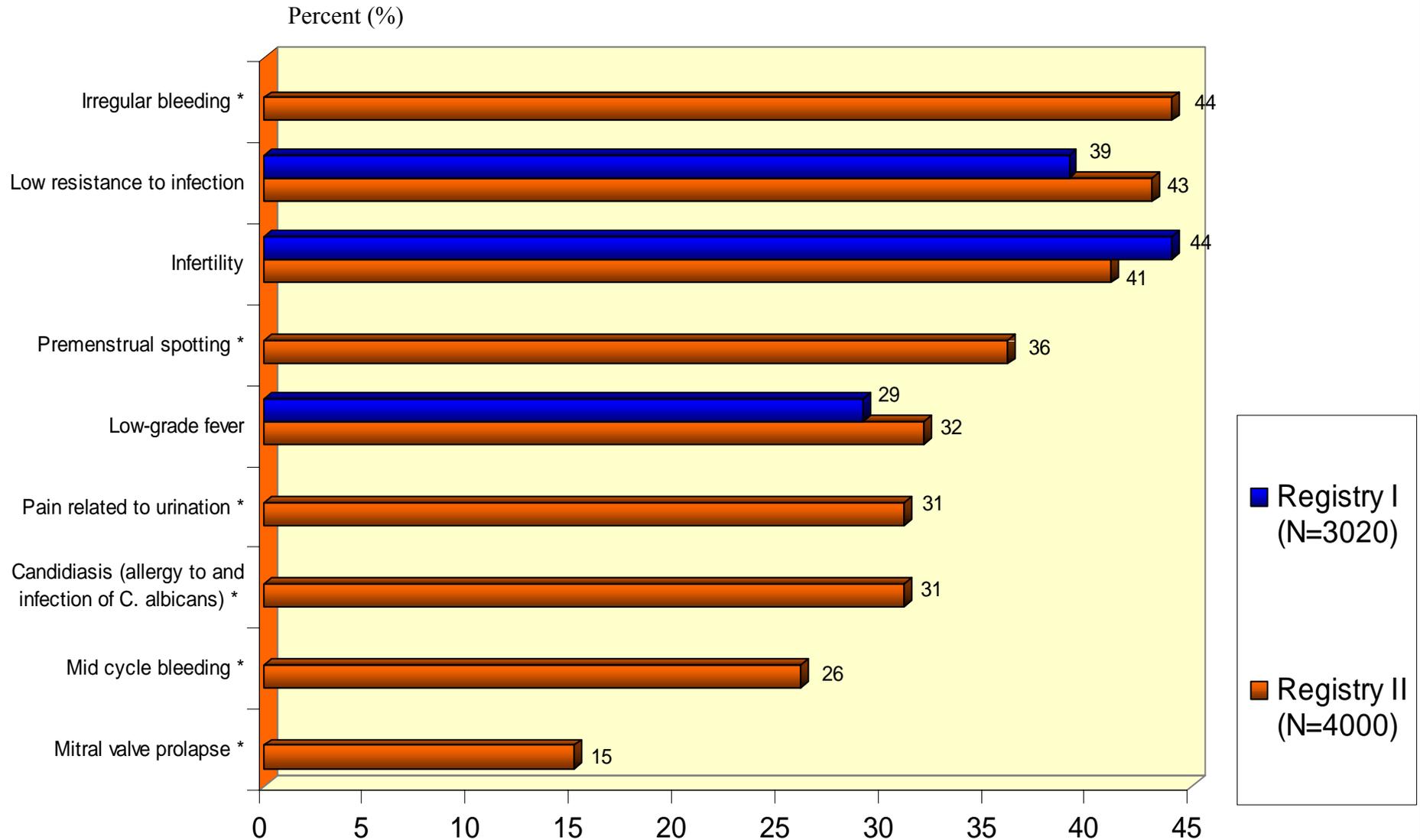
- articles and chapters for medical texts and journals
- presentations and exhibits at medical conferences
- distribution of educational literature to medical personnel

# Symptomatology



Note: pain is the most frequent symptom of endo, followed by fatigue and GI symptoms.

