

Finding your Preferences

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Many patients find that stressful circumstances make the symptoms of interstitial cystitis (IC) worse. Despite the current limitations in our understanding of IC and availability of specific, effective treatments, there are many things patients can do to help themselves. In conjunction with efforts to reduce environmental stressors, patients often need to develop coping and stress reduction skills to help buffer them from the daily hassles of living with a painful disease. Patients who develop these skills often find that their IC symptoms and the suffering that attends them diminish.

Many coping and stress reduction strategies are available, which can make the choice of the most appropriate one for any individual patient a daunting task. One approach to making better choices might be for you to identify your preferred sensory input modalities. Educators use a similar strategy to improve learning by tailoring information delivery to student's preferred learning style. Different forms of patient-focused therapies may activate any of six sensory input modalities; mental, touch (movement), sound, sight, smell, and taste.

Identifying your sensory preferences may facilitate choosing more personally useful techniques, and make it more likely you will be able to learn and use them effectively. This success should enhance your self-efficacy (perception of control over your response to your disease), which is known to help reduce pain and improve functioning in patients with a variety of chronic diseases.

The list of questions in the Preference Calculator below was assembled to assist patients and caregivers in matching coping and stress reduction techniques with sensory preferences. After each question, place a 1 in the cell that corresponds to whether it never, 2 for rarely, 3 for sometimes, and 4 for often applies to you. Adding these numbers up may help give you a better idea of your preferences.

When considering the statements in the Preference Calculator, please try to think about your life as a whole, and try to choose an answer that reflects your preferences throughout most of your life, particularly before you got sick. Your answers are anonymous, so you're really having a conversation with yourself to help you gain more control over your disease. Please be assured that there are no "better" or "worse" sensory preferences, any more than it is "better" or "worse" to have one dominant eye, hand, or foot than another.

| | Never | Rarely | Sometimes | Often |
|--|-------|--------|-----------|-------|
| Mental | | | | |
| I enjoy practicing meditation exercises. | | | | |
| I use mental pictures to help me relax. | | | | |
| Religious experiences are important to me. | | | | |
| My role in the "big picture" of life concerns me. | | | | |
| I enjoy daydreaming | | | | |
| I enjoy philosophy. | | | | |
| The cadence of poetry attracts me | | | | |
| I use my imagination to help me enjoy my life | | | | |
| I enjoy pondering questions about life. | | | | |
| Touch (movement) | | | | |
| Sitting still for long periods is difficult for me | | | | |

| | | | | |
|--|--|--|--|--|
| I enjoy outdoor activities | | | | |
| I like making things with my hands | | | | |
| I enjoy dancing | | | | |
| I enjoy chewing gum or snacking while reading or watching TV. | | | | |
| I learn by doing | | | | |
| I enjoy gardening | | | | |
| I am comfortable hugging shaking hands and touching others. | | | | |
| Sound | | | | |
| I'm interested in or enjoy playing an instrument | | | | |
| I focus in on noise and sounds | | | | |
| I enjoy listening to music | | | | |
| I remember things by putting them into rhyme | | | | |
| Moving to a beat is easy for me | | | | |
| I pick out sound patterns easily | | | | |
| I enjoy many kinds of music | | | | |
| Sight | | | | |
| I enjoy the visual arts (e.g., movies, TV, plays) | | | | |
| I enjoy taking pictures | | | | |
| I grasp information in charts and graphs easily | | | | |
| I often write things down or take notes. | | | | |
| I recall things in mental pictures | | | | |
| I enjoy reading | | | | |
| I use maps easily | | | | |
| I enjoy solving jigsaw puzzles | | | | |
| Smell | | | | |
| If I like a new food, it is mostly because I like its smell. | | | | |
| If I dislike a new cosmetic or health product, it is mostly of the way it smells. | | | | |
| If I dislike a new person I've met, it is mostly because I dislike their smell. | | | | |
| I can easily discriminate between subtle differences in scents. | | | | |
| If I like a new place, it is mostly because I like its smell. | | | | |
| If I like a new person I've met, it is mostly because I like their smell. | | | | |
| If I dislike a new food, it is mostly of the way it smells. | | | | |
| If I dislike a new place, it is mostly of the way it smells. | | | | |
| If I like a new cosmetic or health product, it is mostly because I like the smell. | | | | |
| Taste | | | | |
| I notice the taste of water | | | | |
| I like the taste of a wide variety of foods. | | | | |
| I can easily discriminate between subtle differences in flavors. | | | | |
| If I dislike a new food, it is mostly because of the way it tastes. | | | | |
| I eat foods for their unique taste. | | | | |
| If I like a new food, it is mostly because I like the taste. | | | | |
| I enjoy eating fine food more than cooking it. | | | | |