# Symptomatology



\* These questions were not asked in Registry I survey

# 2006 – Historic Year for Endo

1. The World Meeting on Gynecological Pelvic Pain and Endometriosis, Milan, Italy, May 10-13
2. The Art and Science of Endometriosis: Standardizing the Measurement of Pain and Diagnostic Criteria, New Orleans, Louisiana, October 20

# What's Important to Patients

## 1. Want to be believed

- difficult, due to socially-ingrained biases on female cycle-related pain (in patients/physicians)
- most difficult in young patient/girl and people who cannot express themselves in “medical-eze”

## 2. Solutions

- start each consult with at least a minute or two for the patient to  
express the primary reason they are there
- do not interrupt (research by Stewart, Centre for Studies in Family Medicine, Canada, found patients are interrupted, on average, **18 seconds** after they begin to describe their problems.  
The physician “hijacks” the patient’s agenda.)

# What's Important to Patients

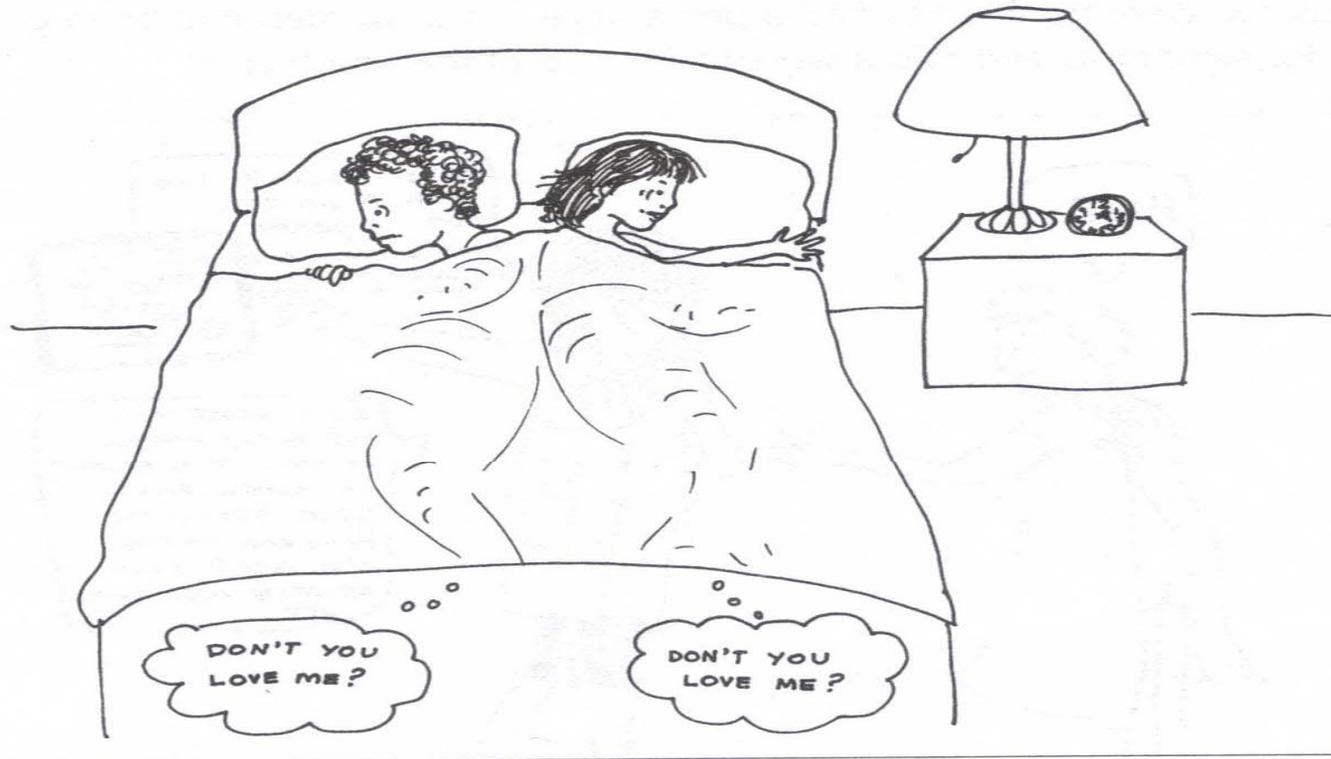
## 3. Acknowledge/Validate

- “What you’re saying is the pain is unbearable, that it keeps you from being able to work at times ...”
- Helps patient feel heard
- Makes visits more personal to her specific concerns

## 4. Want an explanation

- Difficult where complex symptom picture
- If no diagnosis, can explain a step-by-step process for obtaining an explanation for the pain
- "Empty" reassurances not helpful
  - Patient knows something is wrong — telling her symptoms are normal or that nothing was found wrong on the exam (or sonogram, or other test) only increases anxiety
    - can result in loss of confidence and alienation from own body





Thousands upon thousands of letters received at the Association headquarters describe how numerous doctors, mental health people, and husbands of women with endometriosis do not understand that pain with sex is a real physical problem.

I'M HAVING PAIN WITH BOWEL MOVEMENTS,  
AND I BLOAT UP SO MUCH, AND MY  
STOMACH IS SO SENSITIVE TO EVERYTHING.  
DIARRHEA ... IT FEELS LIKE WHEN I HAD  
ENDOMETRIOSIS.

NOW, JOE, YOU KNOW I GOT IT  
ALL OUT. IT'S IMPOSSIBLE TO HAVE  
IT AGAIN. YOU'RE PROBABLY JUST  
SO WORRIED ABOUT IT COMING  
BACK THAT YOU'RE IMAGINING  
THINGS.



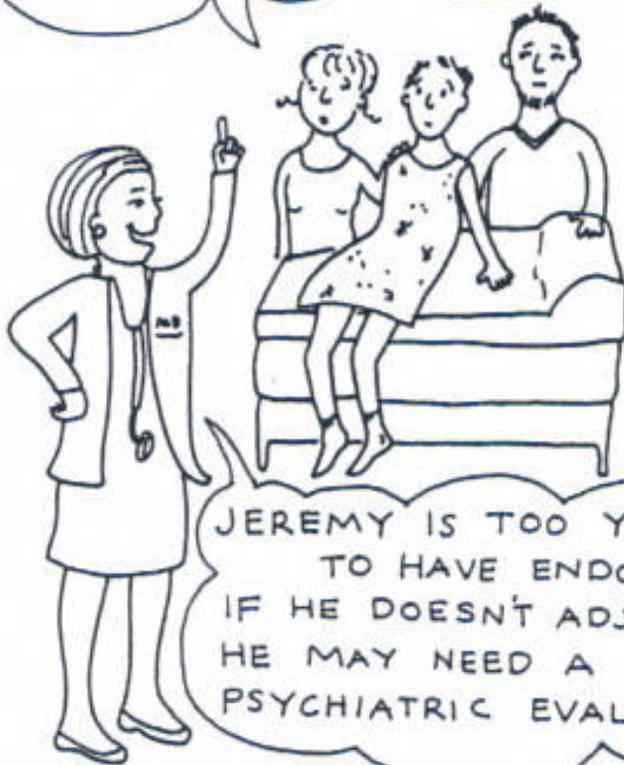
YOU NEED TO  
DEVELOP A NEW,  
PAINFREE ATTITUDE



JEREMY'S UNCLE HAS  
ENDOMETRIOSIS AND  
THINKS MAYBE JEREMY  
HAS IT.

JEREMY, YOU'RE GOING TO  
HAVE TO LEARN TO LIVE  
WITH IT. THIS IS WHAT  
BEING A GUY MEANS

JEREMY IS TOO YOUNG  
TO HAVE ENDOMETRIOSIS.  
IF HE DOESN'T ADJUST,  
HE MAY NEED A  
PSYCHIATRIC EVALUATION.