After obtaining your results, be sure to “validate” them. The Calculator is not a test; it is only an indicator. It can identify your general preferences, your “zip code”, but may not exactly describe you as an individual. If your results don’t exactly correspond with what you thought your preferences were, don’t be concerned. You can test any technique you choose to see if it really helps or not. The primary benefit of the Preference Calculator may be to provide you the opportunity to consider what your true preferences are. If it serves to provide you with the opportunity to become acquainted with coping strategies that are meaningful to you, it will have

served its intended purpose. Moreover, it is only intended to provide direction toward techniques to help you gain more control over your everyday challenges. Diseases like IC also can result in levels of anxiety and/or depression that require professional help, for which the Calculator is no substitute.

Once you have identified your preferences, you can use the table below to identify some potentially appropriate coping and stress reduction strategies. There are many more techniques than those listed; this table is provided only to stimulate your creativity to find which strategy is the best for you. You also can add your current techniques into one of the blank rows to see how it compares with the preferences you identified for yourself.

(+ =activates, ± = may activate, blank = doesn't usually activate)

| | Mental | Touch | Sound | Sight | Smell | Taste |
|---------------------------------|---------------|--------------|--------------|--------------|--------------|--------------|
| Love (hugs, caresses, intimacy) | + | + | + | + | + | + |
| Food | + | + | + | + | + | + |
| Cooking | + | + | + | + | + | + |
| Gardening | + | + | + | + | + | |
| Massage, bath | + | + | ± | ± | ± | |
| Humor | + | + | + | + | | |
| Dancing | + | + | + | + | | |
| Movies, television | + | | + | + | | |
| Meditation | + | ± | ± | | | |
| Tai chi, Yoga | + | + | | ± | | |
| Self hypnosis | + | ± | + | | | |
| Relaxation tapes | + | | + | | | |
| Music | + | | + | | | |
| Body scan | + | + | | | | |
| Reading | + | | | + | | |
| Aromatherapy | + | | | | + | |
| Progressive relaxation | + | + | | | | |
| Autogenics | + | + | | | | |
| Breathing | + | + | | | | |
| Biofeedback | + | | | ± | | |
| Prayer | + | | ± | | | |
| Visualization | + | | | | | |
| Applied relaxation | + | | | | | |
| Self hypnosis | + | | | | | |
| Thought-stopping | + | | | | | |
| | | | | | | |

Once you have narrowed down the myriad self-care techniques to a manageable number, you can fine-tune your choices using a technique described in a marvelous resource entitled, “Tune your Brain – Using Music to Manage your Mind, Body, and Mood” by Elizabeth Miles. The book (a website and 10 different CDs also are available) is an indispensable resource for anyone who prefers the auditory modality, and an example of how the therapeutic potential of other sensory modalities could be developed.

One of the key features of “brain-tuning” is the ability to test the effect that any technique has on your mood. The mood-activity evaluation described by Dr. Miles will permit you to directly test how a particular technique affects you. Once you’ve used the evaluations to confirm your general sensory preferences, you can “audition” new techniques based on their effect on your mood. For example, once you find a piece of music that calms you down (or gets you going!),

you can use the web or a good music store to find other pieces of music in the same category to expand your collection of activities that elicit the desired response.

To test the effect of a particular piece of music (or any other technique that interests you), Ms. Miles has developed the following approach:

1. Choose a time when you feel you need to engage the mood you're testing – for instance, if you are feeling stressed, you might decide to test a relaxation technique.
2. Choose a technique that provides input to your preferred sensory modality.
3. Rate your feelings before beginning by assigning a score from 1 to 5 for each mood element listed, using the following scale:

| | | | | |
|------------|---|----------|---|------|
| Not at all | | Somewhat | | Very |
| 1 | 2 | 3 | 4 | 5 |

4. Assign scores quickly, choosing the first response that comes to mind.
5. Try the technique for about 5 minutes
6. Rate your mood again
7. Tabulate your change for each mood element and add them up. The sum is your mood response rating for the technique.
8. To interpret your score:
 - 31-40 Excellent!
 - 21-30 Very effective
 - 11-20 Useful
 - 0-10 Try something else