# What's Important to Patients

## 5. Patients Want Their Pain Addressed

- Pain Diary Helpful

- More helpful: dynamic, continuous diary, such as Reliefinsite

- dynamic diary tool can help practitioner understand

- broad range of interference in patient's life and —

- dynamic nature of pain and related symptoms leading to

- more effective pain management plan

- (Potentially) Better Support and Understanding from Family and

- Friends



The above illustration shows how users (patients) can dynamically share their pain diary readings with their doctors, family members, and friends. Users can print their pain diary report, or fax it to their doctor. Doctors, and others who have sharing privileges, can also view and print user reports.

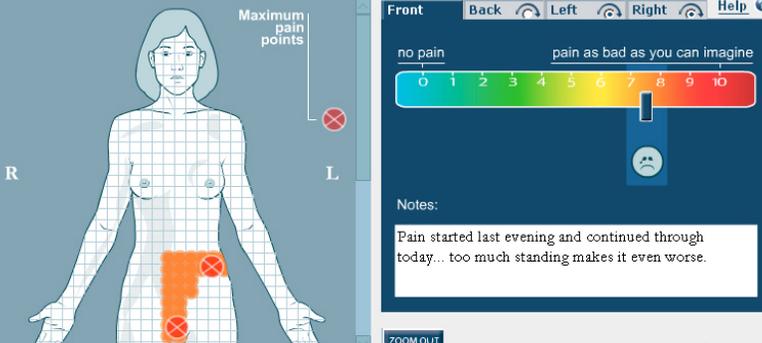
ReliefInsite.com  
on-demand electronic pain diary  
BETA

Setup | Help | Logout

Jane J Doe  
Pelvic Pain

Calendar Body Map Characteristics Symptoms Medication Lifestyle Analysis

Today: Wednesday April 12 2006 New reading for Today



no pain pain as bad as you can imagine

0 1 2 3 4 5 6 7 8 9 10

Notes:  
Pain started last evening and continued through today... too much standing makes it even worse.

Indicate the location and degree of your pain during the past week or since your last reading, if made less than a week ago. For details on how to enter a Body Map reading click on the Help icon to the right of the "Right" tab.

BACK NEXT

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on-demand electronic pain diary  
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Jane J Doe  
Pelvic Pain

Calendar Body Map Characteristics Symptoms Medication Lifestyle Analysis

Today: Wednesday April 12 2006 New reading for Today

### Characteristics / Select

Select Grade Questions Menses

- Aching
- Fearful
- Hot-burning
- Numb
- Sharp
- Splitting
- Throbbing
- Cramping
- Gnawing
- Miserable
- Penetrating
- Shooting
- Stabbing
- Tiring-Exhausting
- Electric Shock Like
- Heavy
- Nagging
- Punishing-Cruel
- Sickening
- Tender
- Unbearable

Other Characteristics: [dropdown]  
Enter New Characteristic: [dropdown]  
Wrenching feeling

Select the word(s) that describe your pain. To add other words select "Enter New Characteristic" from the "Other Characteristics" menu. Enter any comments in Notes at the bottom of the Questions page.

BACK NEXT

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Today: Wednesday April 12 2006 New reading for Today

### Lifestyle

Scale Notes

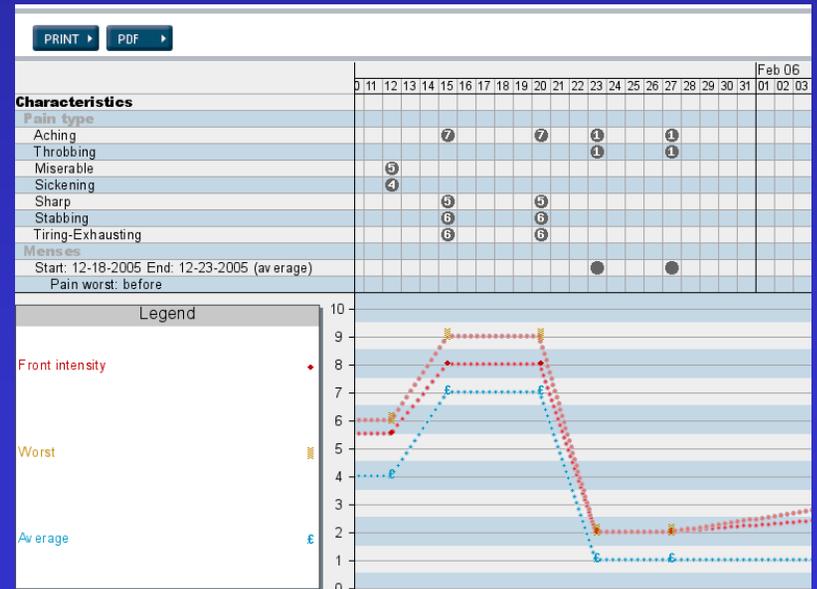
Click on the scales below to show how pain has interfered with your:

does not interfere	completely interferes
* General Activity: 5	Sleep: 6
Ability to Concentrate: 2	Appetite: 2
Ability to Walk: 0	* Normal Work: 6
Ability to Exercise: 0	Financial Impact: 5
Sexual Relations: 1	Relationship with Others: 4
Mood: 4	Enjoyment of Life: 6

\* If you are not working consider General Activity and Normal Work to be your normal household activity.

Indicate how pain has interfered with the above aspects of your life during the past week or since your last reading, if made less than a week ago. Enter any comments in the Notes tab.

BACK NEXT



What's Important to Patients

# What's Important to Patients

## 6. Develop a Plan

- Basic treatment plan
- Pain management plan
  - what to do if pain is at different levels or becomes unbearable; who to call; back-up
  - what to do regarding different types of pain —
    - pain during period
    - pain with sex
    - pain with bowel or bladder function
    - pain from adhesions/during exercise, etc.
- Ideal: written treatment plan
  - written pain management plan

*continued*

# What's Important to Patients

- Individualized
- Specific (pain with sex the main problem? Specifics on dealing with pain with sex)
- Ability to attend work main complaint? Specifics to address that.

## **7. Focus on Customer not the Provider**

- Focus on functionality (PT example)

# Attitudes of Women with Chronic Pelvic Pain to Gynaecological Consult

## What Patients Want

1. Personal care
2. To feel understood and be taken seriously (patients often felt dismissed)
3. Explanation
4. To be reassured

Price J, Farmer G, Harris J, Hope T, Kennedy S, Mayou R "Attitudes of Women with Chronic Pelvic Pain to the Gynaecological Consultation: A Qualitative Study" *British Journal of Obstetrics & Gynaecology* 2006; 113: 446-452.

What's Important to Patients

# What's Important to Patients

## 8. Know and Be Able to Refer to Other Helpful Specialists

- Physical Therapy
- Traditional Chinese Medicine
- Nutritionist
- Massage Therapist
- Environmental Medicine
- Allergist (caution: must be able to diagnose and treat food allergies)
- Fertility Specialist

# Understand what Patients Want

## 1. Support, information/reassurance

- Refer to Endometriosis Association and support groups which provide:

- Support groups
- Crisis Call Listeners
- Correspondence networks for specific issues  
(37 networks, including bladder, bowel/intestine, Candida/allergies, chronic pain, and infertility)
- Outreach Councils (for black women, Hispanics, teens, parents, lesbians, nurses, etc.)
- Information — online, books, CDs, DVDs, newsletters, brochures, etc.

*I've looked at clouds from  
both sides now ...*

"Both Sides Now" by Joni Mitchell

We've only looked at endo end stage (lesions,  
surgical disease)

Let's look at endo from the early stages

- functional orientation vs. mechanical

# From the patient's point of view:

"Endo is a nightmare of misinformation, myths, taboos, lack of diagnosis, and problematic hit-and-miss treatments overlaid on a painful, chronic, stubborn disease."

Ballweg ML "Endometriosis: The Patient Perspective" *Infertility & Reproductive Medicine Clinics of North America: Endometriosis* (Philadelphia, W.B. Sanders Co.): 1992

We may not be able to cure endo, but we can do a better job of helping the patient achieve a better quality of life!