Example of the “relax” scale

| <i>I feel</i> | Before | After | Change (after-before) |
|------------------|--------------|-------|-----------------------|
| Calm | 1 | 5 | 5 – 1 = +4 |
| Loose | | | |
| Breathing easily | | | |
| Quiet | | | |
| Unwound | | | |
| Tranquil | | | |
| Soft | | | |
| Composed | | | |
| Mellow | | | |
| Serene | | | |
| | Total change | | |

In addition to Relax, Ms. Miles has developed scales for Heal, Focus, Energize, Uplift, Cleanse, and Create. The terms used in these scales are listed (slightly edited) below:

| Relax | Heal | Focus | Energize | Uplift | Cleanse | Create |
|------------------|-------------|--------------|-----------------|---------------|----------------|---------------|
| Calm | Relaxed | Sharp | Awake | Lively | Friendly | Free |
| Loose | Strong | Capable | Quick | Interested | Open | Inspired |
| Breathing easily | Safe | Interested | Inspired | Capable | Calm | Fresh |
| Quiet | Relieved | Clear | Vivacious | Cheerful | Supported | Curious |
| Unwound | Calm | Focused | Motivated | Focused | Quiet | Flexible |
| Tranquil | Healed | Analytical | Active | Free | satisfied | Aware |
| Soft | Soothed | Motivated | Talkative | Talkative | Strong | Open |
| Composed | Mended | Logical | Attentive | Playful | In control | Seeing |
| Mellow | Reassured | Quick | Powerful | Alert | Relaxed | Attuned |
| Serene | Well | Present | Excited | Hopeful | Caring | Clear |

(Adapted from Tune Your Brain: Using Music to Manage Your Mind, Body and Mood by Elizabeth Miles (Berkley Books). Used by permission of the author.)

More information, and copies of the book and the 10 CDs in the music series, is available here: <http://www.tuneyourbrain.com/>. Also, if words other than those used above seem more meaningful to you, by all means use them. The whole idea of this approach is to help you learn what works for YOU!

Finding your preferences will make finding the approach that is right for you in a library, bookstore, video store, or community resource easier. If you have access to the Internet, finding an approach that appeals to you is even easier; the sites in the table below may give you a start, or you can use your favorite search engine (mine is www.google.com) to find sites that focus on your preferred modality. A guide to evaluating medical resources on the web is included as an appendix.

| Web Site | Address | Modality |
|--|--|----------|
| The Mind Body Medicine Institute | http://www.mbmi.org/default.asp | All |
| The American Horticultural Therapy Association | www.ahta.org/ | V, A, T |
| Art as a healing force Web | www.artashealing.org/ | V, A, T |
| Therapeutic Resources | www.therapeuticresources.com/ | All |
| Amazon | www.amazon.com | All |
| Barnes and Noble | www.bn.com | All |
| Elizabeth Somer, MA, RD | www.elizabethsomer.com/eindex.html | Food |

Identifying your preferences and selecting techniques that activate them are major steps toward increasing your control over your disease. The only other question to ask is whether you prefer to use them by yourself, or with others. The answer to this question will help you choose whether you might prefer an individual or a group technique, or both.

Once you've chosen a technique, plan to set aside some time each day to practice. Making changes in your patterns of behavior, even desired ones, is often challenging. The best guide to the change process I've found is "*Changing for Good*" by Dr. James Prochaska. Dr. Prochaska describes a step-by-step approach to the change process that is used widely in health promotion. A description of his approach is here: <http://www.uri.edu/research/cprc/TTM/StagesOfChange.htm>

Another technique to consider learning is how to access your "relaxation response". Many of the techniques described help do this, or you can activate it directly. The technique to initiate the relaxation response is a simple practice that once learned takes 10 to 20 minutes a day and can relieve the stress and tension that stands between you and a richer and healthier life. Herbert Benson, M.D. developed the technique at Harvard Medical School (<http://www.mbmi.org/default.asp>), tested it extensively and wrote a book about it entitled, of all things, "The Relaxation Response". There also is, "Beyond the Relaxation response"!

Here is the technique used to induce the relaxation, taken word for word from his book (and used with his permission).

1. Sit quietly in a comfortable position.
2. Close your eyes.
3. Deeply relax all your muscles, beginning at your feet and progressing up to your face. Keep them relaxed.
4. Breathe through your nose. Become aware of your breathing. As you breathe out, say the word, "ONE", silently to yourself. For example, breathe IN ... OUT, "ONE",- IN .. OUT, "ONE", etc. Breathe easily and naturally.

5. Continue for 10 to 20 minutes. You may open your eyes to check the time, but do not use an alarm. When you finish, sit quietly for several minutes, at first with your eyes closed and later with your eyes opened. Do not stand up for a few minutes.
6. Do not worry about whether you are successful in achieving a deep level of relaxation. Maintain a passive attitude and permit relaxation to occur at its own pace. When distracting thoughts occur, try to ignore them by not dwelling upon them and return to repeating "ONE." With practice, the response should come with little effort. Practice the technique once or twice daily, but not within two hours after any meal, since the digestive processes seem to interfere with the elicitation of the Relaxation Response.

After a couple of minutes at step 4, you can begin reading, listening to music, or whatever activity you've chosen, continuing as described in steps 5 and 6. This technique has two benefits; you spend less time attending to your irritations, and the process will reduce their grip on your attention, letting you get on with your life more comfortably. Like any new skill, it's often "2 steps forward, 1 step back" at first. Like riding a bicycle, however, once you're "up and rolling", it'll be a skill you'll be able to use for the rest of your life!

Appendix. 10 Things to Know About Evaluating Medical Resources on the Web

The number of Web sites offering health-related resources grows every day. Many sites provide valuable information, while others may have information that is unreliable or misleading. This short guide contains important questions you should consider as you look for health information online. Answering these questions when you visit a new site will help you evaluate the information you find.

1. Who runs this site?

Any good health-related Web site should make it easy for you to learn who is responsible for the site and its information. On this site, for example, the National Center for Complementary and Alternative Medicine (NCCAM) is clearly marked on every major page of the site, along with a link to the NCCAM homepage.

2. Who pays for the site?

It costs money to run a Web site. The source of a Web site's funding should be clearly stated or readily apparent. For example, Web addresses ending in ".gov" denote a Federal Government-sponsored site. You should know how the site pays for its existence. Does it sell advertising? Is it sponsored by a drug company? The source of funding can affect what content is presented, how the content is presented, and what the site owners want to accomplish on the site.

3. What is the purpose of the site?

This question is related to who runs and pays for the site. An "About This Site" link appears on many sites; if it's there, use it. The purpose of the site should be clearly stated and should help you evaluate the trustworthiness of the information.

4. Where does the information come from?

Many health/medical sites post information collected from other Web sites or sources. If the person or organization in charge of the site did not create the information, the original source should be clearly labeled.

5. What is the basis of the information?

In addition to identifying who wrote the material you are reading, the site should describe the evidence that the material is based on. Medical facts and figures should have references (such as to articles in medical journals). Also, opinions or advice should be clearly set apart from information that is "evidence-based" (that is, based on research results).

6. How is the information selected?

Is there an editorial board? Do people with excellent professional and scientific qualifications review the material before it is posted?

7. How current is the information?

Web sites should be reviewed and updated on a regular basis. It is particularly important that medical information be current. The most recent update or review date should be clearly posted. Even if the information has not changed, you want to know whether the site owners have reviewed it recently to ensure that it is still valid.

8. How does the site choose links to other sites?

Web sites usually have a policy about how they establish links to other sites. Some medical sites take a conservative approach and don't link to any other sites. Some link to any site that asks, or pays, for a link. Others only link to sites that have met certain criteria.

9. What information about you does the site collect, and why?

Web sites routinely track the paths visitors take through their sites to determine what pages are being used. However, many health Web sites ask for you to "subscribe" or "become a member." In some cases, this may be so that they can collect a user fee or select information for you that is relevant to your concerns. In all cases, this will give the site personal information about you.

Any credible health site asking for this kind of information should tell you exactly what they will and will not do with it. Many commercial sites sell "aggregate" (collected) data about their users to other companies--information such as what percentage of their users are women with breast cancer, for

example. In some cases they may collect and reuse information that is "personally identifiable," such as your ZIP code, gender, and birth date. Be certain that you read and understand any privacy policy or similar language on the site, and don't sign up for anything that you are not sure you fully understand.

10. How does the site manage interactions with visitors?

There should always be a way for you to contact the site owner if you run across problems or have questions or feedback. If the site hosts chat rooms or other online discussion areas, it should tell visitors what the terms of using this service are. Is it moderated? If so, by whom, and why? It is always a good idea to spend time reading the discussion without joining in, so that you feel comfortable with the environment before becoming a participant.

NCCAM Clearinghouse

Toll-free: 1-888-644-6226

International: 301-519-3153

TTY (for deaf or hard-of-hearing callers): 1-866-464-3615

E-mail: info@nccam.nih.gov

Web site: nccam.nih.gov

Address: NCCAM Clearinghouse, P.O. Box 7923, Gaithersburg, MD 20898-7923

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